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**DISABILITY INJUSTICE: A LATINO'S CREATIVE  
AUTOETHNOGRAPHIC *TESTIMONIO* ON THE  
ORGANIZATIONAL CULTURE OF HIGHER EDUCATION**

**BY**

**LEONEL ALBERTO DIAZ JR.**

B.A., University of California Santa Cruz, 2010  
M.Ed., University of Southern California, 2012

DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of  
**Doctor of Philosophy**

**Organization, Information, and Learning Sciences**

The University of New Mexico  
Albuquerque, New Mexico

**July 2021**

## **DEDICATION**

This is dedicated to people who defy injustice within learning environments and work environments. Continue to challenge the oppressive systems of this world. Continue to persevere.



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**DISABILITY INJUSTICE: A LATINO'S CREATIVE AUTOETHNOGRAPHIC  
*TESTIMONIO* ON THE ORGANIZATIONAL CULTURE OF HIGHER  
EDUCATION**

**by**

**Leonel Alberto Diaz Jr.**

**B.A., University of California Santa Cruz, 2010**

**M.Ed., University of Southern California, 2012**

**Ph.D., University of New Mexico, 2021**

**ABSTRACT**

Using creative autoethnographic *testimonio* (CAT), a story is told about the injustices within the learning environment and work environment of higher education toward a person with disabilities: sleep apnea, learning disabilities, negative mental health. The author explores the health difficulties of addressing sleep deprivation while attending graduate school and working full-time as a professional. With sleep apnea impacting his health, his mental health declines. As his health declines, there is an increase in discrimination, hostility, oppression, bullying, and toxic masculinity. Initially, the medical system dismisses his declining health and refuses to look further into it. Once he receives medical care to address his sleep apnea, he begins to address problems within the learning and work environment. His experiences teach him stigmas of disability continue to impact people within higher education and the urgent need for universal design.

Keywords: disabilities, injustice, autoethnography, *testimonio*, sleep apnea, creativity

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## LETTER FROM THE EDITOR

It's not an understatement to say that I wouldn't be where I am today without Leonel. He went from being a stranger sitting across the table from me at an interview, to my boss, to a treasured friend who walked me down the aisle on my wedding day. I was overjoyed and honored when he asked me to edit his dissertation, which has been a long time in the making. I was there for some of the events he discusses, and I can attest that his truth is authentic, raw, and emotional. As a White female I cannot say I understand the type of discrimination that he experienced, but I share in his struggles with mental health issues and his words echo how I often feel. Regardless of your ethnicity or gender identity, Leonel's story will tug on your heartstrings and make you feel angry and, at times, even hopeless. His intention was not to sugar coat things but to tell them like they were, and I tried to keep that authenticity as I edited. I hope that reading about Leonel's experience inspires you to start a conversation about the importance of mental health with your peers. And as you read (especially Chapter 4), I invite you to keep this pertinent quote in mind from Leonel's mentor, "We write to avoid the humiliation of silence in the face of cruelty and injustice." I challenge you to confront the cruel injustices in your world, and sincerely hope that Leonel's story inspires you to be a force for change.

-Anna Cairo

## **CHAPTER 1**

### **THE INTRODUCTION**

It is a cloudy Thursday afternoon in Richmond, Virginia. Sitting at a hotel patio next to a fire pit with three ethnic men, we share experiences, stories, traumas, and challenges encountered as young men of color and the health disparities, social economic struggles, and organizational culture problems we encounter on a personal, community, and societal level. We each live in different parts of the country: California, Michigan, New Mexico, and New York. We gather together to participate in the leadership honor society conference for middle school and high school students, for which we serve as faculty three to six times a year, cancelled 2020–2021 due to the emergence of COVID-19 in the United States. As a result, we are spending our unexpected free time having deep dialogues and working on our individual projects. During the past two days, we have engaged in meaningful conversations amongst ourselves along with two feminist women of color. For over four years, we have all served as faculty on the road with several other individuals. We have become a traveling family, often challenging each other to become better individuals and allowing ourselves to be vulnerable by creating a safe space wherever we travel. These moments offer support and healing for us all in addition to reinforcing our knowledge, approaches, and problem-solving abilities. This group of colleagues and friends are my traveling family.

It is not often that I experience these special moments that allow for growth and reflection. Our life experiences are reflective of the similarities that exist in our everyday interactions, even when our identities are unique, directly and indirectly in our roles as students, educators, employees, professionals, and humans. These conversations are

important to allow us to move forward in the face of injustice, discrimination, retaliation, and oppression in the workplace and learning environments. The interaction with my traveling family is highlighted because it is an outcome and solution to a variety of interconnected difficult and negative experiences that will be the focus of my research. Experiences with my traveling family will be expanded in chapters four and five. It is beneficial to have a support group of people to help you through life's hardships. In my particular case, I did not always have supportive people available locally. My personal experiences taught me that health is not taken seriously when it is something that we cannot see or understand. Only those with similarities to my life circumstances have been the most understanding and supportive.

Disability and the impacts our surrounding environment create as well as the challenges it brings to our mental health is the focus of this research study. I will explore issues that exist within the organizational culture and learning environment in higher education that affect individuals with disabilities. Although there are laws and policies to protect individuals with disabilities, the learning environment and organizational culture of higher education have not created an equitable environment to health diversity (Evans et al., 2017). This study uses *testimonio* and autoethnography research methods. These methods allow for storytelling of personal events and experiences relating to disability and organizational culture to describe the discrimination, oppression, and lack of support existing within higher education learning environments and the workplace. Before I dive into my life experiences, let us take a quick review of our world's most recent health concern as it relates to disability and mental health.

Using the COVID-19, or coronavirus, pandemic as an example of health in the world, the virus had not been taken seriously until the number of infected people exponentially increased between 2019 to 2021. For the first time in my airport experience, I witnessed men in the restroom washing their hands for twenty seconds and other men patiently waiting in line to wash their hands. This was opposite to previous travel experiences in which men washed their hands quickly or skipped it. This moment signified a shift in preventative health care that would follow quickly throughout the world. Governors from various states are requesting people to stay at home and practice social distancing (Hauck, Reyes, & Ortiz, 2020). The President of the United States deployed the National Guard to assist states that have the worst outbreaks (Newburger, 2020). In Italy and Spain, people have been given a citation for playing Pokémon Go out in the streets during a mandatory stay at home order (Boom, 2020; Cole, 2020). Even in my personal experience, I have witnessed an increase of people wearing face masks walking at my local park during my regular walk/jog schedule and several people wearing masks and/or gloves while shopping at my local home improvement store, demonstrating how Coronavirus has impacted our everyday lives, from exercising to shopping. Even with all this occurring, not every person takes the pandemic serious, until it happens to them or someone close to them. Two women, one 26-year-old and the other 34-year-old, are warning others to take the virus seriously after being diagnosed with Coronavirus (Holcombe, 2020). Both express the idea of brushing-off the thought of becoming infected. Karl-Anthony Towns, a National Basketball Association (NBA) player for the Minnesota Timberwolves, posted a video on Instagram urging people to take the pandemic seriously (Towns, 2020). He shared that his mother was diagnosed

with COVID-19 and placed in a medically induced coma with a ventilator. She passed away. Stephen Curry, an NBA player for the Golden State Warriors, hosted an interview with Dr. Anthony Fauci, the Director of the National Institute of Allergy and Infectious Diseases (NIAID), on Instagram to answer questions from his followers regarding the virus (Curry, 2020). Their discussion focused on the seriousness of the epidemic, herd immunity, vaccine development, and practices people can implement to improve our current circumstances. Towns and Curry are two of many high-profile individuals that are speaking out to urge our society to take the pandemic seriously. In Albuquerque, a man that had to self-quarantine is advocating for people to heed social distancing rules after coming in contact with an individual who had tested positive for coronavirus (Shone, 2020). In addition, there is always the problem of misinformation such as a so-called “self-check test” that circulated on social media in March 2020 (Elassar, 2020). The false information circulated stated that drinking water, gargling saltwater, and holding your breath would help identify if a person was infected with Coronavirus. There was a report about hundreds of people gathering at a house of worship in Albuquerque amid the pandemic, which involved state police responding to the incident (KRQE Media, 2020) and that resulted in the organization being fined upwards of \$10,000 for violating the state health order.

The largest outcome from this pandemic will be the psychological impact, or mental health impact, people will experience from either losing someone to COVID-19, experiencing severe COVID-19 symptoms, being isolated for extended time, unemployment, financial difficulties, legal difficulties, and other reasons once the pandemic restrictions end. It will also impact those who have been infected by COVID-

19 and experience long-term physical effects (e.g., coughing, fatigue, shortness of breath) which make them temporarily disabled. This unfortunate pandemic experience might represent something greater about why people demonstrate a lack of trust in general. In the United States, it might be a generational experience, as it was reported by the Pew Research Center that 73% “of U.S. adults under 30 believe people ‘just look out for themselves’ most of the time” (Gramlich, 2019, para 2). This represents the individualism in society. In the same age group, 71% believe that people “would try to take advantage of you if they got a chance.” This represents a lack of trust in people. The study also found that when it comes to national issues, young adults are less concerned compared to their elders. This might offer an explanation as to why some people are not taking the pandemic seriously and why others are urging people to take it seriously by sharing their personal experiences. Even with all the prevention efforts and increase in awareness, there will be people that will not heed warnings and restrictions, showing a complete disregard for one of the greatest health concerns to affect our world.

Pew Research Center’s data is relatable: people ignore warnings and restrictions, have trust issues, and do not care about national or global issues. There are moments in my life where I thought some people were exaggerating, over emphasizing, complaining, claiming they have an emergency, or even just seeking attention. The reasoning behind this old line of thought was based upon experiences in which I perceived others to be mentally weak, delicate, or sensitive. Simply said, I lacked empathy during my late teen years and into my early adult years. This thinking was influenced by the social environment in school. I experienced obstacles and challenges like anyone else, constantly pushing myself to achieve more to keep up with others in my cohorts. Always

struggling to keep up with high achievers during my entire educational experience and professional career, I always felt that my abilities were inadequate. I had to put in more effort into every single task because that was the advice given to me by teachers, employers, coaches, friends, and my parents. This mind set created a lack of empathy. My thought during that time in my life was, “If I was able to push myself during all challenges, why are others not able to do the same? No one ever seems to truly care about me, so why I should I care about them?” Everyone might not have this identical thought when it comes to ignoring warnings and restrictions such as those during a pandemic or distrusting people in general, but it has provided me the ability to understand why someone could ignore something they do not fully understand or care to understand. Understanding a subject is different when it is a lived experience that changes your views and makes you question previously gained knowledge. This research study will focus on issues of discrimination, stigma, unsupportive workplace culture, lack of accommodations, and other issues that involve disability in the organizational culture of higher education, both the workplace and learning environment. This includes how my lived experiences would change and challenge my understanding and knowledge of disability, mental health, organizational culture, learning environments, substance use, and learning capabilities. It all started the moment I noticed I was losing control of my own health and the journey I undertook to identify the source of my health decline.

### **The Beginning | Background**

Prior to the biggest change in my health, there were several symptoms experienced that were becoming difficult to manage. Restlessness, lack of energy, weight fluctuation, hypertension, and several other symptoms were increasing each year. It was

difficult to feel positive emotions. Medical providers would always point out that I was obese and losing weight would solve my health problems, even though my blood results would demonstrate a healthy male, something that would often confuse them. They expected to find high cholesterol and glucose levels but instead got results that indicated a healthy patient. As a child, my response to a medical provider was, “You are fat too!” My parents immediately yelled at me and quickly apologized to the doctor while feeling embarrassed for my action. Every annual checkup was the same routine and responses from medical providers. I was overweight, needed to eat healthier, and exercise more often. I never missed an opportunity to tell a medical provider to model weight loss when they were often equally or more obese. As my weight increased, so did the feeling of being tired all the time. My parents always blamed my exhaustion on my decision to not go to sleep early. What they didn’t know was that I had a hard time staying asleep, no matter what time I went to bed.

Feeling tired most of my life, I must have appeared unmotivated as several teachers would always tell me to “try harder.” Some teachers gave me the speech about finding a purpose in life and to not give up. Not knowing any better, I gave it my best. Regardless, it was never good enough. An average student as a child, my parents and teachers sternly asked that I study “harder”. Struggling to memorize the multiplication tables and spelling words, the fourth-grade teacher told me to be like the high achievers in class and learn how to be more like them. I never expected my life to remain like this through high school, college, and graduate school. These remarks to “try harder” have been experienced in my professional career with some employers. Despite struggles, I pushed myself to be better, accepting needing to “try harder” every time, regardless of



my state of mind. By the time the college experience began, what I felt was normal. I thought that I needed to be more disciplined and prioritize my education for the sake of my undecided professional career.

My life would continue to move forward under the same circumstances. The motivation to continue was based upon the few achievements I made and reminding myself that I could push myself to be better each step of the way. In 2014, I began working a position as an academic advisor at a university near my hometown, Compton, California. Only six months of employment were guaranteed based on the funding available in the grant. I had to make the best of it and continue searching for other jobs. Because of my networking, I landed a job right before the grant ended. However, I felt stuck, as if my life was a bubble, knowing there had to be something better. Not enjoying my life, I needed a change of scenery or a new challenge. I had the option to stay as the university announced it would fund our academic advising team for one more year until it identified a new funding source. Instead, I decided to proceed with my choice to leave sunny southern California. During the hot summer in July, I traveled to New Mexico, the land of enchantment, or entrapment, depending on whom you ask. I was ready for changes in my life, but there was nothing that could prepare me for changes I would soon experience.

After being in New Mexico for two years, during the summer of the year 2016, I was diagnosed with sleep apnea, a series of respiratory or brain obstructions that disrupt sleep (Mayo Clinic, 2018). The sleep deprivation took a toll on my overall health. Functioning became increasingly difficult. Over time, I would learn that the people in both my work environment and learning environment would not be supportive of the

impact that the sleep apnea had on my health and overall wellbeing. My health was often disregarded and ignored, which was an unexpected and unwelcomed challenge. From 2015 through 2019, I experienced the greatest life difficulty that would push my limits beyond my own imagination and test my capabilities under the worse circumstances. The concept of “work harder” would no longer be an effective strategy to cope with my new inabilities. Several events, situations, conversations, meetings, conflicts, and confrontations took place during this time that made me see something I did not expect to find, a lack of support given my health condition. Sleep apnea was the beginning of other changes in my health. Unbeknownst to me, sleep apnea was the first diagnosed disability, with other disabilities falling under the mental health category and learning disabilities category. Negative mental health was a joke, an excuse for poor choices, until I experienced changes to my mental health that I could no longer control. It quickly taught that navigating my role as an employee and graduate student with severe health changes would unexpectedly lead toward the discontent of employers and the faculty of the graduate program. Neither employers or the faculty showed any signs of concern for my health and wellbeing while navigating the challenges of trying to be a good employee and student with newfound disabilities.

### **Here’s the Problem**

The World Health Organization (WHO; 2018) estimates that 15% (over a billion) of the world’s population has a disability. In the United States, 61 million adults and 17% of children ages 3 – 17 have a disability. In New Mexico, 28.4% of the adult population identifies as having a disability (NMDOH, 2018). Some people will probably think of a physical disability that can be observed. However, other disabilities are hidden from sight

such as attention-deficit/ hyperactivity disorder (ADHD), deafness or being hard of hearing, and depression. WHO defines intellectual impairments, or learning disabilities, as a state of arrested or incomplete development of the mind (2011). Because learning disabilities are “invisible” (meaning, you cannot tell that a person has a disability just by looking at them), it is easy to exclude this population. There are several methods to being dismissive and inclusive in the way we deliver trainings, instructions, presentations, visual aids, and programs, including conversations. Disabilities can affect anyone short-term and or long-term. Disabilities are all around us, whether we realize it or not.

Mental health, an aspect of disability, is gaining attention across the United States. News stories of suicide and research on mental health continue to appear in news outlets (Caicedo & van Gameren, 2016; Evans et al., 2018; Kim et al., 2018; Pérez, 2018). Discussions of mental health are taking place on a national level in regard to gun violence and mass shootings. The lack of awareness and education on mental health impacts society by creating misunderstood problems that could be solved if mental health was more widely understood (Evans et al., 2018; Fripp & Carlson, 2017). Celebrities like Emma Stone, Dwayne “The Rock” Johnson, Joaquin Phoenix, Stephen Amell, and Gina Rodriguez have been very open to discussing their mental health experiences with their fans on social media, demonstrating a positive shift of mental health views. A study from the University of California Berkley Graduate Assembly (UCBGA; 2015) found that 47% of doctoral students and 37% of master’s students were depressed on their campus. Their top predictors of depression are sleep, overall health, and academic engagement. It is not just students, celebrities, and societal events that affect people’s mental wellbeing.

The discussion of the importance of mental health continues regarding the workforce where “85% of the world’s employees are not engaged or are actively disengaged at work and therefore are not as motivated or productive as they could be” (Gallup, 2017, p. 53). In the United States (U.S.), only 33% of the workforce is engaged. Gallup suggests that addressing basic human needs such as positive workplace relationships, frequent recognition, ongoing performance conversations, and opportunities for personal development will increase psychological engagement. Another study identified that, “only 54% of U.S. employees feel satisfied with their jobs,” leaving 46% that are unsatisfied with their jobs (The Conference Board, 2019). Similar to Gallup, the study also identified recognition/acknowledgement, performance review, educational/job training programs, promotion policy, and communication channels as providing the lowest satisfaction for employees. In organizational culture and academia, students and employees are not happy with their environment. It is evident that issues exist within organizations.

What is your first thought when you think of the term “mental health”? When mental health is discussed, it often carries a negative connotation, ignoring the positive conditions of mental health. This is a result of stigma within society on mental health (Goffman, 1963), which is further discussed in chapter two. To change and challenge views on mental health, I use the term “negative mental health” to encompass several conditions such as depression and anxiety. There is a “positive mental health.” This encompasses positive conditions such as happiness and peace of mind. These terms are not used to describe people. They are used to describe a state of mind. We all experience moments of positivity and negativity, a reflection of our mental health in a specific point

in time. It is not relating to identity or personality. The terms positive mental health and negative mental health will be used throughout to describe a state of mind.

### **Purpose Statement**

With the current increasing attention on disability, I believe it is important to contribute to the literature using personal experiences relating to societal issues. Therefore, I will explore the topics of disability and organizational problems using autoethnographic and *testimonio* approaches. I cannot speak for others with similar experiences, but I can represent the experiences of others through my own words. My experience is unique and will offer insight into why some people are dissatisfied with their organizations and academic experiences.

### **Significance/Implications**

Over the last few years, I have witnessed an increase on conversations regarding mental health in news outlets and social media. Not all aspects of health are noticeable in work environments and learning environments. The goal of this study is to bring attention to an invisible aspect of disability, mental health and learning disabilities, and how negative mental health can impact a person's ability to learn. Understanding the current perspective on mental health in relation to learning, teaching, and employment will provide insight as to what information will be necessary in creating equitable learning environments.

### **Brief Methodology**

*Testimonio* and autoethnography will be the primary methods used for this research study. I will use autoethnography to write joyfully through various emotions (from anger to uncertainty), use insider knowledge, making life better (Adams, 2012),

look at myself and my world (Boylorn, 2008), and allow social justice (Bochner, 2018). Using *testimonio*, or testimony (Menchú & Burgos-Debray, 1984), I share my personal stories to shed light on organizational culture problems and academic problems surrounding my disabilities. Culture plays a role in my experiences, which makes for a great opportunity to include social analysis (Rosaldo, 1993). Rosaldo explains, “What follows urges that social analysis recognize how much of life happens in ways that one neither plans nor expects” (p. 91). We, as researchers, describe and interpret what we believe to be reality and truth. Sharing my experiences regarding my disabilities to my surrounding friends and colleagues led them to sharing their related experiences with me. Those conversations inspired this idea for writing about my personal experiences with disabilities, specifically sleep apnea and negative mental health. The methodology will be elaborated upon in chapter three.

### **Positionality**

After being diagnosed with severe obstructive sleep apnea, every night during sleep, I awoke every two minutes to an obstruction in my breathing. Over a period of a year, a significant amount of weight was gained, and my health worsened. Prior and even during early stages of receiving sleep therapy, I noticed people in my professional surroundings did not believe that my overall health had decreased significantly. I was not functioning correctly when it came to thinking, explaining, and holding conversations, yawning frequently, often resisting falling asleep during conversations. Being a responsible employee and student, I shared the status of my health and how it was impacting me so that people could understand, be patient with me, and most importantly, provide additional support. My plea for help was received by deaf ears. I experienced not

being believed, trusted, and supported in my roles as a graduate student and full-time professional. During this timeframe, I experienced several mental breakdowns, reaching a point where the thought of death became appealing as a form of getting rest and sleep. Few were the people willing to provide any kind of help. My recovery journey was not easy as several events interrupted the healing. There have been several difficulties that occurred that encouraged me to write this *testimonio* and autoethnographic research study, or a study about my personal experience, to bring attention to the issues surrounding health and well-being in an academic institution through the perspective of organizational culture in higher education. After sharing my experiences with colleagues and friends across the United States, they motivated me to study myself and my surroundings as my issues resonated personally to their own lives.

### **Purpose/Aims/Rationale: Why Am I Sharing?**

There have been several instances throughout the severity of my health journey that made me experience not being believed, not being supported, not being accommodated, and not having the resources necessary to be successful. It disheartened me. It made me recognize the issues in the education system and the organizational culture of my employers. There were instances each day that made me want to lose hope, give up, and quit on myself. It was torture. I self-advocated. I wanted to blame myself for every outcome of each day, recognizing I would do things different for a student or employee in my condition. In verbally sharing my experience with those who listened to my stories, I began receiving support. Some began relating to my experience and others began sharing their similar stories. It was these people that inspired me to take action against the social injustice surrounding my health. My focus on this study is to bring

attention to disabilities such as sleep apnea and how it impacts one's mental health, and the challenges I experienced as an employee and graduate student dealing with these disabilities at a university and how it impacted my learning.

### **Overview of Chapters**

The following chapters will elaborate upon my personal experiences and how it all relates to society. Chapter two will be a review of literature relating to disability and organizational culture with an emphasis on higher education as the learning environment. Chapter three will provide my qualitative methods, *testimonio* and autoethnography, and the foundation for it. Chapter four will explore in-depth personal experiences and some relations to popular culture through the use of films, books, news articles, and other sources. Chapter five will conclude by providing my findings, analysis, implications, and recommendations for future research. Chapter six will provide solutions and lessons learned for anyone who may find themselves in a similar position.

### **Frequently Used Terms**

The following terms will be used throughout:

- Traveling Family: faculty in leadership conferences that are colleagues and friends
- Sleep apnea: obstruction of breathing, causing disruptions in sleep
- Positive Mental Health: encompasses positive feelings, thoughts, and emotions such as happiness and peace of mind
- Negative Mental Health: encompasses negative feelings, thoughts, and emotions such as depression and distress



- Learning Environments: places where learning occurs such as universities, colleges, conferences, and other organizations
- Discrimination: showing prejudice through action, speech, and treatment, especially towards race, ethnicity, disability, gender, nationality, religion, sexuality, spirituality, etc.

## CHAPTER 2

### REVIEWING LITERATURE | WHAT DO WE KNOW?

Before diving into my life experiences that motivate this research study, we must understand the research that exists within the fields of disability and organizational culture. In exploring relevant studies, I will use the existing literature to demonstrate the need for my study, beginning with describing disability and associated theories. This will include describing the learning environment in higher education for students with disabilities and the challenges it entails for those students. It will be followed by organizational culture, or the workplace as I like to call it, and explain both the good and bad about organizations relating to disability. The theoretical framework, theories being applied, and the conceptual framework, key concepts within research, will be interwoven throughout this chapter (Savin-Baden & Howell Major, 2013). Combined, this chapter helps the reader understand why *testimonio* and autoethnography are important and how it makes a unique contribution to the literature on disabilities and organizational culture. This will help the reader understand my perspective on disabilities as a graduate student and staff member. The theories and definitions addressed will reinforce the stories shared in chapter 4. In the first section, disability legal requirements, key theories, and models of disabilities are defined. The second section consists of a description of sleep apnea and mental health, disabilities and substance use. This section ends with a description of the literature describing the learning environment.

#### Disability Legal Requirements

The World Health Organization (WHO) defines disabilities as an umbrella term that covers topics such as “impairments, activity limitations, and participation

restrictions” (2019, para. 1). WHO’s definition includes disabilities that are temporary. The Centers of Disease Control and Prevention (CDC) defines disability as “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)” (2019, para. 1). Disabilities impact everyone, whether they have short-term or long-term conditions. WHO states that “over a billion people, 15% of the world’s population, have some form of disability” (first bullet point) and that “between 110 million and 190 million adults have significant difficulties in functioning” (para. 2, 2018). Given these numbers, it is no surprise there have been efforts to support individuals with disabilities through law. The Americans with Disabilities Act Amendments Act (ADAAA) describes disability as an “individual with a) a physical or mental impairment that substantially limits one or more major life activities of such individual; b) a record of such an impairment; or c) being regarded as having such an impairment” (2008). Furthermore, major life activities as described by the ADAAA include things such as caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. It is inclusive of the operation of major bodily functions such as the immune system, digestive system, neurological system, brain function, respiratory system, and more. In short, any body function that limits our abilities significantly is categorized as a disability and will fit under legal requirements. These categories provide the groundwork to understand the legal requirements for an individual to be classified as having a disability. The ADAAA includes protections for individuals with disabilities to avoid any discriminatory practices

in any setting. These legal protections will be further discussed under the workplace discrimination section of this chapter. In my specific situation, sleep apnea (respiratory/learning), Attention Deficit Hyperactivity Disorder (ADHD; neurological/learning), memory retrieval (neurological/ learning), and mental health (neurological) are all disabilities that I experience. These are all invisible disabilities as there are no physical displays other than the way I express myself through verbal cues and body language. Because of these conditions, under the ADAAA I must be accommodated in the workplace and academic settings.

### **Accommodations**

Every disability requires a different accommodation that must be provided to create an equitable environment (Susser & Petesch, 2011). The ADAAA requires all employers to treat all employees equally and provide reasonable accommodations to those requiring it as long as it does not create a hardship to the employer. These hardships can be simply explained as a financial burden to the employer (Ocon, 2006). The process to providing an accommodation is based upon the essential functions of the job description and whether the accommodations are reasonable to fulfill the responsibilities of the job (Susser & Petesch, 2011). Some examples of reasonable accommodations are “make the workplace accessible to persons with disabilities”, “job restructuring, job sharing or job reassignment”, “equipment and furniture modifications”, “part-time and modified work schedules”, “a reserved parking space”, and “leave of absence” (Ocon, 2006, p. 63). Section 12111 of the ADAAA describes reasonable accommodation to include “(A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and (B) job restructuring, part-time or modified

work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.” The ADAA has made it very clear what defines a disability and that employers are required to provide accommodations if they are needed by an individual with a disability. As described above, it also provides some ideas of the types of accommodations that can be provided. The Job Accommodation Network (JAN; [www.askjan.org](http://www.askjan.org)) is a great free online resource that provides assistance to anyone seeking help in regard to disabilities. JAN has a Searchable Online Accommodation Resource (SOAR) engine to help people find reasonable accommodations based on their disability. This resource is available to both individuals and employers. Use it to request accommodations at a workplace that fit the description of “reasonable accommodations” that would not cause any financial hardships to the employer. It is important to note that not all accommodations require financial decisions on behalf of the employer.

### **Disability Theories and Models**

Finding out I had two learning disabilities, there was a moment of relief as there was an answer as to why I experienced certain challenges. When I learned that my sleep apnea and the mental health changes it created were also disabilities, I felt like there was something wrong with me and society would not be accepting of me. It has taken time for me to embrace my uniqueness and realize that it is part of my identity. The following theories and models help provide an understanding as to why an individual would be concerned to be identified with any disability.

## **Stigma**

Stigmas, in general and especially those associated to disability, continue to exist long after Goffman (1963) described it. Stigma is an outcome of ignorance and oppression, not a model or theory of disability. The perceptions of nondisabled people impact those with disabilities through motives and behaviors reflecting stigmas and stereotypes, thus creating barriers for acceptance and integration into the social context of the higher education learning environment (Olkin, 2012; Shannon et al., 2009; Hayashi & May, 2011). Beliefs exist “that all individuals with disabilities are dependent, isolated, and emotionally unstable” (McCaughey & Strohmer, 2005, p. 90). Goffman defined stigma as: “abominations of the body . . . blemishes of individual character perceived as weak, ill, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty . . . mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior [and] tribal stigma of race, nation, and religion” (p. 4). People create stigmas for their perceptions relating to a person’s body, characteristics, and beliefs or place of origin. Goffman describes stigma as taking place through social information (what is perceived in a social setting), visibility (how much it obstructs and conceptualizes), biography (a person’s own narrative), and personal identity (the profiling of conduct and character). People’s social and personal identity affect the decisions in which people enter spaces based on their identity and whether they can “pass”. To pass means blending into an environment without anyone noticing their disability or stigma. Goffman explains that “It is a fact that persons who are ready to admit possession of a stigma (in many cases because it is known about or

immediately apparent) may nonetheless make a great effort to keep the stigma from looming large” (p. 102). He further explains that this will lead some people to live a “double life” in which people will know about their stigmas and others will remain unaware. Disability fits within Goffman’s definition of stigma:

Hence individuals with a stigma, especially those with a physical handicap, may have to learn about the structure of interaction in order to learn about the lines along which they must reconstitute their conduct if they are to minimize the obstructiveness of their stigma. (p. 104)

Because people are stigmatized by others that perceive them not to fit their definition of “normal”, they face obstructions preventing them from “fitting in” to their social norm. As a result, a person with a disability will have to find a way to live a “double life”, or blend into their present environment by minimizing their disability as much as possible, which can be difficult and stressful.

### **The Medical Model**

The medical model focuses on “to fix” or “remedy” disability as a problem within the body while ignoring the role society plays in an individual’s disability (Castañeda et al., 2013; Evans et al., 2017; Siebers, 2008). “Within medical models, societies view ability and disability as rooted in the body; these models conceptualized ability and disability as overriding characteristics of the body” (Hill Collins, 2019, p. 259).

Addressing health through the medical model implies you will receive a cure (e.g., pills, therapy, treatment, prosthetics, eyeglasses), if available. The medical model does not address a person’s environmental conditions contributing to disability such as discrimination, prejudice, and oppression (Evans et al., 2017). This can range from a business not having wheelchair access to a learning environment not providing academic accommodations. Society is not expected to make adjustments for individuals with

disabilities (Evans et al., 2017). A person is expected to utilize “remedies,” such as accommodations required by the ADA. Therefore, the medical model implies disabilities must be cured through medicine and not by societal adjustments.

### **A Minority Identity**

Disability is often seen as a negative aspect of someone’s identity that is based upon that person’s surrounding environment and community. Seibers (2008) explains that disability is a minority identity and argues that it is not a negative identity. He best explains it when he says:

Unlike the medical approach, the emerging field of disability studies defines disability not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but the significant changes in the social and built environment. Disability studies does not treat disease or disability, hoping to cure or avoid them; it studies the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression, attacking the widespread belief that having an able body and mind determines whether one is a quality human being (p. 3).

This way of thinking about disabilities as a study and theory completely changes the way an individual might perceive themselves and others. The focus shifts to identity and recognizes it as a marginalized group along with race, feminism, sexuality, LGBTQ+, and other groups. This way of thinking serves as a model of how to frame disabilities because it moves it from a medical approach to an identity that faces social injustices. It provides meaning to the identity of a group that relates with the term disability. On a personal level, it resonates with me because of my own challenges in accepting being labeled as a person with disability. It was like hitting a learning disability wall and not knowing what to do next (Howland & Gibavic, 2010).



## Identity Development

It is difficult to understand learning disabilities because they are invisible, not displayed physically. Howland & Gibavac (2010) created a theory and model for understanding individuals with learning disabilities. They refer to it as the “Howland/Gibavac Model of Identity Development in Persons with Learning Disabilities”. Their model is based on stage theory of development and grounded in the works of Erickson, Vygotsky, Kohlberg and Gilligan, and Jackson and Hardiman. To best describe their model, I created table 1 to show the two tiers and their categories.

<b>Tier 1: Influential Variables: Social Systems and Timing</b>	<b>Tier 2: Stages of Identity Development</b>
Support Systems	Problem with the Wrong Name
Timing	Diagnosis
Social Receptivity/Acceptance	Grief and/or Relief
Dual Diagnosis	Resistance and or Alienation
Cause of Disability	Passing
<b><i>Multiple Identity Development:</i></b> Multiple Intelligences; Moral Identity Development; Racial/Cultural Identity; Gender Identity; Physical Identity; Belief Systems	Redefinition
<b><i>Cognitive Attributes:</i></b> Learning Disabilities; Auditory/Language Processing; Nonverbal/Visual-Spatial Processing; Memory Difficulties; Executive Functioning	Ongoing Resolution Process

Table 1. Howland/Gibavac Model of Identity Development in Persons with Learning Disabilities.

Each tier has their own figure. Tier 1 looks like a Rubik's cube with each set being a different side of a three-dimensional cube. Tier 2 is a process that the individual goes through based upon what occurs in the first tier. This model does justice to what an individual with learning disabilities will experience when they discover that the learning wall they hit is a learning disability. It is a useful way to understand my own process with learning disabilities. The moment I learned I have two learning disabilities gave me relief, but grief settled in later after realizing how many life experiences were encountered in which I struggled and had been discriminated against for not performing at an expected level as an employee and student. I find myself redefining what it means to have a disability through an ongoing resolution process to be the best I can. It changes my research lens on disability and reinforces how disabilities are still not fully accepted nor integrated into society.

### **Social Model**

The social model of disability (SMD) is best described as separating the views of the individual from society (Oliver, 1990). Before SMD, disability was viewed as a problem based on functional limitations and psychological losses, placing focus on the individual. The SMD reverses and rejects this view. Instead, it identifies the problem as being within society. It does not deny that an individual has a disability. It instead becomes "society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation" (p. 3). The failure of society to provide services becomes institutionalized discrimination to individuals with disabilities. Oliver argues that the medicalization of disability is inappropriate as it sees disability as an illness to be fixed and not a societal issue. "It is

society that has to change not individuals and this change will come about as part of a process of political empowerment of disabled people as a group...,” (p. 5). Oliver’s view of SMD is removing disability as a problem of an individual and focusing on society as the source of the problem for not accepting disabled people as they are part of society. SMD moves away from the medical view on disability and reverses that view to how society perceives disability.

### **Critical Disability**

Critical Disability Theory (CDT) is created from critical theory with a disability studies framework and contains seven elements: the social model of disability, multidimensionality, valuing diversity, rights, voices of disability, language, and transformative politics (Hosking, 2008). The social model of disability, as described above, has three principles that are adopted by Hosking as follows: “Disability is a social construct...”, “disability is best characterised as a complex interrelationship...”, and “...the social disadvantage experienced by disabled people is caused by the physical, institutional, and attitudinal (together, the ‘social’) environment...” (p. 7). Multidimensionality refers to the multiple interconnected memberships an individual has in their life. Valuing diversity plays a critical role in understanding that each person is different and that those differences must not be dismissed. Both legal and social rights are important to CDT as they are a tool to help individuals with disabilities integrate into society as well as provide equity. Voice is critical to supporting the disability community and is important to CDT as it gives the disability community a platform to address ableist notions. Language influences concepts of how disability is viewed and may have a political undertone. It must be acknowledged that language can be both negative and

positive and is important to consider the role of language in CDT. Lastly, transformative politics helps ensure that CDT focuses on theory and practice that is influenced by policy responses to create a just environment for the disability community. Overall, CDT has a strong political influence that is reinforced by the understanding that all people are different, and that society has a role of how the disability community is viewed.

### **Cultural Theory**

Devlieger (1999) defines disability “as a universal interstitial social status, i.e., a status that places itself between recognized categories and statuses and that is neither marginal nor elevated” (p. 297). Understanding this definition builds on the cultural theory of disability (CTD). Devlieger explains that universalistic (the whole) and relativistic (relative conditions of knowing) understandings of disability do not address the complexity of disability and that instead of focusing on one explanation, we should focus on both. Devlieger sees the universal interstitial as a way to “express the potential and the energy that results from a phenomenon that challenges and interrogates existing categories.” Disability is “a source of innovation and creativity” (p. 299). Relativistic claims follow suit in that they focus on the classification of disability terms, social practices, art, spirituality, and religion. Devlieger believes that a healthy interdependence between the dimensions of local, global, indigenous, expatriate (to withdraw/banish), relativistic, and universalistic are needed for cultural richness and resilience. He believes that “the medicalization, professionalization, and globalization of disability have generally ignored and oppressed local development and indigenous thought on disability” (p. 300). Devlieger lays out a path for further research that should focus on language; art;

ritual, religious, spiritual, and cosmological ideas and practices; cultural concepts of human development; gender; political discourses; and tools for development.

## **Social Justice**

Also known as the ableist or disability oppression model, the social justice model addresses ableism, which is discrimination/prejudice towards those with disabilities (Bell, 2013; Evans et al., 2017; Griffin et al., 2007). Ableism, or to be an ableist, means a person is discriminating or being prejudiced towards individuals with disabilities (Merriam-Webster, n.d.a). The following three components are the central focus to this model: privilege and oppression; diversity and intersectionality; and educational mission. Privileged individuals, (in this model, those without disabilities), have led the notion of how individuals with disabilities should be viewed and treated (Evans, 2008). Oppression is “woven throughout social institutions as well as embedded within individual consciousness” (Bell, 2013, p. 22). In this sense, oppression is pervasive, it is restrictive by structural and material barriers, hierarchical because those with disabilities are disempowered, and is internalized by all involved. Hardiman, Jackson, and Griffin (2013) state that oppression has three dimensions: context, application, and consciousness. Oppression can take place at any location in any setting whether it is done knowingly or unknowingly. Diversity and intersectionality are important to understand as each disability has different impacts, and an individual’s background (e.g., race, gender, socioeconomic status, spirituality) can create a variety of scenarios (Casteñeda et al., 2013; Evans, Assadi, & Herriot, 2005). The educational mission of this model is to ensure students with disabilities are provided support, to educate people with and without

disabilities about disability oppression, and change the structures and policies that enable disability oppression (MacKinnon, Broido, & Wilson, 2004).

### **Intersectionality**

Although intersectionality is not strictly associated with disability, it does help to further understand the complexity of an individual's identity. Intersectionality asserts that a person's identity and interactions with their surrounding are "influenced and shaped not simply by a person's race, class, ethnicity, gender, physical ability, sexuality, religion, or nationality – but by a combination of all those characteristics" (Dill & Zambrana, 2009, p. 6). Disability alone cannot be discussed without understanding a person's identity (e.g., gender, race, socioeconomic status, religion). A college student from a first-generation low-income background will struggle more than a continuing-generation student (Evans et al., 2017). The struggle for a first-generation student can include lack of preparation, college knowledge and/or financial literacy. Add a disability to the first-generation low-income student and the goal to succeed academically increases in difficulty. "Taking an intersectional approach is imperative when an individual's experiences are not defined by a single identity but rather by the simultaneous experiences of the multiple identities they hold" (Evans et al., 2017, p. 144). Intersectionality does not exclude key characteristics of identity and instead allows us to understand how the diversity in one person can affect them holistically. At institutions of higher education, other social identities (e.g., women, Latinx, Black, first-generation) are given more attention while "less attention has focused on students with disabilities, which can intersect with other identities to compound students' experience of marginalization

on college campuses” (Vaccaro & Kimball, 2019, p. 219). Intersectionality moves away from one piece of a social identity. It includes how all the components of identity are interrelated. The notion that a person’s ability or disability represents the whole person, which is a stigma, informs us about the social construction that is informed by body politics (Hill Collins, 2019). When we write or speak of disability, we cannot remove the other components of social identity. Each component of social identity will inform others, which will always vary based on which components the person strongly identifies with. Intersectionality will be further explained as a research method for this study in chapter 3.

### **Wrapping Up This Section**

These models and theories described in this first section help move and change the narrative of disabilities from a medical problem to an identity needing empowerment. My perspective is to look at the social environment that negatively impacts a way a person with a disability is viewed, interacted with, and addressed. Therefore, I will primarily use intersectionality as theory, stigma as a model, and the social justice model for this *testimonio* and autoethnography as they are better equipped to help a reader understand the stories about my own disabilities in chapter 4. In the following second section, sleep apnea, mental health, the relationship between substance use and disabilities, and the learning environment of students with disabilities in higher education will be described.

### **Understanding Sleep Apnea**

Sleep apnea is a series of respiratory or brain obstructions that disrupt sleep (Mayo Clinic, 2018). The Centers for Disease Control and Prevention (CDC) reports that a third of United States adults do not get enough sleep which can lead to more severe

issues such as diabetes, depression, and heart disease (2018b). As a result, the CDC declared sleep deprivation an epidemic. In fact, not sleeping for more than twelve to eighteen months will result in death; although even one night with poor sleep can impact performance, personal relationships, and functioning (Walker, 2017). Not getting enough sleep will render a diet useless, decrease healing, decrease memory performance, and can lead to other severe health problems (Buysee, 2014; Walker, 2017). In my case, I was experiencing every symptom of sleep apnea. No one believed how much I was struggling internally, despite the visible change in my physical appearance as I gained weight due to my body's inability to metabolize. You would not know what was wrong with me by looking at me. To everyone, my outside representation is that I am well mentally. Physically, I am overweight, or obese. Other than that, I look like an ordinary person. To provide some context, I was dealing with the following symptoms of sleep apnea:

- Sleep Deprivation
- Metabolism Dysfunction
- Headaches
- Hypertension
- Fatigue
- Excess weight
- Irritability (Mayo Clinic, 2018)

The National Heart, Lung, and Blood Institute (NHLBI; 2018) estimates that about 50 to 70 million Americans have a sleep or wakefulness disorder. Sleep problems are associated with a growing number of health problems, from heart disease to even some forms of cancers. The NHLBI research has determined sleeping a regular seven to eight hours a night lowers the risk of obesity and high blood pressure. Their research has also determined that untreated sleep apnea increases the risk of atrial fibrillation (irregular heart rate that causes poor blood flow), high blood pressure, and diabetes



during pregnancy. As a result of sleep deprivation, I developed high blood pressure and negative mental health. There is much the lack of sleep can do to a person that will impact all aspects of an individual's health and put that person at a higher risk of death (Walker, 2017).

### **Sleep and Learning**

In a sleep study focused on further understanding the brain in relation to sleep deprivation, Saletin (2014) sought to understand the degree of impairments in learning following sleep deprivation in the hippocampus structure of the brain and how selective memory consolidation can be best understood by looking at sleep spindles, which are data waves related to sleep that are small and dispersed. Saletin's study results demonstrated that grey matter in the basal forebrain ([https://en.wikipedia.org/wiki/Basal\\_forebrain](https://en.wikipedia.org/wiki/Basal_forebrain)) should be a predictor for sleep deprivation condition. The loss of hearing and pain in general (sleep disrupting conditions) show a decrease in grey matter. If you have any sort of pain, chances are you won't sleep well. The results also showed that the subfield structure of the hippocampus can predict vulnerability differences in the severity of learning impairment associated with sleep deprivation. This means that the level of impairment can be best pinpointed on the degree of sleep deprivation. In addition, non-rapid eye movement (NREM) recovery sleep quality after sleep deprivation also determined the success with learning restoration. Recovery sleep, as the name suggests, is sleep in which the brain focuses on recovery in our body (injuries, lack of sleep, bruises, etc.). This is different from regular sleep, in which the brain does general maintenance. Last, the study also suggests that based on prior waking instructions (i.e., studying, memorizing, experiences, reminders) leads to

selective remembering and forgetting of discreet item information. Sleep maximizes the forgetting effect.

Saletin's (2014) study differs to others in that it found that learning and forgetting are not unidirectional; they are separate processes. Sleep relative to time awake "can selectively enhance recall for words previously cued for remembering, without such facilitation of items instructed to be forgotten" (p. 57). Sleep deprivation impacts our ability to learn, remember, forget, and heal. Without sleep, the brain is unable to function effectively and begins to affect our overall health based on the degree of sleep deprivation (Buysee, 2014; Saletin, 2014; Walker, 2017). The level of sleep deprivation will dictate the time a person will need to fully recover (Saletin, 2014; Walker, 2017). Saletin's study was unable to identify a way to best determine what the time will be for recovery based on sleep deprivation severity. My own experience reinforces the findings of Saletin's study as I sometimes become impatient in my own recovery process. Curious about your sleep habits? Take Buysee's Satisfaction, Alertness, Timing, Efficiency, Duration (SATED) questionnaire, which can be found in his article (<https://doi.org/10.5665/sleep.3298>). National Geographic's documentary, *Sleepless in America* (<https://youtu.be/1qlxKFEE7Ec>), is worth watching and a great way to learn about the issues affecting our society's ability to sleep.

### **Defining Mental Health**

As an aspect of disability and overall wellbeing, mental health is an integral part of every human. We all experience emotions and feelings of happiness, sadness, anger, peace, and many more. The World Health Organization (WHO) constitution states, "Health is a state of complete physical, mental and social well-being and not merely the

absence of disease or infirmity” (1946, para. 1). The WHO believes that mental health is a fundamental part of society and the determinants related to it are social, psychological, and biological, which at any given time can determine a person’s mental health. The National Institute of Mental Health (NIMH) states that mental health can lead to an illness like depression, and it can either lead to other health problems such as hypertension and diabetes or can occur after experiencing health problems such as cancer, a stroke, arthritis, epilepsy, and many more types of chronic illness (NIMH, 2020). NIMH also emphasizes that people with chronic illnesses are more likely to experience depression. Many different possibilities can change our mental health to becoming negative, leading to illness. The CDC states that there is no single cause for a mental illness and several factors such as early adverse life experiences, ongoing medical conditions, biological factors, substance use, having few friends, and feelings of loneliness or isolation contribute to our mental health (2018a). One study determined that at some point in a person’s lifetime, more than 50% of people will experience a mental illness or disorder (Kessler et al., 2007). Other studies have determined that in any given year, 1 in 5 Americans will experience a mental illness (Center for Behavioral Health Statistics and Quality, 2016) and 1 in 5 children currently or have had a debilitating mental illness (Merikangas et al., 2010).

### **Mental Health in the COVID-19 Pandemic**

Communities of color, specifically Asian, Latinx, and Black, have been hit the hardest during this pandemic in the forms of death, discrimination, and verbal harassment (Choi & Kulkarni, 2020; Depres et al., 2020; Liu & Modir, 2020; Scott, 2020; Stafford et al., 2020; Singh & Koran, 2020; Tavernise & Oppel, 2020; Taylor, D.B., 2020; Taylor,

K.Y., 2020). Asians have been victims of verbal harassment because COVID-19 originated from China (Tavernise & Oppel, 2020). Black Americans are experiencing death due to COVID-19 at three times the rate compared White Americans due to the need to work and health conditions; increased racial profiling because of face masks concealing identity (Liu & Modir, 2020; Stafford et al., 2020; Wolf; 2020). Similarly, Latinx and undocumented migrants are also facing hardships with higher rates of COVID-19 infection, lack of financial support for migrants, and being essential employees (Kim, 2020; Liu & Modir, 2020; Singh & Koran, 2020). These increased experiences of discrimination, racial inequalities, and systemic oppression in communities of color during the pandemic contribute to already difficult challenges of anxiety, depression, panic, trauma, and many other forms of disability. These issues are not new. The pandemic has elevated the issues and brought them closer to the forefront of society. The pandemic has made it more difficult to trust people given that not everyone is taking safety and precaution towards the virus. This is negatively impacting social behavior. It only divides those who support efforts to reduce COVID-19 infection rates and those that believe it to be a hoax. On a positive note, there has been a greater emphasis on negative mental health issues such as anxiety, depression, panic, and substance abuse because of the increase in isolation required to reduce the rate of coronavirus infection. In some cases, disabilities impact a person's decision to use substances (e.g., alcohol, prescription medication, smoking) to cope.

### **Disabilities and Substance Use**

There are many reasons why someone with a disability may turn to using alcohol, tobacco, and other drugs (ATOD). Many studies have made connections on how

substance use and/or abuse can be associated with physical disabilities (Ebener & Smedema, 2011; Samokhvalov et al., 2010; Turner, Lloyd, & Taylor, 2006), intellectual disabilities (Chapman & Wu, 2012; Degenhardt, 2000), learning disabilities (Cosden, 2001; Janusis & Weyandt, 2010; Molina & Pelham, 2001), and mental health (Cochran et al., 2007; Wu et al., 2013; Olfson et al., 2000). Disabilities can be difficult experiences for people depending on their life circumstances and the impact of the disability. The quality of life for a person with a disability can have several factors that lead towards substance use dependence.

### **Physical Disabilities**

Disabilities and substance use require that mental health be addressed, as these topics are related to and influence each other. (Chapman & Wu, 2012; Cosden, 2011; Degenhardt, 2000; Ebener & Smedema, 2011; Samokhvalov et al., 2010; Turner, Lloyd, & Taylor, 2006). Physical disabilities and alcohol use disorders (AUD) can lead to changes in emotional state, social relationships, memory, and thinking (Samokhvalov et al., 2010). The combination can contribute to anxiety and impairments of speech and hearing. A poor quality of life can contribute to negative vocational and psychosocial rehabilitation outcomes for reasons not fully understood (Ebener & Smedema, 2011). Physical disabilities and substance disorders are greater for men, the young (18-49), and persons of Hispanic heritage (Turner, Lloyd, & Taylor, 2006). Turner, Lloyd, and Taylor identified that some of the psychiatric problems relating to physical disability are depression, anxiety, post-traumatic stress (PTS), and conduct disorders, which tend to occur more in men and Hispanic individuals with physical disabilities. About 25% of men report alcohol abuse-dependence compared to women (5.06%). In regard to

psychiatric disorders, nearly 24% of men experience them as compared to women at 25.5%. Hispanic individuals with major depression is over 21%, compared to non-Hispanic White (12.8 %) and African American or Black (9.05%). Substance abuse dependence was reported at nearly 20% for Hispanics, 18.96% for African Americans, and nearly 22.83% for non-Hispanic White. Turner, Lloyd, and Taylor's study results mirror that of a study on individuals with intellectual disabilities by Chapman and Wu (2012). Their review of the literature demonstrates that individuals with intellectual disabilities experience more severe mental, physical, and social consequences to substance use related problems than members of other groups yet remain an understudied population. Other studies have also addressed this regarding physical disabilities (Cosden, 2011; Ebener & Smedema, 2011; Samokhvalov et al., 2010; Turner, Lloyd, & Taylor, 2006).

### **Learning Disabilities**

The literature on substance use and physical disabilities applies to learning disabilities (LD) and substance use. Cosden (2001) conducted a literature review and identified a lack of research. "The data indicate that a majority of individuals with LD do not abuse drugs or alcohol, yet individuals with LD are disproportionately represented among those in need of substance abuse treatment" (p. 357). Cosden also identified a need for risk and protective factors for individuals with learning disabilities. One study identified that children with ADHD with higher IQs were likely to try alcohol or cigarettes at an early age while children with ADHD with higher reading achievement scores were less likely to have an alcohol use disorder (Molina & Pelham, 2001). Another study on college students reported lower alcohol and marijuana use, although prescription

stimulant medication was more likely to be misused (Janusis & Weyandt, 2010). Their results identified a difference on sensation seeking, alcohol and marijuana use, between students with and without disabilities. Their findings suggest that students with learning disabilities are unlikely sensation seeking (using substances to get high or inebriated) due to medication use, anxiety, depression, and the symptoms of their disability.

### **Mental Health**

Naturally, reviewing literature on physical, intellectual, and learning disabilities has relatability to mental health and substance use/abuse. Wu et al. (2013) identified that individuals with panic attacks, generalized anxiety syndrome, and agoraphobia (the fear of places and situations that might cause panic, helplessness, or embarrassment) were more likely to use substance abuse services. They determined the prevalence of service as 11% for persons reporting one co-occurring mental syndrome and 18% for persons with two or more mental syndromes. Data indicated that individuals with depression (13%) were more likely to use substance abuse treatment services compared to those who did not report depression (5%). Another study identified that patients with a mental disorder and substance use disorder (SUD) were more impaired compared to those with just a SUD (Olfson et al., 2000). Olfson et al.'s study identified that men were more likely to have a SUD compared to women. The study also identified that family distress contributed to SUD.

### **Sleep Deprivation**

With 68.8% of high school students sleeping less than eight hours during a school night and 35.2% of adults sleeping less than seven hours a night within the United States, it is clear that the lack of sleep impacts our health through various conditions such as

depression, heart disease, diabetes, cancer, obesity, and substance use (CDC, 2017). A study focused on adolescents identified those with sleeping problems had an increased likelihood of using tobacco, methamphetamine, inhalants, cocaine, ecstasy, marijuana/cannabis, and other drugs (Fakier & Wild, 2011). The study also looked at learning difficulties in adolescents and identified that they were more likely to experience sleep problems which lead to the use of tobacco, cannabis, and inhalants. Another study focused on college students and the use of alcohol and cannabis as sleep aids determined that alcohol was not frequently used to sleep yet cannabis was perceived to aid in sleep (Goodhines et al., 2019). The study determined that "...cannabis sleep aid use may improve same-night sleep maintenance and duration within individuals; however, it does not improve subjective sleep quality or sleep onset latency, and actually increases fatigue the following day" (p. 1043). Contrary to this study, Altman et al. (2019) identified that cannabis can aid in some sleep disturbances, although not all. An individual's perception that cannabis use is positive also "decreased the likelihood of experiencing cannabis-related problems, irrespective of their sleep-related problems, age, or amount of monthly cannabis use" (p. 409). The study identified that older individuals were less likely to experience negative consequences compared to younger individuals. The participants in the study perceived cannabis to provide positive sleep effects such as falling asleep earlier and sleeping longer. Specifically, studying the use of dronabinol, or synthetic Tetrahydrocannabinol (THC) from cannabis, on patients with obstructive sleep apnea, Prasad, Radulovacki, and Carley (2013) determined that the use of dronabinol in doses of 2.5 – 10 mg significantly reduced the apnea hypopnea index (AHI) in patients. AHI calculates the number of times there is a partial loss of breath during sleep. Similar to the



previously mentioned studies, the researchers recommended that additional trials be conducted to confirm their findings. A literature review study focused on several components of the brain (nucleus accumbens, hippocampus, ventral pallidum, ventral pallidum, amygdala, and more) relating to sleep deprivation and reward-seeking behavior during sleep-wake states and their relation to addiction and sleep disorders (Ahrens & Ahmed, 2020). The goal was to develop a model to better understand why only select individuals develop addictions, whether it be food, drugs, or alcohol, and the importance to understand individual differences in sleep-reward circuitry. They state that “there is tremendous individual variation in how these conditions develop, the effects they have on health and social functioning, and how they respond to treatment” (p. 441). To put this simply, there is no concrete understanding as to why only some people develop addictions relating to sleep deprivation and disorders.

It is no surprise that disabilities, mental health, and substance use/abuse can influence one another. Any disability can make a person feel a range of negative emotions depending on the circumstances and their environment. As the above literature shows, depression and anxiety, paired with disability, contains a high risk of leading to substance use/abuse as a possible coping mechanism. My *testimonio* and autoethnographic dissertation research study will contribute to the literature of disability and substance use in chapters four and five.

### **The Learning Environment for Students with Disabilities in Higher Education**

The experience of students with disabilities can be a challenge in the learning environments of colleges and universities. Managing any disability is difficult on its own and the experience it brings varies for each person. Although each disability affects

everyone differently, there are general experiences that are applicable to students in higher education (Denhart, 2008; Heiman & Precel, 2003). For this section, the focus is directly on a general experience of students with disabilities in colleges and universities. Students confront a variety of barriers from being misunderstood, reluctance to seek accommodations, and requiring more time (Denhart, 2008). These barriers vary by disability type. Students with learning disabilities that transition from high school to college continue to experience challenges ranging from stress during exams, requiring visual and oral learning strategies, and difficulties concentrating (Heiman & Precel, 2003). The goal is to provide an overall context of disabilities in higher education by focusing on seeking help, faculty views, universal design, and approaches to improving the higher education learning environment.

### **Reluctance to Seek Help**

In general, students are reluctant to seek help for health problems and it is known that they experience higher rates of morbidity, disability, and mortality compared to their non-college counterparts (Grace, 1997). When it comes to disabilities, several studies have shown that some students are reluctant to disclose and request accommodations (Denhart, 2008; Getel & Thoma, 2008; Hartman-Hall & Haaga, 2002; Heiman & Precel, 2003; Quinn et al., 2009; Rodis et al., 2001). This reluctance to seek help also applies to students experiencing negative mental health such as depression and anxiety. Students do not always seek help until it is too late due to the stigmas associated to mental health and because they might not perceive themselves as having a disability (Quinn et al., 2009). “By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often

unthinkingly, reduce his life chances” (Goffman, 1963, p. 5). It is not easy and even sometimes may be embarrassing or shameful to accept the idea of needing help or being different from others. The stigmas surrounding disabilities are not normalized and seem out of the ordinary. Stereotypes continue to be problems both for students with disabilities and those without as views for low learning potential persist (Greenbaum, Graham & Scales, 1996; May & Stone, 2010). Stigmas and stereotypes are difficult to deal with when there are existing barriers in an unsupportive environment. Some students confront barriers ranging from identity issues, not wanting to disclose their disability to avoid negative reactions, insufficient knowledge to request accommodations and explain their disability, not finding accommodations helpful, and having negative experiences with faculty (Marshak et al., 2010). Even if a supportive environment does exist, it may not be apparent or visible to a person that may feel misunderstood. It is important to note that not all students with disabilities are reluctant to seek help if they were previously in a supportive environment prior to beginning college or university life (Trammal & Hathaway, 2007). The college experience will vary for each student. One constant interaction all students experience is that with faculty, which may hinder or support a student’s academic success.

### **Faculty Views of Students with Disabilities**

Faculty are generally viewed as subject matter experts in their area of study but that does not mean they are experts on teaching students with disabilities. Although this does not apply to every professor, there is a disconnect between many educators and students with disabilities when it comes to creating a supportive environment for learning. Students with learning disabilities fear being discriminated against (Denhart,

2008), and faculty do not always support and believe them. Marshak et al.'s (2010) study identified that some of the barriers students with disabilities confront are faculty not believing their disability, not providing accommodations after receiving the request from the disability office, and not providing additional support such as lecture notes and slides. Some faculty are reluctant or refuse to provide major accommodations like extra-credit assignments, alternate test formats, and alternate course formats because of possible compromise of academic rigor (Murray et al., 2008; Skinner, 2007). This kind of behavior has continued since the 1990s. Beilke & Yssel's (1999) study brought to the forefront the direct experiences of students with learning disabilities and the chilly climate they encounter with professors. Students noted that professors were reluctant to help or even directly address them, interrupted them mid-sentence, recommend the student find another course or question their interest, and would address their disabilities as "their problem," demonstrating the skepticism and prejudice college students with learning disabilities receive. In a study by Bruder & Mogro-Wilson (2010), 61% of faculty felt pity, awkwardness or embarrassment when they interacted with a student with a disability while 18% were unsure about how to interact with a student with disability. However, this has apparently changed as Yssel, Pak, & Beilke (2016) conducted a follow up study and learned that the learning environment for students with disabilities has improved. They believe faculty are more likely to offer help to students but have much to improve when it comes to accommodations, group work, and cooperative learning. Faculty may be willing to support students with disabilities yet do not fully understand learning disabilities to make teaching and exam accommodations meaningful (Murray, Wren, & Keys, 2008). This seems to be a consistent pattern in other studies. A study

conducted on faculty attitudes and practice for supporting students with learning disabilities revealed that faculty are willing to support them but 32% were unwilling to change the format of an assignment and 44% were unwilling to change the format of an exam (Vogel et al., 1999). Faculty are willing to support these students yet their reluctance to change assignments and exams was due in part to the complexity of creating parallel assignments and assessments of student learning, including not wanting to give students with learning disabilities an unfair advantage.

The problem is two-fold. First, both students with and without disabilities are willing to seek help from faculty yet those with disabilities are slightly less likely (Trammell & Hathaway, 2007). Students with disabilities are more likely to seek help from a professor that is known and shows willingness to be helpful and supportive versus one who demonstrates the opposite (Hartman-Hall & Haaga, 2002). If a student receives a negative response, they are likely not to seek help from that person or service again. The learning environment for this group of students needs to improve as this kind of behavior and responses from faculty are unacceptable. Although 71% of faculty will know about campus services for students with disabilities, they are not familiar on how to make exam and teaching accommodations (Murray et al., 2008). The same study revealed faculty with knowledge about learning disabilities had an increased likelihood to provide accommodations than those faculty without. Faculty have limited knowledge about the concept of disability including regulations (Baker et al., 2012). Another study supported the notion that faculty who had received disability training were also more willing to provide accommodations to students with disabilities (Murray et al., 2009).

Second, students with disabilities do need to learn to self-advocate as much as faculty need to be equipped to create supportive learning environments for all learners, regardless of disabilities. One potential solution is to help students create an advocacy plan that focuses on practicing how to explain their learning disability, ask for specific accommodations, and have conversations with professors (Lock & Layton, 2001).

Although focused on helping students with learning disabilities, I believe this is an applicable process for anyone with a disability. Other potential solutions are provided by Roer-Strier's (2002) study focused on providing learning materials to faculty relating to a student's learning disability with the student's accommodation letter, create peer support groups for students with learning disabilities, and teach the students to advocate for change. An oppressive campus climate to students with disabilities will cause those students to feel stigmatized by other students and faculty (Denhart, 2008; Evans et al, 2017; Hutcheon & Wolbring, 2012; Hong, 2015; Dowrick et al., 2005). Madriaga's (2007) study highlighted that negative learning environments caused students to feel that their disability was their problem. Hutcheon and Wolbring's (2012) study revealed that students with disabilities felt that some disabilities were more acceptable than others on campus and also experienced hegemonic (predominant state or group over others) ableism, causing them to internalize ableism. These steps will lead to improvement on the academic experiences of students and will make them feel empowered. Faculty need to take steps to create welcoming and supportive learning environments for all types of learners.

### **Universal Design in Higher Education**

With some college students with disabilities having a reluctance to seek help and some faculty not fully supportive of those students, what needs to change in the higher education learning environment? From my point of view, I believe the learning environment needs to adopt universal design for learning and instruction. Students should view themselves as “intellectually healthy but different” rather than disabled (Denhart, 2008, p. 494). No student should have to feel at a disadvantage or feel that they are lacking anything. We are all diverse learners; a learning environment should be accepting of the differences in thinking. Black, Weinberg, and Brodwin (2015) conducted a study on college students with learning disabilities to focus on their perspectives on teaching and learning. Students shared that accommodations, although helpful, did not fully address their unique learning needs. It was concluded that a universal design for learning (UDL) and universal design for instruction (UDI) approach is needed to improve courses for students with disabilities, which would benefit all diverse learners. Black, Weinberg, & Brodwin describe universal design for instruction as a) “designed to be useful to and accessible by people of diverse abilities,” b) “provide a choice in methods of use,” c) “straightforward, eliminating unnecessary complexity,” d) “information is communicated effectively to the student regardless of ambient conditions or the students’ sensory abilities,” e) “anticipates variation in individual student learning pace and prerequisite skill,” f) “designed to eliminate nonessential physical effort to allow maximum attention to learning,” g) “designed regardless of a student’s size, posture, mobility, and communication needs,” h) “interaction and communication among students and between students and faculty is promoted,” and i) “instructional climate is welcoming and inclusive, and high expectations are promoted for all students” (p. 4). These are

components that are often lacking in higher education learning environments. UDI needs to be at the center of all instruction within higher education. The goal should always be a fair and equitable learning environment inclusive of all students. In addition, UDL needs to be in tandem with UDI implementation. Universal design for learning incorporates three large areas: engagement, representation, and action and expression (CAST, 2020). In short, engagement is creating interest and motivation for learning. Representation allows for information and content to be presented in various ways. Action and expression provide the opportunity to differentiate ways for learners to express their knowledge. Visit [cast.org](http://cast.org) for a breakdown of each area and what you can do to create universal learning. Many studies show support for incorporating UDI and UDL into college and university settings as it benefits students with and without disabilities while making learning and teaching an enjoyable, inclusive, and diverse experience for all involved (Boothe et al., 2018; Evans et al., 2017; Grier-Reed & Williams-Wengerd, 2018; Higbee & Goff, 2008; Lewis & Sullivan, 2012; McGuire & Scott, 2006; Scott, McGuire, & Foley, 2003; Scott, McGuire, & Shaw, 2003; Spooner et al., 2007; Smith & Buchannan, 2012; Walker, 2017). I believe this is the first step in removing barriers to learning and teaching for students with disabilities. No learner should ever have to feel left out, disadvantaged, isolated, behind, or unsupported by anyone teaching or delivering instruction.

The inclusion of social justice in universal design (UD) would also help ensure that an equitable environment is created and sustained within higher education. A social justice approach would require that higher education understand the exclusion power and privilege they hold for students with disabilities, that those individuals are included in all



discussions that may impact them, and that the environment must change to provide equitable opportunities (Evans, 2008; Evans et al., 2017; Hackman & Rauscher, 2004; Lindburg, 2012; Johnson, 2010; Pliner & Johnson, 2004; Shakespeare, 2014). We cannot create assumptions about the needs of the disability community in an education setting. Policies and legislation alone will not ensure that universities are being inclusive of meeting the needs of students with disabilities, including staff and faculty (Hackman & Rauscher, 2004). UD must be implemented into the campus environment to create equitable learning environments (Evans et al., 2017; Orr & Hammig, 2009).

### **Improving Higher Education Learning Environment**

There is a lot that needs to happen to improve learning environments for students with disabilities. In fact, all students would benefit from this improvement. We need to begin with looking into teaching and learning. Heiman & Precel (2003) recommend that we should “examine various teaching methods and special conditions designed to help” students with learning disabilities that includes student “demands and need to adjust to higher education” (p. 256). The primary focus of an institution of higher education is to teach students that are there to learn. Cook et al. (2000) acknowledge the pushback students with learning disabilities receive and recommend that universities do more to further support students by “adopting more effective instructional practices” (p. 39). We might have to start by following the recommendation by Hartman-Hall & Haaga (2002) that an intervention focused on helping educate professors and students on disabilities, accommodations, and the impact of their reactions as their academic setting and its response affect a student’s willingness to seek help. Skrtic (1991) explains what accommodations represent:

Structurally, schools are nonadaptable at the classroom level because professionalization ultimately results in convergent thinking. Given a finite repertoire of standard programs, students whose needs fall outside the standard programs must be forced into them, or out of the classroom – a situation compounded by rational-technical approach to school management, which, by introducing unwarranted formalization, reduces professional thought and discretion and thus reduces the degree to which teachers can personalize their standard programs (p. 178).

In short, if I need additional help in the classroom, I have to find a tutor or accommodation outside the classroom so that I do not impact the instructor's lesson plan. In this sense, disability does not fit within the confines of education as it is not a priority of the educational system. The responsibility of creating an equitable learning environment is left to the individual student. In plain terms, a student with disability is an abstract shape that does not fit in a square shape hole that is education.

Institutions might not be ready to address teaching but perhaps changing the views on disability is a good starting point. Adding staff to serve as Learning Disability Specialists can aid and intervene when professors misunderstand students will be helpful in changing faculty misjudgments (Denhart, 2008). Students also need to be coached to learn how to ask for help and address issues surrounding stigmas (Trammel & Hathaway, 2007) when Learning Disability Specialists are not available. It will be helpful for institutions of higher education to continuously understand faculty attitudes and practices by conducting more studies (Vogul et al., 1999) so that adjustments can be made. Additional studies looking into discrimination by faculty on students with disabilities and reviewing disability theory to create new policies and revise existing policies are needed to ensure the success of this student population (Denhart, 2008). Last, Getzel & Thoma (2008) recommend that further research is needed to understand effective self-

determination skills for the success of students with disabilities in an institution of higher education. They say it is essential to hear the voices of students with disabilities to expand the knowledge and information. Their study revealed that students with disabilities need to have problem-solving skills, self-awareness about oneself and their disability, goal setting, self-management, support systems, know how to seek services on campus, and learn how to form relationships with faculty. It is clear that we do need additional research studies looking into teaching practices, faculty attitude, student services, and academic success. It is my intention to bring my personal disability experiences through a testimony and autoethnographic study. Many of the research studies addressed in this section mirror my own experiences as a doctoral student and my previous educational experiences. I will share my own insight as a student with disabilities to help build upon the research on students with disabilities in higher education.

In the context of higher education, disabilities not only impact students, but they also impact the employees which are often referred to as staff or faculty. The nature of my roles at a university have been both of student and staff, which warrants that I also focus on the interaction between disabilities and staff in the workplace. The learning environment I have described takes place within a university, which is also an organization. Given that universities are organizations, I will describe what organizational culture means in the workplace.

### **Organizational Culture: The Workplace**

Every individual comes with their own personality, values, beliefs, expectations, culture, and several other factors that create their identity. When a group of individuals

come together, it can create several different outcomes such as success, failure, unity, and hostility. Each group will be different based on their identity and their own perceptions. As someone who is unique, I take time to understand and identify the culture of every new space I enter. Understanding organizational culture involves understanding several layers of the people that create that space and the identity they have as a collective (Schein & Schein, 2017).

### **Theories and Definitions of Organizational Culture**

There are many theories and definitions of culture, and it is often casually used to describe a variety of meanings and behaviors (Angouri, 2018). Before I describe my thoughts on what defines culture, I will share some of the theories that exist. Schein and Schein (2017) describe their theory of culture as follows:

The culture of a group can be defined as the accumulated shared learning of that group as it solves its problems of external adaptation and internal integration; which has worked well enough to be considered valid and, therefore, to be taught to the new members as the correct way to perceive, think, feel, and behave in relation to those problems. This accumulated learning is a pattern or system of beliefs, values, and behavioral norms that come to be taken for granted as basic assumptions and eventually drop out of awareness. (para. 16)

Schein and Schein's definition has a focus on learning within the group and the learning that has been shared. The process involves people sharing that learning with each other to create a culture on those patterns and beliefs. In turn, it creates an identity for the group. In a study to determine if scientific concepts expand rationally in regard to organizational climate and culture, Verbeke et al. (1998) sought evidence to demonstrate that organizational behavior develops rationally. They determined that "(1) organizational climate is a reflection of the way people perceive and come to describe the characteristics of their environment, and (2) organizational culture reflects the way things are done in an

organization” (p. 321). Similar to Schein & Schein, Verbeke et al. believe that organizational culture is a reflection of the way people do things. Verbeke et al. also further look at organizations as having climates that are separate from their culture. Organizational climate is centered on how people perceive their environment. This is an important view that I will discuss in regard to shaping culture and demographics. Habermas (2005) theorizes culture “as an ensemble of enabling conditions for problem-solving activities” (p. 22). Habermas further describes it as not just the capacities of knowing, speaking, and acting, but inclusive of worldviews. Elaborating further, Habermas states:

And what is most important in our context, a culture cannot be maintained through drills and full-blown indoctrination; neither can it be maintained solely through the implicit habituation of the young into appropriate language games and practices. (p. 22)

Habermas’ definition includes a view of how our surroundings create our culture, stemming from our language to how we view the world, leading back to how culture includes problem-solving based on challenges. Leaning on the concept of worldviews, Heath and Bryant (2000) state that “Culture is shared and learned as a means by which organization members, employees for instance, come to know each other's views on important matters and share a social reality” (p. 320). Their definition is based on social influence and how that leads people to share and acquire behaviors and attitudes. Surroundings impact the way groups of people perceive culture. Weisinger and Trauth (2002) describe:

[C]ulture does not refer to stable, generalized dimensions assumed to be held in common by members of a particular group. Rather, it is fluid, contextually dependent, and created by actors within a group who may hold conflicting assumptions and worldviews. In other words, ‘culture is what culture does.’ (p. 309)

Their view of culture focuses on the conflicting assumptions and worldviews that are created by the people of a group. Altogether, these theories of culture have the same underlining view that people and their perceptions, beliefs, views, and values create conflicts to be solved, which is a fluid process. Each scholar acknowledges that it is the people who create culture based on something they bring or provide to the group. It is fascinating to me that, culture involves problem-solving which also means that positive, neutral, and negative outcomes can occur as part of the problem solving. These theories and definitions make it clear that culture will vary based on the group and its context. The organization of different views is what creates organizational culture.

Allaire and Firsirotu (1984) describe the various definitions of organizational culture, from ideational system to sociocultural system, and how each led to the various schools of thought (cognitive, structuralist, mutual equivalence, symbolic, functionalist, functionalist-structuralist, historical-diffusionist, and ecological-adaptationist). They group these various schools of thought into the influences of society's values and characteristics, the organization's past history and past leadership, and contingency factors. Allaire and Firsirotu explain that the focus on culture is based on "a confusing mixture of extant values, beliefs, meaning structures, symbols, myths, ideologies and in an assortment of artefacts: rites, rituals, specialized language, lore, customs, metaphors, etc." (p. 209). Given that there are various definitions of organizational culture, Allaire and Firsirotu propose a conceptual framework that best describes organizational culture. There are three interrelated components to their framework. The first component is the sociostructural system that includes formal structures, strategies, policies, management processes, and the organization's reality and functioning. Organization functioning

includes goals, objectives, authority, power structure, control mechanisms, reward, motivation, recruitment, and more. The second component is the cultural system, which is the organization's expressive and affective dimensions. This includes myths, ideology, values, and cultural artefacts (rites, acronyms, lexicon, lore, etc.). This component is affected by society, the history of the organization, and the influences of "contemporary dominant actors and the dynamic interplay between cultural and structural elements" (p. 213). The third component is the individual actors and "their particular endowments, experience, and personality...they become contributors and molders of meanings" (p. 215). Allaire and Firsirotu explain that the actors "strive to construct a coherent picture to orient them to the goings-on in the organization" (p. 215). They add that the actors fabricate their own meaning from the same cultural materials which leads to sharing of meaning over time. This definition describes the many components of organizations. It is very inclusive and encompassing.

Turner (1983) focuses on Levi-Strauss's structuralism in understanding organization. Turner describes what an organization is and how the Levi-Straussian reading of organizations is conducted. In short, Turner suggests that we must look at the organization as a whole and consider each piece important. He mentions that some include their familiarity of organizations and become victims to their own preconceived notions. There is an understanding that some would see patterns and relationships intertwined as a formal structure. Removing these patterns can cause us to lose out on valuable connections. He states, "It is obvious that the formal structure – job descriptions, formal responsibilities, and so forth – does not exhaust the order of values" (p. 195). Turner provides an example of an organization that services electric motors. In the

example, the small firm services various sizes of motors, each with its own unit. Because of the imbalance of workload, one unit begins to experience problems by not being able to keep up with demand and not having enough work orders at times. Turner describes the problem as a balancing ritual as punishment and criticisms take place. This includes the idea of myths occurring, which can be best thought about as rumors, gossip, leaks, and past stories of the organization. This is a structuralist view of a problem. In applying Allaire & Firsirotu's definition of organization culture to this situation, we would consider the sociostructural system, cultural system, and the individual actors. Turner's example with structuralism as a focus identifies the problem to be the process. Allaire & Firsirotu's definition would look at the organization as a whole to determine the source of the problem.

Pakdil and Leonard (2015) focus on the term "lean processes" to encompass all organizational functions. They look at nine dimensions to conceptualize it: "employee involvement; creativity, problem-solving processes, and decentralization; control and standardization; and efficiency, productivity, and continuous quality improvement" (p. 726). Using the competing values framework, they look to create a model to identify the cultural dimensions of managing lean processes (removing procedures that may be wasteful to increase an organization's output such as increasing customer value). They consider the parallels "between organizational culture and lean processes" (p. 736) and determine that culture does affect processes in several ways. Pakdil & Leonard suggest that organizational leaders need to understand the prominent dimension of their organization before making changes. They describe the following five propositions:



- 1) “A firm characterized by an emphasis on group culture will have more effective lean process, in terms of employee involvement and teamwork, compared with firms that are characterized by one of the other three quadrants” (p. 730).
- 2) “A firm characterized by an emphasis on developmental culture will have more effective lean processes, in terms of creativity, problem-solving processes, and decentralization, compared with firms that are characterized by one of the other three quadrants” (p. 732).
- 3) “A firm characterized by an emphasis on hierarchical culture will have more effective lean processes, in terms of control, standardization, and predictable performance outcome techniques, compared with firms that are characterized by one of the other three quadrants” (p. 733).
- 4) “A firm characterized by an emphasis on rational culture will have more effective lean processes, in terms of efficiency, productivity, and continuous quality improvement, compared with firms that are characterized by one of the other three quadrants” (p. 734).
- 5) “A firm characterized by a balanced culture will have the most effective lean processes, compared with firms that are characterized by a single quadrant” (p. 735).

Pakdil & Leonard provide examples of several organizations in comparison to each proposition to demonstrate how each affects an organization. Toyota is an example of proposition 5 in that Toyota focuses on delivering the best product to satisfy customers by investing in people. Using Allaire & Firsirotu’s definition, we can further understand the entire organizational culture that drives the lean process. We can apply how the

sociostructural system, cultural system, and the individual actors impact the balanced culture of Toyota. There are several key factors that create the outcomes of organizations and the best way to understand the organizational culture is by using Allaire & Firsirotu's definition and applying Pakdil & Leonard's lean process concept.

Five dimensions were determined in a study that identified organizational culture across more than 50 countries and argues that people are programmed to think and interact based on their life experiences through schools and organizations. Hofstede (2001) identified power distance, uncertainty avoidance, individualism/collectivism, masculinity versus femininity, and long-term versus short-term orientation as they were identified through a data analysis of surveys. He determined that countries could be positioned within these dimensions and that it correlates to each countries' geographic, economic, demographic, and political indicators. Power distance is defined as "the extent to which the less powerful members of institutions and organizations within a country expect and accept that power is distributed unequally" (p. 98). Uncertainty avoidance means, "the extent to which the members of a culture feel threatened by uncertain or unknown situations" (p. 161). Individualism refers to people looking after themselves and family while collectivism refers to "people from birth onwards are integrated" (p. 225) into groups. Masculinity is described as standing "for a society in which social gender roles are clearly distinct" and femininity as standing "for a society in which gender roles overlap" (p. 297). Long-term orientation looks to "future rewards" through perseverance and thrift while short-term orientation looks to "virtues related to the past and present" through preservation.

Kotter and Heskett (2001) studied several organizations to understand corporate culture and the relation to performance. They determined that corporate cultures can “have a significant impact on a firm’s long-term economic performance,” “can determine the success or failure of firms, can “inhibit strong long-term financial performance,” and can “be made more performance enhancing” (pp. 11 – 12). They don’t believe that strong cultures and strategically appropriate cultures are responsible for high performance. Adaptive corporate culture can “anticipate and adapt to environmental change will be associated with superior performance over long periods of time” (p. 44). The adaptive cultures have a focus on service as a core, staying attentive on customers, stockholders, and employees that does not emphasize directly on the vision and strategy. Kotter and Heskett believe that leadership from the “very top of an organization seems to be an absolutely essential ingredient when major cultural change occurs” (p. 92). They believe it is related to the power required within hierarchies and the interdependence inside organizations. The hierarchy must value leadership at all levels and that includes knowing the values of the organization as well as knowing how to demonstrate behavior.

Using a quantitative and qualitative approach, Denison (1990) studied corporate culture and its close relationship on the effectiveness of organizations. His theory argues that “an organization’s culture has a direct impact on its effectiveness and performance” (p. 175). Based on this, Denison developed the culture and effectiveness model that has four concepts: adaptability (internal flexibility and external focus), mission (meaning and direction), involvement (informal processes and formal structure), and consistency (normative integration and predictability). Each concept has a direct influence on the

effectiveness of the organization. Denison states that creating an effective culture “requires an understanding that social control can be based on consensus and commitment rather than administrative control” (p. 194). He points out each concept is broad and requires concrete skills, which can be difficult. Denison recommends starting with internalized values and setting expectations.

Senge (2006) describes that systems thinking is the fifth discipline to understanding organizational culture. He believes that it fuses the disciplines “into a coherent body of theory and practice” (p. 12). The other four disciplines are building shared vision, mental models, team learning, and personal mastery. Senge states that systems thinking groups these four disciplines together, as he sees them as interrelated and enhancing each other. Systems thinking sees the whole, the interrelationships and patterns, and gains feedback. “In systems thinking it is an axiom that every influence is both *cause* and *effect*” (Senge, 2006, p. 75, emphasis added). The laws of the fifth discipline elaborate on several axioms such as “the easy way out usually leads back in” (p. 60) and “faster is slower” (p. 62). The five disciplines combined allow a balance within an organization that requires each discipline to operate together so that there is no single focus on just one discipline as a solution. One important aspect to highlight is Senge’s view that youth leadership is needed for systemic change. He states that teenagers and young adults “have a strong stake in the future...least invested in the past, giving them a distinctive ability to see the flaws in current mental models and institutional patterns and the courage to create something new” (p. 370). His inclusion of youth in systemic change and organizational culture is a demonstration of the importance of systems thinking in relation to building a shared vision, mental models, team learning,

and personal mastery. Senge is also the only scholar who clearly states there is value in having youth input to an organization.

**My Definition of Organizational Culture.** Given these definitions of organizational culture, Senge (2006) and Schein & Schein (2017) are the two definitions of organizational culture that will be partially applied. Combined, both provide a well-rounded view of organizations and culture as they address problems, systems, and solutions. Both incorporate the need of learning being a shared process. Expanding on these concepts, organizational culture is defined as people bringing a variety of values, beliefs (including spiritual and religious), perceptions, thoughts, knowledge, ideas, language, learning, abilities, and identities (e.g., race, gender, age) to make culture a continuously changing process, seeking to function as one collective to meet the goals, missions, values, and outcomes of the organization. This is the definition in use when referring to organizational structure. Other definitions of organizational culture cannot be supported because they lack inclusion or reference to disability and learning, instead rely upon hierarchy and not group consensus, and focus on business rather than education. This is a gap in their work that demonstrates the lack of acknowledgement to anyone with a disability and excludes that population. All the above referenced scholars have theories and definitions that encompass the multitude and uniqueness that is culture. It is difficult to generalize the culture of every group as several factors can influence one group over another. Yet, disability was not included in that culture. My definition is not perfect or the best; it aims to be inclusive and just.

## **Changing Culture in An Organization**

Changing the culture of an organization can be a challenging process because of the nature of culture that exists. Creating a change requires an “intervention [that] helps an organization develop a culture (behaviors, values, beliefs, and norms) appropriate to its strategy and competitive environment” (Cummings & Worley, 2015, p. 161). It helps an organization have an alignment and focus on the necessary direction. To change an organization’s culture, we have to look at the specifics of the organization to determine which areas will need the most support and understanding. The areas could be things such as goals, processes, values, communication practices, attitudes, assumptions, objectives, and vision. Changing a culture requires that we look at how to best change an organization to change its culture. There are several ways to change an organization’s culture. We can use Lewin’s (1951) change model, the action research model, or the positive model. Each one has a different way of thinking about planned changes.

Lewin’s planned change model focuses on three phases: unfreezing, movement, and refreezing (1951). Unfreezing focuses on psychological disconfirmation, allowing any beliefs to be regarded as incorrect as a way to demonstrate that there are good things occurring within the organization. Movement allows for changes to occur to move the organization forward by focusing on behaviors, values, and attitudes. Refreezing focuses on maintaining the new achieved state in balance and adding steps to maintain the new structure. This is a good simple way of looking at changing an organization. We must change the way the organizations function to improve it and change the culture that exists. Lewin’s model appears to be one directional, taking the process as fast or slow

based on what happens during movement. The model also looks at a top-down approach and does not focus on changing management and leadership.

The action research model has a cyclical process to continuously improve an organization (Cummings & Worley, 2015). With a focus on data collection and diagnosis, it helps prepare for changes as well as evaluation. The eight steps are as follows: (a) problem identification, (b) consultation with a behavioral science expert, (c) data gathering and preliminary diagnosis, (d) feedback to key client or group, (e) joint diagnosis of the problem, (f) joint action planning, (g) action, and (h) data gathering after action. After the last step, it cycles back to feedback to key client or group (step 4).

“These applications are heavily value laden and seek to redress imbalances in power and resource allocations across different groups” (Cummings & Worley, 2015, p. 25). Like Lewin’s model (1951), the action research model seeks to identify a problem and move towards changing it. Unlike Lewin, this model is geared towards evaluating the process to ensure that it is continuously improving and adjusting as necessary. This model is more considerate of people by recognizing that changes will have to be revisited to ensure that things are working. This model takes into consideration all aspects of the organization’s change and includes looking at changes that leadership/management will need to make at their level. It is a more inclusive process. A critique of both the action research model and Lewin’s model is that they do not specifically state that the results have to be positive for the people and might actually focus more on the organizations as a whole. For this reason, the following model is preferred.

The positive model focuses on using things the organization is doing right and building from there. “It helps members understand their organization when it is working

at its best and builds off those capabilities to achieve even better results” (Cummings & Worley, 2015, p. 26). There are five phases to the positive model: (a) initiate the inquiry, (b) inquire into best practices, (c) discover the themes, (d) envision a preferred future, and (e) design and deliver ways to create the future. This model focuses on redirecting behavior towards the positive aspects of the organization. People in work settings usually perceive that they are doing their jobs well and are not happy to hear when they receive negative feedback. The positive model is the most considerate of how people may behave and perceive change. Focusing on changing the way people view a problem can go a long way in helping them think about problem-solving and creating solutions. This model considers what the leadership/management can do differently to be more supportive, placing responsibility on all levels because of its focus on a preferred future. The model is the most inclusive to conduct organizational culture change. It does not focus on identifying “negative” things of the organization. This impacts the attitudes, beliefs, values, goals, and communication practices for everyone and steers it into a positive direction. Before change can occur, there is a need to motivate change among the people, which includes having a good vision.

Having change take place in an organization does require people to have buy-in to the idea of change as it can be an intimidating process and lead to resistance (Cummings & Worley, 2015). Good communication practices, empathy, support, participation, and involvement will lead to a health transition and transformation. Cameron and Green (2015) describe that change may “require different types of attitudes and behavior, accentuating a different set of values and shifting ‘the way things are done around here’” (p. 303). Because of this, it is important to have a vision of what change



will look like and why it is necessary. “Generally, a vision describes the core values and purpose that guide the organization as well as an envisioned future toward which change is directed” (Cummings & Worley, 2015, p. 184). A vision will help establish goals, values, and purpose for the organization and will help with people understanding their roles in the process of making that vision a reality.

**Values and Vision.** Values are set based on the leaders of the organization as they are the ones that oversee the entire functions of the organization and are the ones that direct the values to the employees (Schein & Schein, 2017). Schein and Schein (2017) state that “...when it comes to culture it is not easy to convince people that the present cultural beliefs and values need to change, given that those same belief and values have been the source of the organizations’ success” (ch. 16). People like to know they are valued at the workplace and they want to show they value it as well. Value has to be clearly defined within the organization and will help support change when performed correctly. “The core of culture...is formed by values, in the sense of broad, nonspecific feelings of good and evil, beautiful and ugly, normal and abnormal, rational and irrational – feelings that are often unconscious and rarely discussable, that can’t be observed as such but are manifested in alternatives of behavior” (Hofstede et al., 1990, p. 291). Values are feelings for people. In a study about values, Posner and Schmidt (1994) identified that “having clarity about personal values may be more important, in relation to attitudes about work and ethical practices, than being clear about organizational values” (p. 346). They determined that it is the people that make decisions and thus it is more important for people to show their values over those of the organization. It makes sense. What the organization aims to do is different from that of the leader or manager. An

organization can have values they work towards, but that does not mean that the leader or manager demonstrates those values. This impacts attitudes that people will have towards the organization and its leaders/managers. If a leader/manager shows no appreciation towards their employees, it demonstrates to the employees that they are not valued and will change their attitude towards the leader/manager and or organization. Having goals and objectives is important for an organization and the culture within it. Goals and objectives allow everyone to know what they are working towards and can help with creating strategies (Cummings & Worley, 2015). Goals and objectives allow us to diagnose tasks, prepare for the task, and set the goals to achieve them while allowing to measure it (Cummings & Worley, 2015). Goals/objectives can also be a good way to hold everyone accountable and have a clear path of what everyone should be working towards to make the organization successful, which in turn creates a positive organization culture in which people support each other.

By having clear goals/objectives, a vision, and a clear understanding of values, we can focus on making sure that roles are clear and that any assumptions are addressed. Every organization has to make it clear to each employee the nature of their role, how it helps support the vision and objectives of the organization, and how they contribute to that culture (Cummings & Worley, 2015). A lack of role expectations and understanding can lead to problems, frustrations, work overlap, confusion, overload, underload, and ambiguity (Anderson, 2012). Clearly defining roles can help alleviate the problems. “A role negotiation exercise and a second related intervention called ‘responsibility charting’ can help teams resolve the confusion, conflict, and frustration about roles” (p. 234). With organizational culture changes will come including some role changing, so it is important

to discuss these things with employees to ensure that the environment is supportive. Of course, having goals, processes, values, objectives, and vision will not work if you do not have good communication practices in place.

**Communication.** Communication practices are important to consider in any environment that involves a group of people. By nature, communicating means that there are points to get across and sometimes our own backgrounds change the way we understand or convey our thoughts. With diversity playing a role in our organizational cultures, we must do our best to consistently show respect for everyone. Samovar et al. (2013) recommend that people should a) be mindful that communication produces a response, b) show respect for others, c) search for commonalities among people and cultures, d) respect cultural differences, and e) accept responsibility for your behavior (p. 16). We should practice using positive terms and being aware of how others might interpret our choice of words. We should focus on changing the way speak and the words we choose to being more positive as just a language shift can improve organizational culture (Kegan & Lahey, 2001). We have to recognize our own language to shift it. Rather than placing blame, we can shift to responsibility; even looking at removing our assumptions, we can move towards recognizing that we have assumptions. Sometimes it is the small changes in our communication that will go a long way toward creating a positive culture.

### **Aligning Culture with Strategy and Processes**

Understanding an organization is key to improving the culture of the organization; we must be thoughtful about the strategies and processes that take place to improve the values, behaviors, and accountability of all people involved in the culture. The alignment

of an organization's culture will determine the overall effectiveness of the organization (Cummings & Worley, 2015). "Alignment represents the extent to which the features and operations of one component support the effectiveness of another component" (p. 94, Cummings & Worley, 2015). Cummings and Worley outline the "Comprehensive Model for Diagnosing Organizational Systems" and break it into an organization level, group level, and individual level. Each level has inputs, design components, and outputs. The group and individual level contain culture as an input and eventually output as a team (quality of work life, performance) and individual (job satisfaction, performance, absenteeism, personal development) effectiveness. Culture is not part of the organization level. The inputs are based on the environment. The design components include goal clarity, task structure, team functioning, group composition, and group norms for the group level and skill variety, autonomy, feedback and results, task significance, and task identity for the individual level. To align an organization's culture, you have to diagnose the processes that are taking place to determine whether strategies in place are effective or if new strategies are needed. Culture is complex because there are several variables to what makes us all human. This impacts work environments and creates an organizational culture and climate.

If an organization's structure is functional, it might just be that we have to focus on the people of the organization to be able to change the culture. At this point, strategy has to focus on influencing behavior and accountability. Team-building activities have several practical applications like problem-solving, building trust, increasing motivation, changing perceptions, and demonstrating support (Cummings & Worley, 2015). It is important to note that American culture is very individualistic and working in teams or

being part of a group can be difficult (Lussier & Hendon, 2019). Team building is an effective process as it can help improve and clarify objectives, responsibilities, decision-making, planning, and increase overall understanding (Lussier & Hendon, 2019). To sustain a positive organizational culture, we have to connect accountability and responsibility to this conversation.

In discussing accountability and responsibility, I have to make a reference to ethics. First, accountability “is the personal duty to someone else (a higher-level manager or the organization itself) to use organization resources effectively to complete an assignment” (Lussier & Hendon, 2019, p. 550). Second, responsibility “is the obligation to answer for something/someone – the duty to carry out an assignment to a satisfactory conclusion” (Lussier & Hendon, 2019, p. 549). Third, ethics “is the application of a set of values and principles in order to make the right, or good choice” (Lussier & Hendon, 2019, p. 543). These three concepts work together because the moment there is an unethical action, it tests the responsibility and accountability of the leader/manager and the organization. To be ethical, a person has to demonstrate moral sensitivity, moral judgement, moral motivation, and moral character (Schminke et al., 2007). Ethical behavioral is influenced by the leaders and managers of the organization because they will be the ones to enforce ethical control, participation, and climate (Schminke et al, 2007). Everyone in an organizational culture has responsibility to ensure that the work and the climate is positive. It helps with the process of having personal accountability because it “attends to the observable actions and behaviors of leaders and followers” (p. 3, Quick & Goolsby, 2013). To have accountability, you have to have integrity for yourself and actions because this will impact the integrity of the organizational culture

(Quick & Goolsby, 2013). To be accountable, you have to demonstrate responsibility towards your own actions and responsibility for your organization.

The focus on alignment and the process to reach accountability may require a strategic change. Cummings and Worley (2013) highlight the integrated strategic change (ISC) model as an intervention to change a program or organization. The ISC model has four phases: (a) performing a strategic analysis, (b) exercising strategic choice, (c) designing a strategic change plan, and (d) implementing the plan. My focus is on the ISC model because it is a very simple and effective strategy for changing organizational culture and aligning culture to improve values and accountability. The challenging part to organizational culture is identifying the source of resistance, or problem-solving as Schein & Schein, Habermas, and Weisinger & Trauth would argue. It takes patience to understand the culture of any group to influence the day-to-day work, behaviors, values, and reactions. There are several domains and dimensions to organizational culture because every person in a group brings a diverse perspective and view of our shared world.

**Shaping Reactions.** Shaping the reactions of people through organizational culture carries a lot of possibilities to what will work best (Hayes, 2014) to influence attitude and perceptions to help improve behaviors. Porter et al. (1975) recommend modifying work structures, control structures, and reward structures to shape reactions in an organization as it will help improve how employees view the organization. In a quick revisit to Schein & Schein's (2017) definition of culture, learning is passed on to new members of a group. A group has its own sets of knowledge that will require them to revisit periodically, even if the changes are small. The culture that a group holds will

influence behavior and eventually impact perceptions and attitudes. I personally think that people care about the organizational culture and will react based on what the general consensus is of that culture. For that reason, you have to demonstrate some level of passion, trust, and commitment to transform the organizational culture and reshape reactions.

Introducing fun, enthusiasm, joy, and meaningfulness are great ways to demonstrate passion (Boverie & Kroth, 2001). “Passion is loaded with emotion, with desire, with action, and with thought. Passion is at the root of creative genius, personal transformation, and notable events” (p. 2). Demonstrating some level of passion can influence an organizational culture. Take, for instance, a previous organizational culture I experienced. My former supervisor was consistently coming up with new research ideas and includes the entire team to further develop thoughts. We once had an impromptu meeting just to discuss what types of research projects everyone would be interested and which we should prioritize for grant applications. This random meeting motivated everyone to be creative as it was an opportunity to pick our future work responsibilities. Boverie & Kroth (2001) state, “Passion evokes images of deep commitment to another person, to an idea, or to a cause” (p. 5). Along with demonstrating passion either as a leader or employee, you have to provide opportunities for growth. Michaels et al. (2001) state that you have to assess the performance and potential of people, which can take place in the form of promotion, compensation, and development opportunities. Focusing on talent management will help improve organizational culture in ways that foster growth and increase commitment (Michaels et al., 2001). These theories will help even with demographically diverse individuals.

Verbeke et al. (1998) theorized organizational climate as the way people perceive and define the setting. Organizational climate is important to connect to individuals that are demographically diverse because it affects the way they perceive the organizational culture and shapes their attitudes of the organization. "Underlying the concept of relational demography is the construct of demographic similarity that characterizes the degree to which an individual's demographic attributes are shared by other members of a social unit" (Riordan & McFarlane Shore, 1997, p. 343). In their study, Riordan & McFarlane Shore examined gender, race-ethnicity, and tenure in the workplace and hypothesized that the greater the similarity between individuals and composition of the work unit, "the more positive the individual's attitudes will be toward the work group" and "the higher the individual's perceptions will be of opportunities for advancement" (p. 345). Their study concluded that race plays a role in attitudes of a work unit along with opportunities for advancement. We have to consider how to manage diversity because people who are demographically diverse have historically been underrepresented, which can be seen by historical events such as the Civil Rights, Black Lives Matter, Me Too, and Disability Rights movements. "An important ingredient for the success of every organization is to be proactive and initiate change before major problems develop" (Ocon, 2006, p. 3). With globalization changing organizational culture, it is important to promote diversity as it will shape the attitudes and morale of new members entering the organizational culture and demonstrate strong morals and ethics (Ocon, 2006). This will mean promoting organizational change which will be discussed in the next section. There are several aspects of diversity as it includes race, gender, disabilities, religion, age, sexual orientation, and much more (Adams et al., 2000; Cummings & Worley, 2015).



There are several ways to ensure that individuals that are demographically diverse are fully supported such as mentoring, trainings, coaching, career ladders, and even diversity trainings for the entire organization to help improve the organizational culture.

Altogether, we have to consider self-categorization theories in the workplace. Hogg & Terry (2000) describe self-categorization as “a development of social identity theory or, more accurately, as that component of an extended social identity theory of the relationship between self-concept and group behavior that details the social cognitive processes that generate social identity effects” (p. 123). Their theory elaborates on how people can either give or take an individual’s categorization (“normative behavior, stereotyping, ethnocentrism, positive in-group attitudes and cohesion, cooperation and altruism, emotional contagion and empathy, collective behavior, shared norms, and mutual influence”; p. 123). This can happen at an individual level or at a group level. This leads to the creation of a “prototype” that may be applied to the group or individual and it includes beliefs, attitudes, feelings, and behaviors. People will either focus on their commonalities or choose to separate themselves based on their differences. Inclusion is important in organizational culture because having a healthy organizational climate will help support all individuals regardless of demographic differences. In turn, this helps influence how we shape reactions of people in the workplace.

### **Disability and Organizational Culture**

The whole world is a learning environment. Learning is always happening all around us. In the context of my autoethnography, my learning has taken place within a university setting where my roles have been both graduate student and staff member. Both roles are different and yet I have found common ground in the world of disability.

Universities, as welcoming and inclusive they appear to be, are no different from any organization when it comes to problems related to disability. Discrimination, lack of support, and lack of changes continue to occur within higher education. The fourth section that follows will explore themes of disability relating to staff and faculty as employees.

### **Disability, Staff, and Faculty at Institutions of Higher Education**

Issues of disability exist for staff and faculty within colleges and universities. Evans et al. (2017) explain “staff and faculty members who have or acquire disabilities are rarely studied in research on disability in higher education” (p. 199). Evans et al. explain the workplace does not provide the same level of support as it does with students. A disability/accessibility resource center for staff and faculty does not exist and resources might be scattered across various entities such human resources and the Equal Employment Opportunity Commission (EEOC) office. Human resources and organizational policies see “work disability” as a reason an employee will not return to work and does not provide a social justice perspective. Depending on the type of disability, there might not be funding available to provide accommodation requests. Per the ADAAA (2018), a reasonable accommodation is only possible if it does not cause a financial burden to the employer. This situation may cause some people to avoid disclosing that they have a disability that requires an accommodation. Staff and faculty members might be reluctant to share they have a disability, especially during an interview, as reasonable accommodations are subject to the hiring employer and that person’s personal views on disability (Carpenter & Paetzold, 2013; Santuzzi, Waltz, Finkelstein, & Rupp, 2014). The issues exist at all levels of an organization as some

people can develop disabilities after being hired, especially psychological disabilities, or those related to mental health. Price (2011) states that psychological disabilities (e.g., depression, anxiety, bipolar disorder) can make interpersonal interactions and engagement in planned and spontaneous social activities challenging per the nature of those psychological impairments. In higher education, events and programs occur during many days or evenings during a semester. Attendance may be required or optional. Although if the staff or faculty choose to not attend those events and programs, especially those required or “highly encouraged,” it would set a negative precedent of the person. These types of conditions, even when the disability is disclosed and met with a lack of support, will create a negative health and wellbeing environment that is toxic on an employee’s psychological state (Loisel and Côté, 2013). This is partially due to the continuing existence of stigmas (Goffman, 1963). “People with disabilities are not immune from societal attitudes about disability and may internalize the same stereotypes and stigma as their nondisabled colleagues” (Evans et al., 2017, p. 204). Improving the organizational culture of higher education will not be resolved by policies and politics. On that note, next I explore issues of workplace discrimination.

### **Workplace Discrimination**

In section 12112 under Title 1 of the ADAAA, discrimination is explained as “no covered entity shall discriminate against a qualified individual on the basis of disability in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.” This includes mental health, or psychological state. The section elaborates by including job practices that adversely affects an applicant or employee because of

disability, not providing accommodations, and asking or requiring medical documentation or exams. Discrimination varies depending on the disability and workplace because not all disabilities are the same (Cavanagh et al., 2016). “People with mental health disabilities experience the most stigma at the workplace. Negative views and attitudes were predominant among management and employees due to [skepticism] of a disability, and the absence of clear symptoms (e.g., those with clinical depression). People with mental health disabilities are more prone to overt and covert discrimination” (p. 32, Cavanagh et al., 2016). Cavanagh et al. (2016) identified that an employer’s lack of knowledge on individuals with disabilities create negative attitudes, lack of support, lower employment rates, and even greater hardships for people with mental health disabilities. Work schedules are also another form of discrimination as the current 8am – 5 pm work schedule favors morning larks over night owls (Walker, 2017). Some people are more functional at night while others are more functional during the morning, which is completely normal given that we all have differences in our sleep health (Walker, 2017). Employees are rarely given the option to pick a work schedules, unless there is a strong case for a reasonable accommodation for a disability.

There is also an intersection between class and disability that needs mentioning as it will change the way an individual with disabilities is viewed due to the resources that are readily available to those who can afford them versus those who are unable to receive assistance due to financial hardships (Casteñeda, Hopkins, & Peters, 2000). Employees with learning disabilities are fearful of being discriminated based on their disability and the stigmas that surround it (Goffman, 1963; Greenbaum, Graham & Scales, 1996). This leads to thoughts on ableism and how some groups will receive more attention than

others such as those based on race, sex, gender, class, age, and other backgrounds (Casteñeda, Hopkins, & Peters, 2010). There is oppression that comes with disability and deafness that is often ignored such as being harassed verbally, physically, and sexually (Davis, 2010). Ableism is a problem that leads to stereotypes and other forms of oppression. These issues have occurred for decades as there has been a lack of concern that eventually led to the disability rights movement (Bryan, 2010). Activism would lead the way to causing several disability rights groups to band together and push for legislation to support individuals with disabilities, which led to the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. The disability community continues to experience discrimination even after the passing of legislation. Casteñeda, Hopkins, & McCants (2010) state, “Challenging ableism truly requires that we recognize how this oppression is manifested on the individual, institutional, and culture levels of engagement” (p. 529). Under a historical context, it is no surprise that discrimination continues to occur in the workplace and that challenging ablest notions must continue to improve workplace culture and support for individuals with disabilities.

**Disability: Organizational Strategies & Workplace Culture.** Organizations have several strategies available that will improve the workplace for individuals with disabilities by reducing stress, reviewing policy, making worksites more accessible, and being more supportive. Cooper and Cartwright (1994) believe that in order to reduce stress in the workplace, there are two sets of questions that must be answered: “1. What is the existing level of stress within the organization? Is job satisfaction, physical and psychological health better in some areas than others? How does it compare with other occupational groups/populations? In other words ‘have we a problem?’ 2. If so, can we

define the problem and what's causing it? What are stressors? Are they departmental/site specific or organizational wide" (p. 464)? Although their focus is on job stress, I believe these questions are applicable for individuals with disabilities not feeling supported or properly accommodated. The lack of support does lead to stress and I say that from personal experience. This is a good starting point to remove barriers in the workplace and begin creating an environment that is supportive and accepting. Cavanagh et al. (2016) points out that part of the issue is the lack of experience employers have working with individuals with disabilities. Their study identified that employers that had more experience working with individuals with disabilities were more accepting and provided better support. This suggests that leadership and management play a role in the success of individuals with disabilities in the workplace.

In a study regarding a culture of health (COH), "employees who reported the greatest leadership support and employee engagement within each employer's workforce did, in fact, perceive greater support for their health" (Payne et al., 2018). Leadership at organizations are key to promoting health programs and helping foster a healthy environment for all (Payne et al. 2018). To create a healthy work environment, organizations should commit to having: a) low levels of stress, b) high organizational commitment and job satisfaction, c) low sickness, absenteeism, and labor turnover, d) good industrial relations, e) good safety and accident records, and f) no fear of litigation (Cooper & Cartwright, 1994). Supporting employee wellbeing is a "more cost-effective and more focused way of reducing stress in the workplace" (p. 468). The best approach is to support all employees by making work environments welcoming and supportive of all. Payne et al. (2018) explain:

The negative employer-level effects thus suggest that, across organizations, high levels of leadership support and employee engagement tend to co-occur with relatively low levels of perceived support for health. In contrast, employee-level effects help explain why individual employees' perceptions of support vary within an organization. Our findings indicate that employees who reported the greatest leadership support and employee engagement within each employer's workforce did, in fact, perceive greater support for their health. (p. 1561)

Cavanagh et al. (2016) acknowledge that "there is a lack of support for career prospects, with people with intellectual disabilities because they are generally assigned menial job roles" (p. 31). The way individuals with disabilities in work settings are perceived has to change and it has to begin with those who lead and manage the organization (Ocon, 2006). Individuals with disabilities are also just people that are just more diverse and unique than most. We have to change the way individuals with disabilities are viewed.

### **Changing Workplace Culture: Work Experiences and Career Progression.**

The Healthy People 2020 objectives set forth by the United States Department of Health and Human Services regarding disability and health has set their goal to "maximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, healthy equity, and quality of life among individuals with disabilities of all ages" (2010). To address the health needs of individuals with disabilities, there are three action principles (WHO, 2008) that are focused upon by Healthy People 2020. What follows are the three principles with sub-action points applicable to the workplace and education:

#### **1) Improving the conditions of daily life by:**

- removing barriers in the environment using both physical universal design concepts and operational policy shifts

2) Addressing the inequitable distribution of resources among individuals with disabilities and those without disabilities by increasing:

- Education and work opportunities
- Access to needed technologies and assistive supports

3) Expanding the knowledge base and raising awareness about determinants of health for individuals with disabilities by increasing:

- The inclusion of individuals with disabilities in health promotion activities

Given these Healthy People 2020 action principles, organizations can focus on reviewing or implementing operational policy shifts, creating more opportunities in work and learning environments, and improving access to technology and assistive supports. Individuals with disabilities must be included in all disability related health promotion activities. This serves as a starting point in addressing work experiences and career progression.

**Workplace Learning Environment Application – Universal Design (UD).** The most empowering and unique characteristic about individuals with disabilities is the diversity of learning. Although universal design was discussed in the learning environment section, it is also applicable to the work environment. To address issues of disability in the workplace, the best theory and model to implement is universal design (Evans et al, 2017; Hackman & Rauscher, 2004; Orr & Hamming, 2009; Lindburg, 2012). Several, if not all, problems regarding accommodations for individuals with disabilities can be resolved if we focus our attention to incorporating universal design during every process (Evans et al, 2017; Orr & Hammig, 2009; Lewis & Sullivan, 2012). There are five key principles to UD that must be executed: “1. Implement universal



design at the beginning of the design process to eliminate the need for additional accommodations after implementation has begun. 2. Create learning environments that promote cultural sensitivity, flexible learner interactions, and authentic learning experiences. 3. Make all instructional materials accessible. 4. Organize instructional materials focusing on layout to provide logical progression of information ensuring clear and simple navigation and/or readability. 5. Provide flexible instructional alternatives for expression when possible” (Lewis & Sullivan, 2012, p. 355). These principles will ensure that we incorporate the diversity of teaching for diverse learners. These principles, focused on learning, apply to the workplace because we can make several tasks universal and flexible.

Another way to think about universal design is by looking at the Multimodal Diversity Model (Lewis & Sullivan, 2012), which provides “strategies to use when attempting to include diverse learners in the design of instruction” (p. 355). The model combines physical, cognitive, and cultural diversity with the three principles of universal design for learning (multiple means of representation, expression, and engagement). Their model is a wheel with three levels and three categories, each containing several strategies. The following are examples of strategies under engagement and cognitive: offer success rich practice, clear sequential instructions, flexible assessment, and ensure easy navigation. As another set of examples, representation and physical (think tangible items or physical items viewed) the following: use smooth fonts, use simple sequential layout, offer text transcript, provide alternative text tags for graphics, and offer audio and text versions. These are some of the many strategies that are applicable to work environments. When we incorporate universal design to the workplace, we bring in the

theory and models of disabilities that help create positive supportive environments for the success of all employees. It levels the playing field for the success of all and not just some people. Universal design is a holistic approach to how people learn but it also contains value when we apply it to how people work. It is inclusive of all learners, not just individuals with disabilities.

### **Higher Education Has Not Changed**

Disability impacts all of us at some point in our lives. The organizational culture of higher education is not considerate, and it discriminates in the process. “Although higher education has improved in providing accommodations and services to students with disabilities since the Americans with Disabilities Act (ADA), it has lagged very far behind in recognizing and incorporating disability across the curriculum” (Davis, 2011, para. 18). The academic culture and practices have not changed to be inclusive of individuals with disabilities. Other signs that show this lack of changes are attendance policies that require students to be physically present in the classroom (Potter, 2014) as well as the lack of internships and programs for students with disabilities (Dowrick et al., 2005). Although the process to request accommodations can be uncomfortable, college students must provide evidence to support their requests (Seale, 2006). If this is happening at the student level, this is also happening at the employee level for staff and faculty as I have mentioned earlier. The stigmas and stereotypes are impacting people’s decisions to not want to disclose for a variety of reasons such as fear of being discriminated against or losing their jobs for not being able to be high achieving performers (Evans et al., 2017; Loisel & Côté, 2013; Goffman, 1963; Olkin, 2012; Shannon et al., 2019). Given that policies do exist, and students, staff, and faculty all

continue to experience concerns about their disabilities, it demonstrates that organizational culture cannot be changed with policies alone. A shift in the entire organization needs to occur.

Problems of disability within higher education stem from the organizational culture that has been in place for decades. “Professional behavior in schools is governed more by institutionalized, cultural norms than it is by rational, knowledge-based actions designed to improve instructional effectiveness. Things are done in certain ways simply because they have always been done that way” (Skrtic, 1991, p. 176). Even with ADA being law, higher education has not updated or modernized its organizational culture to be inclusive of all people (Skrtic, 1991). The field of education has yet to change as far back since the 1960s and probably even earlier (Boyd & Crowson, 1981; Skrtic, 1991). Schools are underorganized systems which prevent change (Weick, 1985). It is very much a silo system due to its ambiguous nature. “The conditions of order and tightness in organizations exist as much in the mind as they do in the field of action” (p. 128, Weick, 1985). People leading the institutions have rooted values, mindsets, presumptions, and commitments that continue a cycle that hardly changes. “The professional and machine bureaucracies are nonadaptable at the macro level of the organization because both use the principle of standardization to produce standard products or services” (p. 165, Skrtic, 1991). When something does not work, the organizations re-standardize, re-rationalize, and re-formalize. No significant change occurs. Symbols and ceremonies, such as adding a specialist or a program, are used to indicate change, even though they are just illusions of change because those moves don’t change the real inner workings of the system such as teaching practices and student services (Skrtic, 1991). These issues have continued to

persist without a real change to the functionality of the organizational culture of higher education. Higher education, as it stands, will not create changes to support all individuals with disabilities. Adding more policies will not change the toxic environment. Changes need to happen at every institutional level in higher education.

### **Conclusion**

At first glance, issues of disability and organizational culture appear to be complex, but they are not. An organization should be welcoming to all people regardless of their backgrounds. That is not the case when you incorporate topics of disability. An institution of higher education should be incorporating all aspects of successful organizational culture to avoid having people feel stigmatized, discriminated, conflicted, isolated, ignored, and misunderstood. Change is slow but it does not mean it has to be stagnant. The current organizational culture of institutions of higher education is unsuccessful. If it did include universal design and inclusivity for people with disabilities, I would not have reasons to write an autoethnography about how I was treated as a student and a staff member in regard to having a disability that impacted my overall wellbeing. Identifying a disability is not an easy process of identity development and it should not have to feel like your social environment is against you every step of the way in a learning environment and work environment. No person should feel like they do not belong within a classroom or workspace. My personal stories in chapter four will highlight why higher education is not an inclusive environment for diverse learners and workers. It will include stories of empowerment and inclusion. In chapter five, I will use intersectionality to analyze my personal stories to the literature and demonstrate the many issues that continue to exist for the disability community. Chapter six will include

recommendations, advice, and techniques for people finding themselves in similar situations. Although my stories are mine alone, it does not mean these types of situations are not occurring to others. In fact, many people inside and outside of higher education are confronting similar experiences. It was sharing my personal stories with colleagues and students in higher education across the United States that encouraged me to tell my stories to support the literature on why individuals with disabilities continue to be excluded.

## CHAPTER 3

### HOW IT ALL WORKS (METHODS)

In my professional career, I have worked in three research-based centers that employed me through research grants. The commonality amongst all three jobs was the focus on quantitative research with none to minimal focus on qualitative research. A mentor at one of these centers said to me, “If there isn’t an ‘n=1’, your research won’t fly.” My former supervisor echoed this as we considered what kind of research grants we would pursue. He said, “Qualitative research does not bring in money to our center unless you have a strong quantitative focus to pair it with.” This type of thinking is referred as the “gold standard” (Yin, 2016). I do not believe one method of research to be better over the other. Each has a use and purpose (Cartiere, 2012; McLafferty & Slate, 2010; Strijker et al., 2020; Walker, 2017). A qualitative method is chosen for this research study because qualitative data can be powerful through the sharing of stories, *testimonios*, experiences, expression, and more, which enhance the understanding on the subject and provides a richer context that completes a view. The topics addressed are based upon my own experience, which does not require me to find and identify research participants. Tierney (1998) explains it best when he says, “by studying someone as if he or she is a portal, we define the research subject because he or she is different, because his or her world is not the same as our world” (p. 58). Researchers often treat research subjects (people) as if they are entering an unknown place or world that we must examine and study. We treat research subjects as an exploration to a new place when in fact they live in the same world we live in. Unless someone has a portal gun to travel to other planets, galaxies, or even the multiverse (yes, I am referring to Rick Sánchez from the animated

series, *Rick and Morty*), it is bizarre to want to study someone else because they are different from me. We cannot behave as if another person lives in a different world. In other words, why would I want to study a person or a group of people, and as a researcher, act as if their world is different from mine when it comes to issues of disability as a student and employee? My personal experiences relating to disability are meaningful and insightful as much as studying a group of people or individual. Using the combination of *testimonio*, autoethnography, performance, and *ars poetica* qualitative methods, my story will be rich in content and provide an insider view, or as Tierney says, “a portal,” on disability and mental health in organizational culture and learning environments.

### **Ontological and Epistemological Perspectives**

Qualitative research allows us to understand “how people cope in their real-world settings” (p. 3) and “enables you to conduct in-depth studies about a broad array of topics” (Creswell, 2013, p. 6). The research goal is to provide an in-depth understanding of an interconnected series of life experiences that is based upon several realities in social environments. The ontological perspective to qualitative research is based upon “philosophical beliefs about what constitutes social reality” (Yin, 2016, p. 338) and “the nature of reality and its characteristics” (Creswell, 2013, p. 20). In connection to my research interests, using a qualitative approach will allow me to share a complex experience regarding disability and mental health in relation to organizational culture and changes to learning capability. Using an emic approach, best described as the “adoption of an indigenous orientation or perspective,” will allow me to provide a direct insider perspective (Yin, 2016, p. 355). Even though the experiences of disability are different

for everyone, there are aspects of experiences that are relatable amongst people. Because autoethnography is based upon an autobiographical approach that allows others to re-live the researcher's experience (Ellis, 2004; Schwandt, 2007), my research will have multiple realities due to the nature of disability and the various experiences surrounding each state of my health in the settings of organizational culture and learning environments. I want people who read my research study to understand the severity of disability, how to better support people in organizations, and improve learning environments.

Creswell (2013) describes epistemology as the process by which “researchers try to get as close as possible to the participants being studied” (p. 20). Yin (2016) states that it is the “philosophical underpinnings of researcher's beliefs regarding the nature of knowledge and how it is derived or created” (p. 335). In my research process, my epistemology is focused on defining a life altering experience. I want readers to be able to connect to me as the research subject and understand my life experiences to bring a greater understanding to mental health problems in the United States of America (U.S.). In teaching students about oral history and autoethnography, Saldaña (2016) quotes himself stating to his students, “Don't connect someone's dots' – connect his or her *motifs*” (emphasis added, p. 157). In choosing testimony and autoethnography, readers do not interpret my writing. Patterns and connections to the themes of organizational culture, learning environments, and disability will reveal several issues.

### **Rigor and Trustworthiness**

Traditionally, to ensure rigor and trustworthiness, qualitative research has a strong data collection procedure - it addresses bias, triangulates, and provides a rich thick description (Creswell, 2013). Traditional qualitative research studies other people, not the



self. In some ways, “We assume that we know our world, and the intent of a study is to understand other worlds” (Tierney, 1998, p. 58). There are many experiences our own personal worlds have to offer that do not require us to study someone else because “they have been defined as a problem or as exotic” (Tierney, 1998, p. 58). It is easy to study a group of people or an individual, but it is much more difficult to study and unpack one’s own life experiences as a research study. The development of my disabilities demonstrated to me the inequalities, oppression, and stigmas that exist towards individuals with disabilities. My experiences are valid as much as the experiences of a research participant would be to any researcher. If I were to study individuals who have experienced inequalities, oppression, and stigmas in the workplace or in a learning environment, there would be things that they would share and omit based on their level of comfort with me as a researcher. They might provide in-depth details or surface-level details. It might even require that I study more people. The advantages of telling you about my lived experiences are that I will share in-depth details and breakdown those details to recreate the memories associated to my disabilities in the face of injustice. In short, it is my testimony about injustices regarding my disabilities. I have the ability and willingness to share my disability-related problems in-depth to contribute to the literature on workplace problems and learning environment inequities. It is discrimination to question and challenge the interpretation of the problems I confronted because by doing so, it demonstrates support for injustices, intolerance, hostility, discrimination, and oppression. Qualitative research has more to prove than quantitative research because it is more open to interpretation (Savin-Baden & Howell Major, 2013; Saldaña, 2016). There are more realities to explore and make reason out of to understand the subject at hand

(Creswell, 2013; Savin-Baden & Howell Major, 2013). “We are cautioned to maintain a sense of scientific rigor in an era of evidence-based accountability, yet also encouraged to explore more progressive forms of academic research reporting such as poetic and autoethnographic representations” (Saldaña, 2016, p. 289). The one sure way that my study will demonstrate rigor and trustworthiness is based upon successfully connecting readers with my experiences and reinforcing my experiences rigorously using intersectionality. Savin-Baden and Howell Major (2013) state that “In qualitative research, the researcher is a human instrument with many potential biases that should be considered, while in quantitative research, the instrument is a test or experiment that may be validated” (p. 16). Because I will be using intersectionality, it changes and challenges the traditional research mindset on bias. In my use of testimony and autoethnography, I tell my truth and realities. As Hill Collins (2019) states, “intersectionality had a strong critical edge, one that reflected its ties to resistant knowledge projects and its commitment to decolonizing knowledges within academic venues” (p. 15). Crenshaw (1989) first coined the term “intersection” as she explored the oppression of Black women through race and sex, as the two terms were often treated exclusively from each other. Crenshaw wrote that you could not separate race and gender as the two were interrelated in cases of oppression. Intersectionality provides a means to address bias by changing the view on bias and removing that mindset to allow for honest, reflexive, intersectional research. This is the very idea that Crenshaw had when discussing issues of racism and oppression that impact Black women. *Testimonio* and autoethnography, supported by intersectionality, will challenge me to dissect life events that are associated to trauma, discrimination, oppression, and toxic masculinity.

## Testimonio

“I’d like to stress that it’s not only my life, it’s also the testimony of my people” (Menchú & Burgos-Debray, 1984, p. 1). I believe that as humans we have experiences that are homogeneous and heterogeneous, sometimes focusing on one end more than we should. With over a billion people in the world with a disability (WHO, 2018), I am not alone. Other people will have relatable experiences to my own. Following in the path of Menchú, my writing is my *testimonio*, or testimony, to experiences that no one should have; yet many people do. Menchú’s life experience in Guatemala is a tragedy, representing a multitude of problems for the impoverished Guatemalans and the K’iche’, an indigenous Mayan group. Her testimony brings awareness to the racism, oppression, politics, violence, suffering, and deaths that were occurring to Guatemalans and most likely continue to occur to some level today. Menchú’s testimony is reflective of what many innocent people experienced in Guatemala. She did face criticism by Western scholars, questioning the authenticity of her experiences simply because her work did not follow the traditional norms of academia (Brittin, 1995; Delgado, 1999; Arias, 2001). Those who questioned the validity of her experience were those who could not grasp the devastating experience of an indigenous Mayan woman and believed *testimonio* was illegitimate for bringing awareness in third world countries (Brittin, 1995; Delgado, 1999; Arias, 2001). By using *testimonio* as described by Menchú, her approach in bringing awareness to injustice is supported through my own contribution of utilization of the method. “Testimonios, which have been widely used in Latin America to personalize the denunciation of state violence and to demonstrate subaltern resistance, gain their narrative power for the metaphor of witnessing” (Warren, 1997, p. 22). As Warren

describes, it “represents eye-witness experiences” and presents “evidence for judgement in the court of public opinion” (p. 22). The *testimonio* is a powerful method for research writing. Montejo (1993) uses *testimonio* to share his experiences as an insider to describe a “collective story (of expropriation and exile) and, at the same time, elicit a strong commitment from anthropologists to promote issues such as social justice, self-determination, and human rights in the politics of native people” (p. 16). His experiences bring attention to the violence, injustices, and displacement within his life, demonstrating what others experience and providing a close view to the life experiences that some of us will never see. I use *testimonio* for three reasons: a) to share my personal experiences with disabilities in a work and academic setting, b) to build upon the concept of *testimonio* within the organizational culture and learning sciences fields, and c) to connect to my indigenous Mayan culture. Menchú is the first and only Mayan scholar I learned early in my life because she is a representation of the Mayan community. It reinforces and grounds roots of Mayan identity development as a descendant of once mighty indigenous people. Her *testimonio* serves as a catalyst of problems that were once unknown and hidden from the public, like Montejo. It is important for me to connect my research study to my indigenous roots to honor my own family’s Mayan genealogy and lineage. I cannot speak or write on behalf of other people, but I can use my *testimonio* to bring attention to the issues that impact the wellbeing of people in a work environment and learning environment. *Testimonio* is the forefront of my research method and will be supported by autoethnography. From here on, I use *testimonio* and testimony interchangeably as a stylistic choice. I use both *testimonio* and autoethnography combined as it broadens my writing style to share my experiences. It allows me to

authentically write with honesty, vulnerability, reflection, and candor. Without testimony, my truth cannot be proactively written. Without autoethnography, my truth is not accepted as research by the standards of academia. By nature, testimony is my direct experience as I witnessed issues regarding my disability unfold as a student and employee. Autoethnography, as I explain below, allows in-depth exploration of my personal narratives. This will create a stronger approach to my life experiences with disability.

### **Autoethnography**

To make sure I describe my experience to the best of my capabilities, I focus on using autoethnography, which can refer to “the ethnography of one’s own group or to autobiographical writing that has ethnographic interest” (Reed-Denahay, 1997, p. 2). I am using autoethnography because it “has been assumed to be more ‘authentic’ than straight ethnography. The voice of the insider is assumed to be more true than that of the outsider in much current debate” (p. 3). Autoethnography allows me to explore myself and connect my experiences to society, much like ethnography. It provides “the ability to transcend everyday conceptions of selfhood and social life is related to the ability to write or do autoethnography. This is a postmodern condition. It involves a rewriting of the self and the social” (p. 4). As much as I could study an individual or group of people, my own life experiences provide insight to issues of disability in organizational culture and academic settings. Tierney says that “Autoethnographic texts create the possibility for a reclamation of voices that have been either absent from traditional social science texts or misrepresented as ways to understand whole schemas of cultures” (Tierney, 1998, p. 66). I agree. I am very marginalized as a first-generation, American, Latino, low income,

individual with disabilities and will explore the intersectionality of these identities in Chapter 4. I need to reclaim spaces that should represent me. In understanding the paradoxes of the self and our self-narration, Herzfeld (1997) explains that how we choose to highlight our own narratives would not be the same as those we would use in field work. He states, “Yet they shadow our personal trajectories in ways that can be mutually illuminating” (p. 169). Herzfeld further explains that our narratives “have the most to teach us when they force us to confront the inevitable dissonance within ourselves” (p. 169). Studying of the self does reveal the dissonance within life experiences that makes us question our beliefs and actions, thus providing powerful insight. This puts the researcher in a vulnerable and insightful position to provide knowledge that is unattainable from traditional research methods. Herzfeld explains autoethnography as:

a coherent vision of the paradox-plagued self, described by people who, no less than anthropologists, are theorists – practical theorists, to be sure, but articulate exegetes of the politics of selfhood for all that...But they are also couched in terms of categories understood to be semantically labile; and in this the shepherds, who (like the working-class English) have nothing to gain from maintaining the sober face of semantic stability, differ radically from bureaucrats (whose interests depend on it) (p. 189).

Autoethnography will allow me to roam freely in the landscape of academia, as I only represent myself in the context of organizational culture and learning environments within my surrounding field. I do not have to concern myself with representing or interpreting another person’s or persons’ experience. Focusing on the works of Maxine Hong Kingston’s *The Woman Warrior*, Michael Arlen’s *Passage to Ararat*, and Marita Golden’s *Migrations of the Heart*, Fisher (1986) says “The recent proliferation of autobiographical works that take ethnicity as a focal puzzle seems to be poorly accommodated within the traditional sociological literature on ethnicity” (p. 195). Fisher

supports these works as autoethnography and states they are important to discussions on ethnicity that challenge traditional research. “What thus seems initially to be individualistic autobiographical searchings turn out to be revelations of traditions, recollections of disseminated identities and of divine sparks from the breaking of the vessels” (Fisher, 1986, p. 198). Studying the similarities and differences of our life experiences and who we are as individuals and groups of people are all equally important. There are several revelations I carry to inform my readers of the issues surrounding disabilities in learning environments and workplace from a first-generation male Latino. As Fisher states:

One needs authentic anchorages that can allow a kind of dual or multiple tracking (between self and other), that generate a rich, sympathetic curiosity for detail and cultural logic, that can be subjected to mutual criticism or mutual revelation from both traditions (p. 201).

Given that this autoethnography is based on my disabilities and mental health, specifically sleep apnea, there are several anchorages that are derived from my various states of minds. Some of my anchorages are memories of being sleep deprived and being told I am underperforming as an employee, being on the verge of suicide and being told I was disengaged in class, being severely depressed and not being believed because I did not look like there was anything wrong with me. Although there are several other anchorages, I can move from my current healthier state of mind back to previous states of minds and refer to those as the “other” to write rich detail. Each state of mind has its own story and experiences, many of which I hope people can connect with. In some ways, Fisher explains dream work and alternative selves as ways of exploring both the past, present, and future as a way of further understanding our own identities. Resemblances have the capability to connect us just as much as differences can separate us. As Herzfeld

(1997) states, “In a universe in which people differentiate themselves by blaming others or by contrasting their respective understandings of personal accountability, they must share a common idiom in which to do it” (p. 193). Our homogeneous and heterogeneous experiences written through an ethnographic method are effective in communicating relatability. I believe that “we must make ourselves vulnerable, willing to enter into dialogues with those with whom we will disagree and understand not only the point of disagreement but also the scaffolding on which it is based” (Tierney, 1998, p. 57). Being open and aware of disagreement will lead to an honest discussion with you, the reader. Being vulnerable is not an easy choice as a writer; but it will allow for an authentic conversation. Adams (2012) explains autoethnography as “a research method that uses personal experience in order to understand and critique cultural experience” (p. 181). Much of my experience with negative mental health has relevancy and implications about work culture and academic culture. This requires that I analyze my experience and my surrounding. Boylorn (2008) shares that “autoethnographers look in (at themselves) and out (at the world connecting the personal to the cultural)” (p. 413). In unpacking my experience with negative mental health and disability, there is much that relates and differs to my personal culture as well as the culture of academia and workplaces.

### **Social Critical Theory: Intersectionality**

There are several philosophies and theories within qualitative research such as critical social theory, pragmatism, phenomenology, post-modernism/structuralism, social constructionism, and constructivism (Savin-Baden & Howell Major, 2013). Each seeks to understand a subject through a different lens. For my purposes, intersectionality, a social critical theory as described by Hill Collins (2019), fits best for my qualitative approach.



Although Crenshaw (1989) first wrote about intersections of race and gender, it was not intentionally focused as a method for discourse. It was a term used to argue the various aspect of identity could not be separated when studied as research. Hill Collins provides an updated understanding of intersectionality to theorize social inequality such as racism, sexism, disability, and colonialism directed towards social change. Hill Collins states that she uses “intersectionality as a lens for examining how critical analysis and social action might inform one another” (p. 3). She further explains that “Many everyday people offer compelling explanations of their social worlds” (p. 5). This description of intersectionality as a social critical theory best fits the methods for my study. My world provides insight to what many would ignore or cast aside due to their own privilege. My motivation is that “Intersectionality is gaining currency among higher education scholars and practitioners because it acknowledges an individual’s multiple social identities, thus creating a more complete portrayal of the whole person” (Wijeyesinghe & Jones, 2019, p. 4). This is fitting as organizational culture and learning environments often have unique individuals in their settings that allow for more than one approach to create a successful environment for all. It also “centers the voices of people and groups previously overlooked or excluded, especially in the analysis of inequality and efforts to remedy specific social problems” (Wijeyesinghe & Jones, 2019, p. 10). Intersectionality provides a holistic lens to dissect experiences without needing to isolate pieces of an individual or group of people by looking at how our race, gender, abilities, and more are impacted by the social world.

Using intersectionality provides me a lens to dissect my experiences with disability and mental health as a first-generation Latino male college student. My

experiences have dealt with discrimination in systems of power, thus serving as a catalyst to critically analyzing organizational culture and learning environments. Hill Collins states:

For people penalized by colonialism, patriarchy, racism, nationalism, and similar systems of power, experiences with oppression are often the catalyst for critically analyzing these systems and taking action within them. Experiences provide a reason why people are willing to take on the tough job of theorizing. (p. 12)

According to Hill Collins, research often requires us to interpret data and remove bias, yet intersectionality does not require that I remove my bias or fit my experiences within a theory. Intersectionality has the following core constructs and guiding premises: relationality, power, social inequality, social context, complexity, and social justice. Relationality “shifts focus away from the essential qualities that seemingly lie in the center of categories and toward the relational process that connect them” (p. 45). Hill Collins explains that “Intersecting power relations produce social divisions of race, gender, class, sexuality, ability, age, country of origin, and citizenship status that are unlikely to be adequately understood in isolation from one another” (p. 46). I cannot examine my disabilities separate from my identity (e.g., race, gender, socioeconomic status, generational status). My identities cannot be isolated from disability as they all play a role in my social environment. My identity informs my experiences of inequality due to having disabilities in the workplace and learning environment. Each part of my identity plays a role in my experiences of discrimination, inequalities, and stigmas. As described in Chapter 2, organizational culture does not account for disability, identity, and learning of the people who work within it, resulting in the creation of inequalities.

Social inequality moves away from frameworks that see each inequality as separate entities. It rejects notions that it is inevitable due to it being “hardwired into the

social world, into individual nature, or into both” (p. 46). Social context is focused on how knowledge production is organized, including that “social locations of individuals and groups within intersecting power locations shape intellectual production” (p. 47). Given the iterative and interactional nature, complexity examines “the connections among seemingly distinctive categories of analysis” (p. 47). Last, social justice focuses on ethics and how that intersects within scholarship and practice. Hill Collins explains “the significance of social justice as a core theme within intersectionality is increasingly challenged by norms that place social justice, freedom, equality, and similar ethical issues as secondary concerns within acceptable scholarship” (p. 47). She explains that these constructs inform one another, which have led to varying intersectional projects. These core constructs make intersectionality “a powerful tool for understanding, constructing, and deconstructing: the experience of identity, the complex and mutually constituting nature of social identities, the relationships between identity and larger social systems, and the interwoven nature of manifestations of social oppression” (Wijeyesinghe & Jones, 2019, p. 11). Hill Collins fits the core constructs within her three dimensions of critical thinking: metaphor, heuristic, and paradigm. She states that these dimensions “constitute the critical thinking tools that surround the process of doing social theory” (p. 49). Those dimensions allow for intersectionality to shape and reshape as needed through its core constructs.

Intersectionality fits well with autoethnography and testimony as it helps support personal experiences and identity, justifying a person of color who has often faced opposition of truth and reality. Combined with *testimonio* and autoethnography, it creates the conditions for intersectionality because it does not require isolation of one piece of

identity. It encourages intersections of identity regarding disability and organizational culture. *Testimonio* and autoethnography allows an exploration of identity. “Speaking from experience threatened epistemic norms, not just because the content was unflattering to elites, but more importantly, because doing so rejected the norms themselves” (Hill Collins, 2019, p. 141). By challenging the norms, a threat is created to those that maintain them; they fear losing power and confronting change. Experiences against discrimination and oppression should not require justification. Intersectionality creates a framework that allows me to explore the interconnectedness of my identity (e.g., race, gender, abilities) within the context of organizational culture and learning environments and focus on topics that are also the core constructs of intersectionality: relationality, power, social inequality, social context, complexity, and social justice. As Hill Collins states:

Critical social theory that refuses to look away from the hard questions that accompany oppression and social injustice is needed more now than ever. Change is not new, and critically analyzing a changing social world has been the special task of critical social theory (p. 287).

For these reasons, intersectionality is used as social critical theory. Recent literature (e.g., Evans et al., 2017; Vaccaro & Kimball, 2019; Wijeyesinghe & Jones, 2019) support the importance of intersectionality to understand the identity of diverse people. Regarding what college campuses can do to support students with disabilities, Vaccaro and Kimball (2019) state that “discussions should focus on disability as a marginalized identity and as an identity that intersects with race, gender, class, sexuality, and religion to shape the life experiences of students in unique ways” (p. 219). In my case, developing disabilities and trying to make sense of them through other aspects of my identity was challenging. When environments that are meant to be supportive show disregard for my disabilities, it makes

me think about how my identity (e.g., gender, race, socioeconomic status) is impacted in the higher education workplace and learning environment by those in positions of power and authority. This research study uses intersectionality as theory because it compliments *testimonio* and autoethnography to understand and fully explore my marginalized identity and how it intersects with my race, (dis)abilities, and gender. Disability cannot be separated from other aspects of my identity. There is no way to turn off an aspect or aspects of anyone's identity. Every aspect of identity is interconnected to our social environment. There is no way to turn off one's nationality, gender, sexuality, ethnicity, religion, and everything else that makes us who we are as people. My experience can inform the need for changes to organizational culture and learning environments.

Intersectionality "highlights how people – as members of multiple groups of individuals – experience marginalization and inequality, even in movements designed to further social justice and institutional change" (Wijeyesinghe & Jones, 2019, p. 5). My experiences with disability and mental health have demonstrated to me how easy it is to become marginalized and confront inequality, injustice, discrimination, and oppression simply because I was not performing like everyone else in my environments.

### **The Use of Theory**

Theories help align the methods used to carry out research. "Methods are the procedures undertaken for carrying out the study. They are the tools of the investigation" (Savin-Baden & Howell Major, 2013, p. 333). My literature review helps guide and align the methods further. It also adds an ethical lens by creating a strong rationale for the theoretical analysis of methods (Savin-Baden & Howell Major, 2013). In doing so, the research can demonstrate value and alignment. Using multiple methods for data

collection also helps align the research so that there is consistency (Creswell, 2013).

Altogether, it helps the research design have a direction and purpose. There is a level of pragmatism that needs to be addressed with qualitative research. Creswell (2013) best describes it when he states:

In practice, the individual using this worldview will use multiple methods of data collection to best answer the research question, will employ multiple sources of data collection, will focus on the practical implications of the research, and will emphasize the importance of conducting research that best addresses the research problem. (p. 28)

One approach will not address my research focus because it will restrict my experiences, writing style, and authentic voice representing my identity as a whole. The multiple approaches of *testimonio*, autoethnography, and intersectionality combined will help guide my research by allowing me to express my authentic self as I confronted injustices due to my disabilities. Pragmatism has a focus on the outcomes (Creswell, 2013; Yin, 2016), which aligns with my personal views for my dissertation. I do not want to just focus on my experience. Testimony and autoethnography do not restrict writers from sharing more than one experience, much like Menchú sharing multiple experiences of the oppression and injustices in Guatemala. The authentic anchorages, as Fisher (1986) defined, hold my experience with disability that warrants a full exploration of the range of emotions I endured in the higher education workplace and learning environment. I plan on focusing on solutions and problem-solving for others that may find themselves in situations like my own. These solutions and problem-solving experiences complete my experiences. Having the theory, literature, methods, and data collection align with one another help me create a rigorous and trustworthy contribution to research.

## **Performative Autoethnography and Performance as Theory**

During some of the improvement stages of my disabilities, I was invited to deliver a webinar on mental health for higher education professionals and provide training on disabilities and substance use to prevention specialists. These two experiences are performances that took place as a form of healing and empowerment not just for myself, but for those who attended my performances. These were not a traditional webinar or training. Both required participation of the audience as they connected the content delivered to their communities and their lives. Performative autoethnography, simply stated, is a performance of thoughts, ideas, embodiment, and connection to societal issues and exploring it through an understanding of how “we” and “I” connect, my reflexivity, vulnerability, and intersectionality (Alcoff, 1991; Tierney, 1998; Madison, 1999; Pezzullo, 2003; Calafell, 2013; McIntosh and Hobson, 2013).

Because of intersectionality, I will focus on “I” and how it relates to “we.” My intent is not to generalize my experience, but to demonstrate that my experience provides value and is relatable. Describing dealing with the “I,” Tierney (1998) states, “We have arrived at a time in which we must at least struggle, if not understand, where we as authors and researchers fit in the pictures” (p. 53). It might make some academics uncomfortable using “I,” but it is necessary to address why using “I” is important to autoethnography. In discussing “I” and “we,” Calafell (2013) explains that researchers using performative autoethnography can address the privilege and dominant power structures by incorporating accountability, reflexivity, and intersectionality into their work. She states:

I wonder if we might push ourselves toward a new level of vulnerability, and as Jones and Madison argue, more labor in our reflexivity; a vulnerability driven by

love, driven by rationality, and an ethic of care. A vulnerability, love, and care that allows us not only to see our reflection in the “I”, but also in the “we” that may be based in an Otherness that is not our own. (p. 11)

I will push myself to being accountable, reflexive, and discussing the intersections of my experience in relation to my roles as a graduate student and employee. In unpacking my disabilities and negative mental health experience, there is much that I need to reflect upon regarding the intersections of my interactions and health. “Methodologically, intersectionality suggests something far more radical about the process of theorizing than quiet contemplation by a lone scholar who is removed from the social world” (Hill Collins, 2019, p. 13). Personal experiences and making sense of it will be shared with my audience. This is a difficult topic to discuss. Accountability for my actions in this writing process will take place. Alcoff (1991) describes the problem of speaking for others in how there is a need to understand how a person’s social and privileged location can have implications about representation and truth. Alcoff states that there are ways for a person to reduce the danger of speaking for others by examining, resisting motivation and reasons for speaking, becoming reflexive and evaluating the content and meaning, being accountable for their speaking, and carefully analyzing words we use. I have to look at the various ways my life stories can be understood. Tierney provides three points to shape the researcher/author role: 1) the reflexive culture – “my search is not so much about why someone acts a particular way but about how it is that he or she has come to act that way,” 2) the reflexive subject – “the text becomes the language that enables us to move across groups, to include rather than exclude,” and 3) the empathetic identity – “we enable empathy to circumscribe our relations” (p. 55-56, Tierney, 1998). Reflexivity will allow me to navigate a difficult account of a portion of my life with my audience. It will



guide my thinking as I write about myself as a researcher and author. There will be emphasis on the importance of the circumstances that led to my experiences and the inclusion of people that have life similarities to my own. It is important to set this focus first because my *testimonio*/autoethnography will be speaking for myself yet there will be implications to how it connects to work environments, school environments, social settings, socioeconomic status, ableism, identity development, and access to health services.

My experience leading a webinar and training is a form of theory that will be best enhanced through the use of performance. Performance theory is situated within autoethnography. In discussing performance as theory, Madison (1999) makes the argument that performance is just as meaningful as theory. She says that:

It is more than language, gatekeepers, belonging, respect, or isolation. It is all and nothing more than recognition. You think you know something, but theory leads you to know it again. You were always aware of power, beauty, pain, language, race, and yourself. But theory circles you back to all of them, including yourself. (p. 109)

My thoughts on performance as theory leads me to believe that being connected to myself as a research subject allows me to further think about the intersectionality that my experience will demonstrate. Madison further states, “Like good theory, performance is a blur of meaning, language, and a bit of pain” (p. 108). To help my audience best understand how my mental health impacted my abilities negatively, the inclusion of myself becomes important in providing a view of a segment of my life and what it implicates. In addition to Madison’s concept of performance, I incorporate McIntosh and Hobson’s (2013) view on performance that includes reflexive engagement because of the “embodied process of” reflexivity (p. 3). They use reflexivity as a process for addressing

failure and take it a step forward by bringing in ethics, social justice, privilege, and coalition building into their performance. Pezzullo (2003) addresses environmental racism through the use of tours as a cultural performance. Community and societal issues are raised as to how a company harmed the environment and community without taking responsibility for their actions. Pezzullo states, “I consider how toxic tours as cultural performances help build communities of resistance through acts of politicizing memory” (p. 228). By focusing on a community, Pezzullo brings discussion of politics, culture, the environment, injustice, and justice. The cultural performance serves as an act of social and environmental justice to bring awareness to issues affecting a community and using them as a representation of the many issues that occur in our country. Focusing on disability and mental health requires that I address privilege, ethics, and social justice that my personal experience merits. This includes my two performances with the webinar and training I provided to other professionals because the performances were informed by my own personal experiences with disability. Like Pezzullo, I utilize performance to engage the audience in a journey rather than presenting information in a traditional mode. This study provides strong evidence for why we need to rethink our organizational and academic environments and the inclusion of disability/mental health as an important element in promoting supportive environments to improve learning and working conditions.

### **Ars Poetica**

I have chosen to incorporate the use of ars poetica (the art of poetry) as explained by Faulkner (2007) because it allows me to be creative and situate myself as a storyteller. Faulkner explains, “What I am arguing is that poetic truth is not only some extraction of

exact words or phrases from interview transcripts or our personal experience but rather requires a more focused attention to craft issues” (p. 221). Unpacking my disabilities and mental health experience has proven to be difficult because there is much that I need to revisit and the memories bring forth pain, depression, anger, and frustration in connection to my identity (e.g., gender, race, class). Intersectionality will allow me to unpack those experiences and it will be enhanced through *ars poetica*. I want my readers to understand and feel my emotions as I unpack the memories, discuss my recommendations, and explore implications for addressing disability in the workplace and learning environments. A good example of the power of *ars poetica* is the poem *Certified* by Griffiths (2018). In her poem she tells the life and health problems of her mother. She writes, “Her medical files could fill a room, a mansion. Insurance & charts. X-rays. Letters from specialists. The results of tests that would judge her impossible future *Impossible*. So many referrals. So many prescriptions. It was another language” (p. 66). Griffiths’ words and voice carry vivid imagery that express frustration, pain, and agony. Her emotions amplify as her poem continues. “There were recipes she cooked. Recipes of meds to keep her here with us. Blood pressure, cholesterol, anti-rejection, vitamins for endless deficiencies. Then the death certificate. Multi-organ failure. July 28, 2014. Time of death: 7:09 P.M.” (p. 67). In her words, you get the sense of someone searching for every possible remedy to survive, only to have their life end after a fierce battle with declining health. In *ars poetica*, you can hear an individual’s tone of voice, feelings, and thoughts. Madison (1993) address theories of the flesh in that a person’s circumstances shape knowledge and philosophies. Madison uses reflexivity to analyze herself through narrative and storytelling. In doing so, she addresses black feminist

thought in poetic transcription and how it enables us to hear a person's voice through tone, rhythm, inflection, pronunciations, tempo, vernaculars, and accents. It allows for a greater understanding of identity and social settings. Madison carefully uses rhythms within speech that are "consistent with the black tradition of acknowledging that words are alive with sounds that condition their meanings" (p. 216). Poetic transcription of moments in my life revolving around disability will allow me to further develop my voice. It will help amplify my own stories. In describing the effectiveness of Chicano poetry as a vehicle to expression and personal experiences, Fisher (1986) writes, "The search for enabling histories and myths in much early Chicano writing took the form of seeking out *cuentos* (stories), and much of the literary ideology was one of capturing and preserving an oral culture" (p. 221). My identity as a Chicano/Latino within learning environments and workplaces carries many thoughts that are my histories and *cuentos*. Within my own stories will be stories of my own cultural upbringing that influence my Mexican identity. Cox (2011) uses the poetic work of Chrystos, a Native American, to explore the "contact zone," which means the relationship and connection that the writer creates to connect with the reader as a way to allow them to understand their life. Using autoethnography, authenticity, and audacity, Cox fully explores the meaning behind two poems by Chrystos and the need for the reader to participate through their own reaction. Cox believes that the way poetry is taught to be understood needs to be changed to an ethnographic/autoethnographic lens. "The kind of change that can make slow progress toward cultural mediation occurs in singular classroom discussions or in small acts of empathetic and aesthetic interpretation, and in careful attention to the speech acts of others" (p. 69). Poetry is a strong tool for sharing *cuentos*, voice, experience, and

expression. It will require readers to pay careful attention to how I craft my words in those instances. I aim to be clear so that I am not misunderstood. The use of poetry will only amplify my experiences to convey my voice and thoughts through their rightly associated expression.

### **Film, TV, and Music**

Given that topics of disability and mental health often appear in cinema (film and television) and music, there will be moments where I reflect upon myself through viewing cinema or listening to music and connecting it to my surroundings. Similar to ethnography, cinema depicts stories, whether fiction or nonfiction. “The telling of history is linked to the telling of stories, both textual and cinematic (as is often remarked, the Latin word *storia* contains both meanings)” (p. 194, Rony, 1996). Analyzing race through cinema, Rony explores several works to understand how race and indigenous groups have been researched, constructed, defined, and presented. Rony’s use of ethnography sheds light on how cinema was used as a research tool that often gazes indigenous groups and races as inferior, prehistoric, or as Rony often uses, “savages.” On a similar path, Boylorn (2008) addresses race and reality television shows through autoethnography. Boylorn argues how the oppositional gaze is utilized and represented to an audience and the implications this has to black women. Boylorn identifies how there is only a binary identity for black women on television as either highly educated, attractive, and ambitious or high school drop-out, unattractive, and listless. This leads into the stereotypes of black women and the perception that television creates. Music as autoethnography has similar effects in which it is also self-reflexive and allows the writer to “understand and communicate personal stories behind their creative experiences,” (p.

6, Ellis & Bartleet, 2010). Ellis and Bartleet explain that autoethnographic works are written in the first-person voice and “appears in a variety of creative formats; for example, short stories, music compositions, poetry, photographic essays, and reflective journals” (p. 7). They explain that musicians, like autoethnographers, also write about their lived experiences and seek to find meaning, make sense, reflect, and process their thoughts. Using music, whether your own or published by others, can be used to tell stories about understanding anxiety as an illusionary deceit (Godwin, 2019), being an occupational therapist and asking the readers to listen to specific music tracks while reading their autoethnography (Wimpenny, Gouzaouasis & Benthall, 2018), or reflecting on trauma of Jewish suffering and finding solace in opera music (Golderbeg, 2018). Autoethnographic research allows us to address societal issues through personal experiences of the self and others using creativity and art. The incorporation of these forms of autoethnography will allow me to use the autoethnographic gaze to “zoom backward and forward, inward and outward” (p. 37, Ellis, 2004). For these reasons, I will be addressing cinema and music as it relates to my own reality of how society views disability. I may even consider writing a song about my experience with disability within this study.

### **Creative Autoethnographic Testimonio**

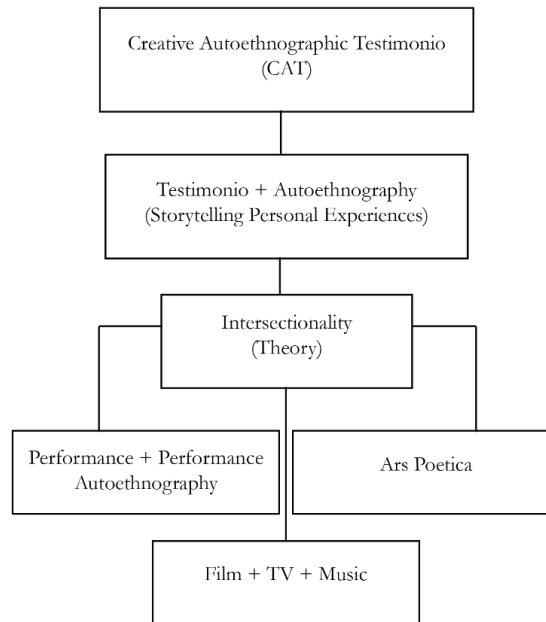
Combining autoethnography, ars poetica, performance, and testimony with the support of intersectionality, I created one term to describe them as one: creative autoethnographic testimonio (CAT). Rather than deciding on one method to convey my personal experiences with disability in organizational culture and learning environments, I decided that a combination of methods would allow me to be creative and effectively

share my life stories. It allows for fluid creative writing, reflection, and intersection.

Figure 1 shows my thought process in combining methods and theory. As someone with indigenous Mayan roots, Mexican culture, and creative talent, developing a writing arena for myself will allow me to be successful and effective in sharing a variety of experiences, stories, and expressions. Tierney (1998) encourages me with his words:

How I write about a particular investigation ought to vary from group to group as long as my basic premises hold; however, for too long, we have assumed a one-size-fits-all approach to academic writing that, in asserting the author's overly academic voice, all too often silences others. (p. 63)

Figure 1. Creative Autoethnographic Testimonio



Combining several qualitative research methods to clearly articulate the words in my mind will create a wider reach beyond an academic audience. It represents one key piece of my own identity, which is to question and challenge notions that restrict the diversity of people in the forms of oppression, injustice, discrimination, racism, colonialism, and every other “ism” in existence. From here on, I will refer to my combination of

qualitative methods as creative autoethnographic testimonio as my defiance to those that believe there is a one-size-fits-all approach to academic writing.

### **Setting Sail**

The experiences in our lives can be relatable to others and have the ability to connect people together through the sharing of those experiences. In chapter 4, my primary research topic, disability with an extra emphasis on mental health, has wide applications to work environments, school environments, social settings, socioeconomic status, ableism, identity development, and access to health services. My personal experience also includes larger implications that relate to politics, education, injustice, stereotypes, discrimination, identity, health services, masculinity, and race. I will use my personal journal entries, workplace documentation, artwork, medical documents, and past conversations with some people to support my stories. It will be important to follow suit with Alcoff (1991), Boylorn (2008), Calafell (2013), Hill Collins (2019), Menchú (1984), Tierney (1993; 1998), and others in making sure that I do not speak for others, use reflexivity, and carefully analyze my words. I have to ensure that I remain reflexive in my storytelling, much like Madison. I can analyze masculinity, race, and stereotypes in my environments and focus on creating an understanding of space, much like Boylorn. In following Pezzullo's approach, I can connect my experience to the impacts on the community, the politics, discrimination, and injustices that occur. My experiences will connect to the wider cultural, political, social contexts, and meanings. I undertake the task of using CAT, as Tierney (1993) said, "to challenge the oppressive structures that create the conditions for silencing" (p. 4). Chapter 4 begins with describing myself before I learned of my disabilities and the impacts. I will let myself ebb and flow to my current



present and what I have learned will be described in chapter 5. In chapter 6, I will provide recommendations for people in the context of the self, the organization, and the learning environment. The research question: “how have unexpected disabilities impacted my life, impacted the way people view and treated me as an employee within organizational cultures, and impacted the views and treatment by faculty of me as a student in an academic program?” will be answered. Like any good story, let me start at the beginning before my health decline.

## CHAPTER 4

### RESPONSES TO DISABILITY IN ORGANIZATIONAL CULTURE

I need to fall asleep. I can't keep this up.

Why won't my mind shut off?

How late is it now? I'm so tired. I need to fall asleep.

Why is my mouth so dry? Why am I so thirsty?

It's almost time for work and I keep waking up.

I don't understand what wakes me up. I must go back to sleep.

*Alarm rings at 6:30 AM.*

Again? I just want to go back to sleep.

Before being diagnosed with disabilities, I would not have considered that disabilities can be invisible, especially to the people around me. Life is different when you have Attention Deficit/Hyperactivity Disorder (ADHD), memory retrieval difficulties, sleep apnea, and unexpected mental health developments like anxiety, depression, panic, and post-traumatic stress disorder (PTSD). People are quick to judge without once considering that all people are different. I have been the recipient of prejudice, discrimination, and oppression several times based on my health in both the organizational culture of the workplace and learning environments of higher education. Each negative interaction tears you down, one piece at a time. In my case, I even began to question my own existence. In each section, I described the lived experiences first. Those experiences are followed by reflexivity second. The goal is for you, as a reader, to understand the *testimonio* first before understanding my reflection. In some brief moments, I do both combined to demonstrate my thought process while going through

difficult moments. Before I set you on a journey through my life, there are some things for you to consider.

### **Warning / Alert / Caution**

This is difficult. The negative experiences held in memory are difficult to relive, rethink, and reshare. They left me traumatized, paranoid, and depressed. It makes me angry. It is sad. There is a piece of me that wants to stop writing, never look back at any of these experiences. Dark memories are painful. This isn't easy. The bright memories, serving as anchors, illuminate my path to avoid becoming lost. I navigate my past. As I take a deep breath, I acknowledge my pain and suffering. As I exhale, I begin to let go.

### **Trigger Warning**

The events that I describe in these chapter may be triggering to readers who have suffered with suicidal thoughts. If at any point you need to stop reading and come back to it, please do so. You may also call the National Suicide Prevention Hotline at 1-800-273-8255.

### **Rise of a Change Agent: My Brief Background**

Social justice has been important to me since the day I was born. My parents migrated in the 1980s from Mérida, Yucatán, Mexico to escape the rural conditions in search for a better life in California. Given that schools in Mexico are cost-prohibitive, my parents never completed their education. As a child, I was their translator for English to Spanish and vice versa. Unknowingly, I was also speaking Mayan and Spanish as I translated English for them. I learned to speak Mayan alongside my Spanish vocabulary. My father's jobs never provided benefits such as health insurance options, job security,

and career advancement. We were considered a low-income family in an urban environment. We often faced discrimination due to our language barriers and appearance.

Raised as a first-generation child in the city of Compton, California, my hometown, once notorious for gang activity and violence, was and now is a peaceful area that experienced turmoil over the Watts Riots, Rodney King Riots, and several acts of police brutality on Blacks and Latinxs. As minorities, we were all treated unfairly. Our schools were underfunded and lacked educational services. Our nearby trauma hospital, Martin Luther King Jr. – Harbor, was closed in August 2007 for a variety of violations and problems, severely impacting all health services in the area. The hospital was known as the place “where people go to die” due to the lack of care from hospital staff. These conditions impacted the wellbeing of the communities. As a community, we had to learn to be tough and strong or we would not survive. Injustice was all around us. Music groups like Rage Against the Machine and Niggas With Attitude (N.W.A.) encouraged our communities to fight against the oppressive system by being vocal and advocating for each other.

Growing up as a straight male Mayan, Latino (Mexican and Chicano), and American in the city of Compton, witnessing the many events affecting my hometown, I had to become a change agent. No one should experience oppressive and unjust conditions in a place they call home. I thought this was something I would not experience outside this community. Oh, I was so wrong. I would soon learn that injustice was also present within higher education, both as a student and professional.

## **Motivation**

My motivation for sharing my creative autoethnographic *testimonio* is an act to fight injustice and intolerance. My first college writing professor and mentor, Don Rothman, would often say, “We write to avoid the humiliation of silence in the face of cruelty and injustice.” Don taught writing through the view of social justice and diversity. He believed in the power of writing and reading as a way to dismantle oppressive structures. I hope that my writing encourages people to dismantle oppressive structures in higher education.

## **Before It All Changed**

Unbeknownst to me, my health was declining for many years. I was active at taking care of my health. Prior to 2014, I ran three half marathons, had lost 80 pounds, ate healthy, and had ways to relax. The first half of the year 2014 marks the last experience of what I thought was normal: drinking coffee to wake up in the morning, exercising daily before or after work to keep awake, enjoying healthy meals on a regular basis, and excitement towards outdoor photography. Given the environment I lived and worked in, I thought feeling tired and wanting to sleep more was a normal thing to want. Medical doctors kept telling me to eat healthier and lose weight to improve my health. According to them, that was all I needed to live a happy healthier life. My life was not great; it was not terrible. I thought it was average.

In the second half of 2014, I made the decision to move to New Mexico (see Appendix A for a timeline of events of this chapter). My life in California was good. I had family, friends, and a community. I felt the need to leave my comfort zone because I felt stuck and thought I had to do something that would challenge me to grow and

improve upon myself. My life was becoming boring and lacking meaning. I thought an adventure in an unknown and unfamiliar environment would re-energize my spirit and mind. Little did I know that I would find the greatest challenges to my life that would push me beyond my limits. This second half of the year would be the beginning to my health decline and the beginning to oppressive experiences in the organizational culture of higher education work environment and learning environment.

### **The Unfolding of Sleep Deprivation**

I can't think. I'm stuck.

Yawning; sudden inhale, deep exhale.

I can't focus. I'm blank.

Eyes tearing up. Empty mind.

I'm tired. I need rest.

Dreading it. What to do?

At first, I thought that my move from living near the sea level, about 80 – 700 feet depending on where in southern California I was living, and moving to an altitude over 5,000 feet, nearly a mile, in Albuquerque was impacting my health. Able to run five miles without a problem in California, in New Mexico, I was struggling to run two miles without stopping. The people I met in my new job shared it might take me a few months to readjust to the new altitude. Patience, I had to develop. My patience began in July 2014 and would eventually end in August 2020. I thought my restless nights were attributed to being in a new location, new time zone, new sounds, and new environment. Feeling tired, I made the best of each day. I maintained my usual routine of exercising four to six times a week, eating healthy, and sleeping about eight hours each day.

Caffeinated tea and coffee were part of my waking routine Monday through Friday with weekends resulting in longer sleeping periods to bypass those delicious hot liquids. This seemed fairly normal to me.

As each day and month passed, functioning increasingly became difficult. To go about my routines, it took more effort. I began losing joy in the activities of everyday life, even in the smallest moments such as watching television shows and photography. After visiting two different clinics seeking medical attention, both medical doctors concluded nothing was wrong with me based on the blood sample test results. Their only concern was my hypertension, which was about 145 systolic over 87 diastolic. Their recommendation was for me to lose weight, eat healthy, and get more sleep by going to bed earlier or sleeping longer. Neither medical doctor was willing to dive further into my exhaustion as both believed I needed to modify my health (e.g., eating, sleeping, exercising).

Each medical visit increased my frustration due to the lack of support and inclination from the medical doctors to identify the source of my health problems. I did as each asked. I made sure I exercised every day, even if it was an hour walk. I focused on having a primarily vegetarian diet, with some vegan options on some days. I had a bedtime of 10 p.m. with a wake-up time of 7 a.m., giving myself a nine-hour window for sleep. None of this was helping. My body was sore each day from my exercise. I was gaining weight despite eating healthy and exercising. In fact, I was always hungry even after having a meal. I was waking up each day with a pounding headache, nearly identical to a very bad hangover from a heavy night of drinking. Except, there was no drinking on my part. This pattern of exhaustion would continue onto the summer of 2016.

Tossing and turning;  
no comfort in snoring.  
Thoughts rushing;  
non-stop fussing.  
Peace out of sight;  
frustration at night.  
No dreams;  
no self-esteem.  
Is this reality?  
Or a fatality?

### **A Sleepless Night**

Am I awake or asleep? Was I just walking around the living room? Did I fall asleep and wake up from a dream? I can't look at the clock again. Time is moving and I'm not sleeping. What is keeping me in a sleeping awake state? I have not been drinking coffee. Maybe I should just get up and watch TV. Wait, should I just get up and do something if I'm not going to sleep? I thought I had just laid down to sleep. I need to stop thinking and go back to sleep. That sounds like a good idea. Maybe it was the sugar in my dinner that is keeping me up. Is there enough sugar in a salad and piece of bread to keep me awake? I need to quiet my mind. Did I just go outside for a walk and come back? My legs feel tired. Why do I feel more awake now than during the day? Just shut up and sleep. Did I just fall asleep and wake up again? Let's count sheep. 1 sheep. 2 sheep. 3 sheep. 4 sheep. 5 sheep. 6 sheep. 7 sheep. 8 sheep. 9 sheep. 10 sheep. 11 sheep.



12 sheep. 13 sheep. 14 sheep. 15 sheep. 16 sheep. 17 sheep. 18 sheep. 19 sheep. 20 sheep. 21 sheep. 22 sheep. Can sheep really jump over a fence? Did someone put a curse on me? Why do I feel like I am asleep and physically immobilized while thinking? Did I just fall asleep and wake up again? I need to sleep. What if I died and ended up in hell? Is this darkness the void or purgatory? I just want fucking sleep. Fuck this. Someone please help. HELP! HELP! Can someone hear me? I'm losing it. These nightmares need to stop. Did I just hear someone? HELP! Why can't I hear my own echo? This is just a bad dream. I need to sleep. Calm the mind. Calm the mind. What time is it? I can't keep looking at the clock. Okay. Okay Okay. I'm falling asleep, finally! I can sleep. *The clock alarm rings.* What the fuck!? I just fell asleep. I can't keep going to work like this. *I look at the clock.* Wait, it's Saturday...Someone just kill me already. These headaches are becoming a slow death.

### **Deprivation Severity**

A lack of sleep will push our brain to create an imbalance of mood states as it swings from one extreme emotion to the next and can easily make the need for a positive emotion lead to addictive substance use (Walker, 2017). There never was another good night of sleep since I left California in the summer of 2014. I began questioning my reality. I wondered if I died or got in a car accident, resulting in a coma, while on my drive to New Mexico. My two medical visits got me nowhere. I was gaining weight while eating healthy. Perhaps I needed to enjoy my life and stop with this whole healthy bullshit and eat whatever I wanted. Whatever was wrong with me, I could not figure it out. I was taking vitamins, drinking chamomile tea, drinking moronga tea, taking melatonin, taking hot showers before bed, turning off electronics twenty minutes before

bed, and using essential oils like lavender and a good night blend to help me sleep. None of it was working. I did not realize it then, but I had developed depression and anxiety. My metabolism had slowed down drastically. I began drinking alcohol to help me sleep. I then followed by using cannabis to sleep. Sleep deprivation does lead to unhealthy habits and a decline of health (Walker, 2017).

**Depression and suicide ideation.** There was no joy in my days. Time was non-existent. Everyone was happy all around me. I felt alone and ignored. It's like sitting in a dark somber room with no color or vibrance. No one cares. Death would bring me peace. The thought of rest resulting from death was becoming tempting. There was no energy in me to go through with a suicide. I had been trained in suicide prevention as a Resident Advisor during my undergraduate student days. I knew very well suicide would cause more harm to my family than it would to me. Suicide was not an option, but it was a tempting fantasy. I just really wanted to rest and did not care how I achieved that rest. A complete stop in the activities that made me happy such as playing video games and photographing the outdoors occurred. I eventually stopped eating healthy, stopped exercising, and stopped doing many things. Focusing on making it through a workday and getting through the courses I had enrolled in was my objective. Sometimes, I wondered, did I need to shift my thinking to working harder? I gave each day every ounce of energy I could muster. It just was never enough. Depression is a sinking feeling. Shifting my thinking did not change the way I felt and functioned. Sustaining a positive mindset became impossible. It was easy to be left alone to drown in misery.

My friend Anna recently reminded me of the time I called her because I was feeling suicidal. She recalls, "I remember one day you called me and were in a bad place.

You were having suicidal thoughts and needed someone to talk to. I think that day we talked for two or three hours over the phone. I was listening and trying to be supportive. It made me realize how much you were struggling and how much you were going through that I didn't know about." Although I do not remember this moment, I believe her. She was the first to recognize my health decline and cared for me the most.

**Anxiety.** There were days where I just could not stop shaking, whether it was just my legs or my entire body. Things that were once easy (e.g., delivering presentations, speaking with students, group meetings, social activities) had become daunting. My self-esteem disappeared. During class discussion or work meetings, contributing to a conversation was intimidating. The fear to forget what to express intensified. Many times, I would forget whatever I was doing. Looking at a daily schedule made me scared and overwhelmed. It became difficult to breathe, as if I was suffocating. There was never enough air to fill my lungs. My heart rate would increase. Hypertension readings were rarely at a normal level, averaging at 150 systolic over 90 diastolic. Lost and hopeless, no longer in control of my life. It was easier to withdraw when possible. When I could not withdraw, I just wanted to run. I felt afraid to interact with my social environment. My confidence in speaking was gone. Questioning every thought, I could not think or act fast enough.

**Depression and anxiety combined.** In the video *Homeostasis* (<https://vimeo.com/480125906>), Stuart (2020) represents the isolation caused by the COVID-19 pandemic and how it can easily lead to depression, anxiety, and many other negative mental health conditions. Images 1 and 2 are stills from *Homeostasis*. In image 1, you see a shadow figure in the center of the room with a young man on the floor

attempting to stand. The unknown of life can create fear, uncertainty, anxiety, depression, and many other mental health changes. The video exemplifies what our personal environment represents under negative mental health conditions. In my case, depression and anxiety made my environment feel and look run down like the home of the young man. I was often scared of what was looming around me as if it was following me around without any way to get rid of it. I could not run away from it much like the shadow figure. Depression and anxiety can feel like the way the young man moves from one space to the next, often distressed, lost, confused, scared, concerned, and hopeless. It is difficult to get back up when you are being held down with depression and anxiety. In image 2, the shadow figure and the young man join their hands. This scene happens towards the end of the video, showing the young man return to normality. In one way, it represents that confronting our fears is a step towards normalizing our lives. In another way, it also represents the challenge of confronting negative mental health. In my counseling sessions, I have learned that confronting my depression and anxiety through acceptance and normalizing allows me to move forward. Stuart accurately portrays negative mental health during isolation that is applicable even before the pandemic and will most likely stay relevant after the pandemic ends.

**Metabolism and sleep.** Sleep deprivation caused my metabolism to not function as effectively, resulting in poor dietary choices (Walker, 2017). As Walker explains, sleep deprivation does contribute to obesity as it leads people to make healthier food choices and instead of burning fat, the body reduces muscle. As time without good sleep passed, eating healthy was unfulfilling. I was gaining weight even while eating healthy and exercising on a regular basis. I increased my food intake thinking I needed more

calories although it did not make any sense that I was gaining weight. Any large amount of food was not taking away the feeling of hunger. My body needed more energy to function. It could not metabolize efficiently. I slowly began snacking, increasing the frequency as time moved. My meal portions slowly increased. In turn, feeling hungry



added to the increased lack of focus and motivation that were already impacted by sleep apnea, depression, and anxiety. No meals satisfied me. Walker summarizes this by stating, “short sleep...will increase hunger and appetite, compromise impulse control within the brain, increase food consumption...decrease feelings of food satisfaction after eating, and prevent effective weight loss when dieting” (p. 178). Remember those medical doctors telling me to eat healthier? There was no way their recommendation was ever going to be effective during sleep deprivation. Unfortunately, my efforts to be healthy were rendered useless with ongoing sleep deprivation.

**Alcohol and sleep.** With lack of sleeping came the need to find something that would provide a positive response to helping me sleep, drinking alcohol. Drinking alcohol negatively affects sleep quality as it impairs a person’s ability to have restful and rapid eye movement (REM; dreaming state) sleep (Walker, 2017). My alcohol intake slowly increased over a period of three to four months. I mostly would drink on

weekends to help improve my quality of sleep. I drank hard liquor before bed to help me relax and tire me out. Initially, I thought it was helping me sleep. It became a habit. I looked forward to Friday, Saturday, and holiday weekends so that I could drink. As time went on, I began noticing that I was feeling worse on mornings in which I had a few drinks the night before. The morning headaches were worse. Alcohol was not helping me sleep better. It was making it worse. Luckily for me, it encouraged me to stop.

The feeling of a hangover long after I stopped drinking made me realize that even without alcohol, I experienced similar tiredness and all-day headaches. This is because both lack of sleep and alcohol impact the brain's prefrontal cortex (Walker, 2017). This region of the brain was causing a stupefied state: daze, sedation, sluggish, no dreaming, and so on. As Walker explains, the lack of REM sleep built up, leading to what would become daytime hallucinations, delusions, and gross orientation. This is known as delirium tremens (Zarcone, 1978). Without alcohol, sleep deprivation was causing similar hangover effects as my prefrontal cortex was impacted. In fact, my future sleep medical doctor confirmed that sleep apnea was causing me a hangover-like feeling because sleep deprivation and alcohol impact the prefrontal cortex. I always felt a hangover even when I was not drinking. Imagine going through many years of your life feeling this way. I was fortunate to not develop alcohol dependency/addiction. My entire health was declining every day. Since alcohol was not effective at helping me sleep, I moved on to something that is known to make a person sleep.

**Weed for sleep.** In my desperation to improve my health, I decided to use the most controversial natural plant in society, cannabis, or better known as marijuana and weed. Initially, I was skeptical it could help me in any way, especially because the

research on cannabis is mixed on whether it truly helps with sleep and other health conditions (Altman et al., 2019; Fakier & Wild, 2011; Goodhines et al., 2019; Prasad, Radulovacki, & Carley, 2013). In comparison to my experience with drinking alcohol to sleep, cannabis proved to be more effective. This includes my use of cannabidiol (CBD) oil. With depression, anxiety, and suicide ideation at bay, cannabis was effective at helping me reduce the symptoms of all three conditions. Using cannabis did help me sleep. It made each day tolerable. It allowed me to relax both physically and mentally by primarily using it to sleep. Though I would wake up tired, I did not feel as exhausted as I did without it. Thoughts that once would keep me up at night had diminished. I did experiment and learned that the indica strain of cannabis was more effective at helping me relax compared to the sativa strain of cannabis, including the hybrid combination of sativa and indica. Although I had wishful thinking this would improve my health and return me back to a healthier state, it only sustained me from getting worse. There were days in which I felt on the verge of losing my mind into the abyss. Using cannabis kept me away from thinking about suicide and giving up on my life. It helped ease the tensions of stress, anxiety, and depression. Joy and happiness were easier to experience. Cannabis helped me concentrate and gave me the motivation to run errands, study, cook, watch television, and interact with friends. Without it, I mostly stayed in my bed contemplating my life choices. Cannabis helped me cope with my declining health conditions.

### **Identifying Sleep Apnea**

As I have mentioned before, medical doctors/primary care practitioners (PCP) were not able to identify the root to my problems. Each doctor approached my health

through angles that were not addressing the source of my problem: losing weight, controlling hypertension, referring to counseling services, and dietary changes. In late August 2016, I attended a routine dental appointment. Doctor Rose gave me a full dental screening because I was a new patient. He asked, “how well do you sleep?” I shared the health difficulties experienced. Doctor Rose became the first medical professional to diagnose me with sleep apnea. He explained that I had a narrow airway (throat) and given the health conditions I shared, he was very sure I was experiencing sleep apnea. Utilizing a head shot photo taken of me by a dental hygienist, he described how my neck/throat suggested a narrow airway (see Image 3). He made a few recommendations for sleep clinics and urged me to address it soon as it would help improve my health. Sitting in my car after leaving the dentist’s office, I decided to search sleep apnea on the Internet. Every website I read gave me a sense of relief that I may have found the culprit of my health issues. As with reading about any health condition, I learned that sleep apnea could result in death while I slept. This would heighten my urgency to get treated. It created a fear that death in my sleep could happen any moment I slept. Sometime later, I read that Carrie Fisher, best known for playing Princess Leia in *Star Wars*, may have died from sleep apnea (Miller, 2017). My soon to be sleep doctor would also confirm this possibility. In the months that followed, I hoped not to die in my attempt to sleep each night, making my circumstances more challenging. It still amazes me that a dentist identified the source of my health issues and not a PCP.

I was astonished by the long wait lists to see a medical sleep specialist. I cannot recall how many sleep clinics I called, but it was difficult to get an appointment that was not four or more months away. I am sure I called all the clinics in Albuquerque, New



Mexico. I eventually found one clinic that could schedule me for an appointment within three months, and that was





because someone had called to cancel the appointment earlier that day. I guess you can say that was luck. These became the longest months as I now had a possible cause for my declining health; I wanted it treated right away. I would call different clinics every other week to get an appointment sooner, but there was nothing available.

Three months passed; I finally got to consult with a medical sleep specialist. In October 2016, I received confirmation of signs for sleep apnea from a nurse practitioner (see Appendix B). I was scheduled for a sleep study to determine the cause of sleep apnea. I wish it would have taken place the same day. It took another two months of waiting to receive a sleep study. The long wait was due to the lack of availability in appointments.

Waiting two months for a sleep study to help resolve my sleep apnea felt eternal. I would call every two weeks to get something sooner. I was not lucky.

It was early December of 2016 when I was able to go into the hospital for an overnight sleep study. There was some fear and resistance to go into a hospital. It made me feel defective. After all, I had been misdiagnosed several times within my life and feared being told that sleep apnea was not the source of my declining health. Alone, I made my way into the hospital and got checked-in and escorted towards the sleep clinic waiting area for my overnight stay.

As I waited, a sleep technician approached and led me towards my room for the night. It took the sleep technician over an hour to prepare me for the sleep study. Several sensors were connected throughout my head and body to monitor for all possible vitals to best identify the source of my sleep disorder (see image 4 and image 5). My head had the most sensors. Each needed to be carefully glued to my head, as each one corresponded with a different region of the brain. My heart, throat, stomach, and legs also had sensors attached. As if it wasn't uncomfortable enough, there was also a video camera in the room that would provide data to the sleep technician to match with the sensors' data as well as to monitor my physical activity. As explained by the sleep technician, the goal of having all the sensors, a possible continuous positive airway pressure (CPAP) machine, and video camera was to gain enough data to identify what was going on in my sleep that was affecting my overall health in order to create a treatment plan tailored specifically to me. Once I was fully wired, it was time for me to go sleep at 9:45 p.m. After four hours, the data confirmed sleep apnea. I was awoken and connected to a CPAP machine by wearing a face mask to receive the air. I would be awoken again at 6 a.m. to ensure a full eight hours of sleep for me, and a full eight hours of data for them. Not wanting to wake up and leave, I wanted more sleep.

Image 4.	Image 5.
Wired Full Body	Wired Head Annoyed
	
<i>Note. These are photos of me as I was prepared for the sleep study. These images are from a second sleep study I had to undergo in March 2018.</i>	<i>Note. Sleeping with sensors is not comfortable. You can't see it, but there are too many sensors attached to my head. Look at the cables!</i>

Those last four hours of sleep felt like minutes. I do not recall what I dreamt, but I do remember thinking that I was awake the entire eight hours. “I do not think I slept at all,” is what I groggily said to the sleep technician as all the sensors were being removed carefully from my scalp. “You passed out the moment I turned the lights off and closed the door. You did not wake up a single instance. Your brain activity was very high, which most likely is related to you dreaming all night. Our sleep is very fascinating. Each person is different. It’s why I like my job,” said the sleep technician. This was the first time in a long time that I actually felt awake, energetic, and happy. The feeling would not last all day, but it was a great indication that sleep apnea was at the center of all my health issues.

After a month of waiting for the data to be analyzed to create a sleep therapy treatment, the sleep study results revealed obstructive sleep apnea and waking up nearly every two minutes, or twenty-nine times per hour (see Appendix C). During those two minutes, I was not breathing. The results identified that the elevation and lack of humidity in New Mexico was enough to make my preexisting sleep apnea severe. That is right, my sleep apnea was preexisting. The only reason my sleep apnea had never become severe prior to moving to New Mexico was because there was some humidity in my prior environments. In short, I was not sleeping from July 2014 to December 2016 and had never gotten a good enough sleep in my life.

### **Treatment**

From January 2017 to August 2020, I would undergo several adjustments to my sleep therapy treatment. I received a bilevel positive airway pressure (BiPAP or BPAP) machine, which provides both inhale and exhale pressure rather than just inhale pressure that a CPAP provides. The first sleep therapy plan was not very effective. Although my sleep slightly improved, it was not effective. During my third visit for therapy adjustment, the nurse practitioner said to me, “This might be as good as your sleep ever gets and you’ll have to live with it for the rest of your life.” Upset, I replied, “That is some fucked up advice you are giving me.” I spoke with Jennifer, a medical assistant, immediately after to provide her with my complaint. She acknowledged that the nurse practitioner was known to disregard sleep health after initial treatment. She recommended me to her favorite sleep doctor and set me up with an appointment.

Dr. Shanna Díaz, not related to me, turned out to be the best medical provider I have had care for me in my entire life. She began her career as a Doctor of Philosophy in

psychology and decided to pursue a medical doctorate in sleep health due to noticing how much her patients complained about not sleeping enough. She has been very supportive and encouraging during my sleep recovery. Both Dr. Díaz and Jennifer would become the most helpful and caring duo to get me back to fully operational. Dr. Díaz once said to me, “I wish patients were more like you. You come in with notes on what is working, what is not working, what you are noticing, adjustments you make on your own, hunches about what you think you need, and you provide me with enough data to help make adjustments to your sleep treatment.” Every adjustment to my sleep therapy was helpful. We struggled to identify a good sleep therapy plan. I was feeling sick every day. I was not getting a full night of sleep. I was still waking up exhausted and any injury, as simple as a paper cut, was requiring additional time to heal. We tried several modifications to my sleep therapy (e.g., full facemasks, nasal pillows, nasal mask, pillows, new bed mattress, new bed sheets, room air filter). I was able to resume eating healthier and exercised three to four times a week. I was encouraged to continue this strategy as a way to combat my hypertension and get my metabolism moving again. We would eventually find out the root cause of why I was still experiencing difficulties sleeping.

**Allergies and nose.** In the early spring of 2017, it dawned on me to get an allergy test because I kept sneezing both at my work and home environments. I visited an allergist for help. After an allergy panel test, the results showed that I was allergic to dust mites and German cockroaches. Given that German cockroaches were non-existent in my environments, dust mites were responsible for making me sick. Allergy medications provided immediate relief after a few days. As this process took place, I had also decided to visit an Ear, Nose, and Throat (ENT) medical doctor.

At first, the ENT medical doctor thought my nasal turbinates (<https://www.verywellhealth.com/turbinates-types-purpose-and-disorders-1192107>) were swollen from an allergy reaction. My nose was also crooked, obstructing my breathing. After using my allergy medications for a month, I revisited the ENT medical doctor to see if my nasal turbinates had changed. To our disbelief, they had not changed. In October 2017, I underwent surgery for a deviated septum (rhinoplasty), to reduce the size of my very large turbinates, and remove my uvula. The rhinoplasty straightened out my nose to maximize my breathing. My uvula was removed as it would often get itself stuck in my nasal passage, causing an obstruction. The healing time from my surgery was a little over two months. In January 2018, I would fully heal and return to Dr. Shana Díaz for an update.

***Addiction and near-death moment.*** One of the challenges to having the nose surgery was my nose filled with gauze, removing my ability to breathe through the nose for a week. It was difficult to use my BPAP for a week as the mask I wore, at that time, covered my nose and mouth. The slightest touch to the nose was extremely painful. Because of the difficulty to retain any information immediately after a surgery, I was unaware an opioid was prescribed after the hospital release the same day. I relied on using prescribed opiate medication, OxyContin, to reduce pain during my sleep.

After three days of recovering, my housemate noticed I was taking OxyContin frequently. He asked, “Are you taking those as prescribed?” Confused, I read the prescription label. “OxyContin. I don’t think I am able to reach the four hours. So yeah, I’m taking them closer to every three, or three and a half hours. Wait, isn’t this an opioid?” He replies, “Yes, it is. You need to be careful with it.” As the day progressed, I

caught myself having a difficult time staying away from OxyContin. Noticing a reduction of pain, I caught myself wanting to take the medication. Any slight discomfort in pain made me want to take OxyContin to reduce any feeling of pain. On the fourth day, resisting using the opiate proved difficult. This led me to use a CBD relief salve on the outside of my nose. Unsurprisingly, it worked! It relieved the pain. Although it was not effective during use of my BPAP, the strong pressure from wearing a mask caused too much pain. I managed to get myself to use it only during bedtime. The urge to take less OxyContin was not easy. A reduced metabolism and lack of sleep made the craving for pain reduction difficult to resist. Three days before having nose gauze removed felt long.

The night before my follow-up appointment, or day seven, I found myself sitting on my bed with my legs crossed. There was a light blue color illuminating my room. As I looked around, I looked at my bed only to find my body lying there. “You poor fool,” I said to myself. I was sad. Looking at my own body, my chest rose and dropped. It repeats. “Oh no, I’m dying.” I fell forward towards my body, reawakening in my body. “I can’t breathe,” I thought. Attempting to breathe through my nose, it hurt. I could not inhale. The air coming from my BiPAP machine did not help. Due to not being able to fully secure the mask with a swollen nose, air leaked continuously. I could not move my limbs. Paralyzed. Not knowing what to do, I accepted death. Resisting closing my eyes became increasingly difficult. Attempts to inhale failed. The light in my room darkened. “I’m dead. Three. Two. One. Wait! There’s air in my lungs!” Exhale. Deeply inhaled. Quickly, I made an effort to sit on my bed and remove the BPAP mask. Breathing as if I was running, “How did I just see myself nearly die? Where did that blue light come from?” I had just experienced an obstruction of air in my sleep, or better known as sleep

apnea. Somehow, my throat closed. I do not understand how I was able to identify that an exhale would remove the obstruction. I have never once seen myself sleep. The vivid image was too realistic to be a dream. Afraid, I chose to not attempt to sleep again. Staying awake for the next six hours, it was time for my surgery follow-up appointment.

Trembling and traumatized, I entered the ENT clinic. As the gauze, plastic, and stitches were removed from my nose, I explained to the nurses the night experience along with my addiction to OxyContin. They assured me that I had experienced a sleep obstruction in my breathing and that I was very much alive. My nose healed as expected, allowing me to continue to use my BiPAP mask correctly. The nurses recommend I take half an OxyContin pill if I really needed it, else it was best I discontinue. They supported the use of CBD relief salve, although the surgeon/medical doctor disagreed because cannabis is a street drug. I do not think he knew the difference between CBD and weed. CBD originates from hemp and is completely legal. Weed is currently legal medically and or recreationally in some states, while illegal in other states. Weed contains tetrahydrocannabinol (THC), which causes what many refer to as a “high.” Still trembling, the nurses decided to keep me in the clinic for an additional half hour, helping me calm down before releasing. They allowed me to process the near-death experience with them. “It wasn’t your time to die,” said one of the nurses.

Fearing death in my sleep for the next three months increased my appreciation for life. Death provided encouragement to continue moving forward with life, to make the best of it. With the possibility of death that night, I survived a last second to breathe again. If this is my second chance at life, I must reach my best potential. There has not been a week where I forget this near-death moment. It encouraged me to enjoy my life.



**Sleep study #2.** On March 2, 2018, a second sleep study was conducted as Dr. Díaz determined it was necessary to restudy my sleep since the anatomy of my nose had changed, allowing for more air. Identifying allergies contributed to understanding why I felt sick and helped remove a barrier to my difficulties sleeping. Unlike my first sleep study, I received my sleep results nearly three months after my sleep study. This was attributed to a shortage of medical professionals available to analyze sleep data. After receiving the new sleep data, Dr. Díaz modified my sleep therapy with the hopes this would finally give me a full night of sleep. There was a significant increase in sleep quality, yet something did not feel right. The best way to describe what my days felt like is as follows: have you ever had a day where your cell phone is only charged to about 50% and it does not make it through your day? That was how each day felt. Once my energy depleted, the remainder of day was a struggle. I began to think that there was some kind of brain damage from the accumulated sleep deprivation. This motivated me to visit a neuropsychologist.

### **Neuropsychology Assessment**

Wanting peace of mind and knowledge on the extent of any possible brain damage, I sought a neuropsychologist. It was not easy finding a neuropsychologist that would accept my health insurance. I called nearly ten neuropsychologists before finding Dr. Barbara Koltuska-Haskin. Through the months of May and June of 2018, Dr. Koltuska-Haskin performed a series of 22 different tests (e.g., mini-mental state, Wechsler adult intelligence scale-IV, Gestalt tests, finger tapping, ADHD, PTSD, Hooper visual organization test) once or twice a week during a three-to-four-hour period of time. Her goal was to not overwhelm me with tests. She preferred to break testing into smaller

chunks of time. During each session, she took time listening to my story about my health and brain concerns. Conversations were always pleasant, peaceful, calm, and thought provoking. See Appendix D for the neuropsychological assessment findings.

**Mental health: depression.** Dr. Koltuska-Haskin determined I did not have clinical depression to merit a major mood disorder. She did acknowledge that I did have a history of depression but not enough to be concerned. This diagnosis made me realize that my mental health had improved since beginning my sleep therapy. It made me happy. She believed I was overstressed, most likely a result from being an employee and a graduate student. She recommended that I would benefit from counseling, yoga, and meditation.

**Learning disability: ADHD.** Dr. Koltuska-Haskin did identify that I did have both attention deficit and hyperactivity disorders. In fact, while writing this research study, I have taken multiple distraction breaks. Not surprised by this finding since I always suspected myself to have ADHD, I did not expect to be on both sides of the ADHD spectrum. It is also moderate and not severe. Sometimes I just lose attention on things that are not interesting. Other times, I cannot stop doing the things that I enjoy. It is easy for me to lose attention when I am using my auditory ability (listening). As she wrote in my diagnosis, “He has compromised concept formation ability and is somewhat impulsive and, at times, preservative.” She continued, “Presently, he has some difficulty initiating and completing a goal-oriented behavior and has some difficulty with the entire task of determining what is to be done, formulating an approach for doing that, and then monitoring his behavior to be certain he has solved the problem appropriately.” About 10 years prior to this entire health situation, I had learned several time management

techniques to address ADHD. A friend and mentor noticed my ADHD based on his personal experience with ADHD. Having a medical confirmation of ADHD was a relief. Learning that I had lost all my training to address my ADHD was difficult to accept. Dr. Koltuska-Haskin assured me that if I did learn to manage it before, I could do it again. I was not very welcoming to the news of having a second learning disability: memory retrieval problems.

**Learning disability: memory retrieval.** Per her assessment, Dr. Koltuska-Haskin identified that I was experiencing difficulties with recalling information. I still remember how she described it to me. “Most information travels from point A to point B. In your case, information travels from point A to point C, and maybe even another point before reaching point B. Your memory storage is working well. It is your ability to recall information quickly that takes some time. Be patient. It’ll come to you.” On the diagnosis results, she wrote, “His delayed recall was also in the average range, which indicates that he has average ability to recall verbal and nonverbal information after a delay.” This was difficult to accept because it made me feel defective, broken, useless, and unimportant. Dr. Koltuska-Haskin assured me that everything I learn is in my mind and I required patience in recalling information. The sooner I could accept it, the sooner I could identify solutions and work arounds.

**Ambidextrous.** Although this is not a learning disability and not relevant to this research study, it does play a role in accepting my abilities. This is an ability that provides an added benefit and was easy to accept. Dr. Koltuska-Haskin did identify something about me that I did not expect. I am ambidextrous. She confirmed that I was, in fact, born left-handed and was trained to become right-handed by my parents,

primarily my father. She said I could fully train myself to use my left hand if I decided to take the time to do so and should allow things that feel natural with my left to continue. Since then, I often switch to left-handed while brushing my teeth, driving, cooking, and even swinging a baseball bat. In terms of ableism, it has made me realize society's preference for right-handed people. In fact, applications (apps) on mobile phone devices are often right-handed. Go ahead and look at your phone's apps. Given that I am retraining myself to be left-handed, I find it annoying and discriminatory to not have left-handed options for many things. I will give you a few items to think about: microwaves, doors and door handles, and musical instruments.

### **Back to Sleep Therapy**

Shortly after receiving my neuropsychological results from Dr. Koltuska-Haskin, I revisited Dr. Díaz to continue improving my sleep in August of 2018. After all, we were making progress. During a consult, I asked the following question: does ADHD affect sleep? Dr. Díaz reviewed the data from both my sleep studies. In both studies, there was an unusually high amount of brain activity that took place as I slept that was not understood initially. With the perspective of ADHD at hand, Dr. Díaz confirmed that ADHD was affecting my sleep. ADHD was the answer to why I had an unusually high amount of brain activity in my sleep. She realized every time a sleep technician changed the air pressure settings during my sleep studies, brain activity spiked. This suggested awareness in my sleep, even if I had no memory of it. ADHD was the last piece of the puzzle as to the difficulties with sleep therapy. There was nothing I could ever do to resolve it on my own given that I never had a medical confirmation of ADHD. It never once occurred to me to share my personal diagnosis of having ADHD. I did not think or

know that ADHD could impact sleep. Walker (2017) explains that a lack of sleep in a child will make it appear as if the child has ADHD. Lack of sleep will cause a person to have attention deficient or even hyperactivity. Naturally, lack of sleep is rarely brought up when addressing the potential of a person having ADHD. This made Dr. Díaz and I wonder if I really did have ADHD or if the lack of sleep was causing ADHD-like symptoms. This led to a somewhat difficult conversation with Dr. Díaz.

Dr. Díaz recommended that I undergo treatment for ADHD. I was hesitant and resistant to the idea. If I did have ADHD, I wanted to learn how to manage it without medication as I had once done before as an undergraduate college student. The reality was that it would take an unknown amount of time to relearn how to manage ADHD. Dr. Díaz recommended that I view it as a temporary solution until I could get off the medication, allowing enough time for my brain to relearn sleep. We came at a creative compromise. Rather than treating the ADHD directly, Dr. Díaz suggested we should instead treat my sleep apnea as insomnia. She recommended I take Doxepin, a medication used to address difficulties sleeping such as insomnia as well as depression, anxiety, and chronic hives. Dr. Díaz believed that all I would need was a very small dose, enough to help me sleep and shutoff my ADHD. If it worked, we could gradually stop use of the medication once I relearned how to sleep.

**Doxepin.** From August to October of 2018, I underwent the use of Doxepin. It took me about two weeks to find the right amount of dosage. I started with five milligrams, which is a few drops but enough to put me to sleep within twenty minutes. I began to experience the side effects of Doxepin the next day: anger, irritability, rage. From day one, I would reduce the milligrams by one every three days. By the end of

week two I had reached two milligrams of Doxepin. The side effects had decreased but were still present. I also noted that my ADHD was almost non-existent during these two weeks. It was strange not being impulsive and preservative. I felt mellow. Over thinking felt reduced. My creativity ceased. For the first time in my life, there were very quiet moments in my head. I could stare at nature without dozens, if not hundreds, of thoughts rushing through my head. I was not enjoying feeling aggressive from taking the Doxepin. I decided to try something to remedy the side effect.

Remember how I mentioned I was using cannabis and CBD oil to sleep? During the sleep therapy treatments, at times, I used cannabis to continue assisting in my sleep. There were moments during my sleep therapy treatment where I would discontinue use of cannabis for about three to eight weeks before deciding to resume. Sometimes I would continue to not use cannabis. There was never a consistent pattern. Given that cannabis would make me feel happy, I wondered what would happen if I used it again while being medicated with Doxepin to counter the negative side effects. I would use cannabis before bedtime and CBD oil during the daytime if needed. Surprising, cannabis did counter the side effects of Doxepin. Dr. Díaz was impressed by my finding and encouraged I continue to use cannabis alongside the Doxepin.

Finally! The best sleep in my entire life. If there is one song that represents what I was going through in my feeling of happiness, it is the song “Walking on Sunshine”

(<https://www.youtube.com/watch?v=iPUmE-tne5U>) by Katrina and the Waves (1983).

To be specific, the chorus of the song is most relatable to me:

Oh, yeah, now I'm walking on sunshine, whoa!  
I'm walking on sunshine, whoa!  
I'm walking on sunshine, whoa!  
And don't it feel good.

Hey, all right now.  
And don't it feel good. Hey, yeah! (0:51)

I was feeling extremely energetic, happy, excited, confident, rested, clear minded, and grateful. The feeling was as close as I have ever been to feeling happy, as if I was walking on sunshine. My world felt reversed from a dark gloomy dimension or something like that. It felt great. My ADHD was still affecting me in many ways through my lack of time management. I was beginning to dream every night. Many of those dreams were depression and nightmares, but there were also moments of hope and happiness in my dreams. For the first time I was sleeping, and I had hope the health problems I gained would reverse. This changed quickly.

### **Dilated – Watch Your Head: Concussion**

On Sunday, October 28, 2018, I was out for a walk in the sunshine at my local park. I was enjoying the morning breeze, power walking as I played Pokémon Go on my smart phone. A friend invited me and another friend to brunch. Excited, I decided to cut my walk short so that I could get home, shower, and drive to the restaurant. There is an arroyo that is fenced off so that vehicles do not drive through it. The fence is rather short with an opening for people to walk through it. It is tall enough for anyone under five feet tall to walk without needing to lower their head. Because it serves as a short cut towards my neighborhood, I decided to take it to maximize my time. As I approached the fence, I miscalculated raising my head and rammed my head against the pole. Suddenly, I thought, "That lawn looks like a good place to sit." I kept walking. "This sidewalk makes a good place to lay down and nap." I forgot where I was and where I was going. I thought I was dreaming. I kept walking confused. Once I realized being near my home, I told myself to shake it off. I showered, dressed, got in my car, and drove to the restaurant

without thinking. My friends asked why I was quiet. I explained I hit my head. One of my friends decided to look at my pupils. It reminded her of the times her son had injured himself with concussions while playing contact sports. “Your pupils are dilated,” said my friend. She was sure I had a concussion. I believed her.

On the following day, I attended a scheduled appointment with Dr. Díaz to follow up on my sleep therapy treatment. I used the opportunity to have her perform a concussion check. She confirmed that I had a low to mild concussion. She estimated it could take as few as three weeks and as much as a year for me to recover from the concussion. She encouraged that I be careful in my exercise for the next few weeks and allow myself to sleep as brain injuries have a slow recovery. As per routine, I provided her an update on my sleep before the concussion and how much better I was feeling. She was happy to hear that we finally had found an effective sleep therapy treatment. She asked that I contact her as needed and reminded me that my sleep therapy might need adjustments along the way. I had her provide me with a medical note for both work and school in the event anyone questioned the validity of my new injury. I did not think of it much.

As each day progressed, I began noticing changes. I felt emotionless. I would suddenly feel depressed. In the first week, I made an unexpected visit to urgent care, believing I was experiencing a heart attack. Dr. Fritch, a medical provider, examined me and said my heart was healthy. He also confirmed I had a concussion and that I was experiencing the effects of it. In my case, I was going through depression, anxiety, and panic. He recommended that I stop using Doxepin to allow my brain to heal naturally. I was afraid to lose the sleep I was having each night. His recommendation was to stop use



for a few days to see if it helped. Depending on the outcome, I could return to it or discontinue for a while.

Fearful, I attempted Dr. Fritch's recommendation to stop using Doxepin. Within a week, I noticed that my ADHD was gone. My mind was quiet. There were no impulses or rumination. Overthinking ceased. I once sat on the couch in the living room staring at the wall for over an hour without thinking. The only reason I remember the time was because I had sat down, looked at the time wondering what I should do with my Saturday. I could not think of anything. When I checked the time, more than an hour had passed. Watching television or being in front of a computer was hurting my vision because of the concussion. In fact, I even visited my optometrist to check my vision. My vision had changed, specifically on my right eye as a result of my head injury. I was recommended to stay away from screens and bright lights for a few weeks. This was a difficult task as both my roles as student and employee require computer use. Overall, it felt like all positive emotions had left once again. The negative emotions were slowly starting to gain traction.

## **Counseling**

In January of 2019, I decided to search for a mental health counselor to address my concussion aftereffects. The decision to attend counseling was initially difficult. Accepting my inability to help the self and requiring help was challenging, but it was empowering. I wanted to improve and return to a healthier state of being, even if it required self-exploration with the help of another person. This action to seek counseling would empower me over time as I processed difficult experiences and memories relating to discrimination of disability. This eventually would teach acceptance. Finding a

counselor of a Latino or Black background was impossible. Most counselors were women and nearly all counselors were from New Mexico. Many of the counselors called had waiting lists. I spent a few weeks calling and waiting for responses, all of which were rejections. I gave up on finding a male from a Latino or Black background as they were nearly nonexistent. Just as I was giving up hope, I received a call from a counselor.

I first met with Cami, my new counselor, in February 2019. Although she is a woman, and White, she was originally from southern California and had moved to New Mexico just like I had. There was comfort in knowing she was from my home state. I knew she would understand my Californian personality and upbringing. She was instrumental in helping me cope with my concussion and quiet mind. She would play a larger role in my life as time moved forward.

In April of 2019, it was the fourth week on my third new job at the university and it was an ordinary day. It was late in the morning when I suddenly began to experience an uptick of anxiety and panic. Quickly, I began taking deep breaths and slow exhales as I learned from a Yoga instructor. I could hear the hallway clock ticking. My work computer's fan was making too much noise. My computer's programs were providing too many notifications. The ringing of phones in the office was annoying. My heart rate increased. The air was insufficient. The heating system's noise was obnoxious. I could not stop thinking. All the things I needed to accomplish; I felt the need to run away. Chaos. It felt like chaos. Feeling overwhelmed, there was a sudden feeling of comfort. I felt confused. Deep breath in. Deep breath out. Deep breath in. Deep breath out. "Stay calm. Stay calm," I repeated to myself. As I lost my sense of reality, a familiar feeling emerged. Have you ever seen a dolphin, whale, sea lion, or any other sea mammal

unexpectedly emerge from the ocean? That is exactly what my ADHD was like in that moment. “Surprise! I’m back!” I had lived five months without any ADHD symptoms. On a random April day, it reappeared in my life. As the realization dawned, I laughed. It was like reuniting with a relative or family member I had not seen in ages. Since the concussion occurred, my personal life outside of work and school had felt quiet, lonely, and boring. It was like my ADHD returned from an extended vacation. Some people would probably be disappointed to have their ADHD return. I was excited it had returned. It is a part of who I am as a person and an integral part of my identity. This is where Cami would continue to be helpful in our counseling sessions.

Reintegrating ADHD into my life would prove to be a challenge once again, which included dealing with the trauma, self-esteem, anxiety, depression, and anger of the discrimination I was receiving as a student and employee. I’ll return to this discrimination in a later section. Counseling alone was not enough to help me with ADHD. That same month of April, I began visiting the Accessibility Resource Center at the university and met with a learning specialist to relearn time management. I lost all control of ADHD during my sleep deprivation and concussion. I did not want to return to using Doxepin to help me sleep and manage ADHD.

## **ADHD**

Bring Me the Horizon (2015), a rock band, has a song named “Avalanche” (<https://www.youtube.com/watch?v=UNaYpBpRJOY&bpctr=1613524541>). This song is about ADHD and what it feels like when it is undiagnosed. Even though I was diagnosed, I spent five months without ADHD due to the concussion. The moment it reemerged into my life on a random April day in 2019, metaphorically, it was like an avalanche. “It’s

like an avalanche. I feel myself go under, ‘cause the weight of it’s like hands around my neck. I never stood a chance.” After the first day of my ADHD’s return, I felt stuck in place. There was so much going on in my mind. The weight held me down. At times, I felt suffocated, much like being choked. I started one task and found myself doing something else within five to 10 minutes. Some might interpret this as procrastination, but it is not a choice as the mind of a person with ADHD is wired differently (Tuckman, 2009). It is difficult to control and change at will. “I need a cure for me ‘cause a square doesn’t fit the circle. Give me a remedy ‘cause my head wasn’t wired for this world” (Bring Me The Horizon, 2015). I could not sit still and focus for more than 10 minutes at a time. I just wanted to go outside and have fun. I kept playing games on my smart phone and navigating the Internet for interesting articles to read and videos to watch. I could not even sit still to watch an episode of a favorite TV show without being on my smart phone or having a distraction in a hand. Even the things that interested me were difficult to complete. It is difficult to sit with one interest without being pulled in by another. It really was like forcing a square to fit a circle. I knew I had a medication that could help but I wanted to address it on my own terms. “My heart is frozen over, and I feel like I am treading on thin ice, and I’m going under” (Bring Me The Horizon, 2015). It was difficult to find motivation and care to accomplish any task, whether it was directly related to my own life or not. I would much rather stare at the wall and experience pareidolia, or finding patterns creating images, instead of doing anything. Sometimes I was waiting for things to fall apart, much like being on thin ice. I expected things to fall apart on me regardless of my decision to do something about it or not. If by this point you are confused by what I am describing, it is because you have never experienced ADHD.

While writing this paragraph, I have stopped several times to play a game on my smart phone, listened to other songs, walked around the kitchen wondering what I am cooking for dinner, replied to a text message, and stared out the window wishing to be out and about on a snow day. It has taken me over an hour to write this one paragraph because of ADHD.

Despite this initial struggle to manage and cope with my ADHD, I would not trade it away for anything. In fact, I distracted myself as I wrote that previous sentence because it was more entertaining to text message a friend than to keep writing. I find myself having several advantages with ADHD. When I really am interested in something, I will not stop until that process is complete, despite frequently losing concentration. It will bother me if I do not complete it. I will even pace myself to make sure I give that something my all. Although, sometimes, this is not the case and impulses take me towards an unexpected interest, making it difficult to complete one task in one sitting. As Dr. Koltuska-Haskin said to me during my neuropsychological assessment, my abstract thinking is very high. I can make sense of the most abstract situations in life. I can see the beauty to Jackson Pollock's abstract paintings and find meaning to each one. I can look at one situation and find several perspectives to it. My creativity has no boundaries. My messy room is well organized to my mind. My small piles of messes serve as landmarks for the things that are within that pile. I may have a hard time listening and taking notes. I would much rather learn by doing and making mistakes. But within that lies the problem of society which does not allow for learning by mistakes and errors.

Failure should be enjoyable because it teaches me something that does not work and narrows the possibilities of what will work. I am more likely to remember mistakes.

It is this reason that makes me enjoy playing video games in my spare time. Every mistake I make within a video game helps me improve my skills within that game. To me, that is learning. Reading a book to learn, listening to a person lecture to learn, and doing an activity to learn is boring and unrealistic. I would rather get my hands dirty, metaphorically and literally.

From experiencing all the health problems as a result of sleep apnea, I have learned about the importance of sleep, mental health in society, healthcare limitations, health and disability discrimination in higher education, and the ableist mindset society has about anything that is not common or normal. Society will never recognize this level of learning because there is no educational degree associated with my experience, despite its validity. Work environments and learning environments are not designed for and are not welcoming to anyone that does not fit the box of what has been defined as an educational or work environment. It was not easy managing my ADHD, but I did re-learn how to reintegrate it into my life and accept it as a part of my identity rather than perceiving it as a disease. By the end of the year 2019, I fully incorporated ADHD into my whole being. Although sometimes annoying, it entertains me and makes me feel unique. The time with a concussion did reteach me how to sleep without medication and allowed enough time to create a new sleeping routine. By the time my ADHD returned, it did not disrupt my sleeping pattern.

### **Fully Rested**

While my sleep had improved significantly by the end of 2019, I could get more out of my sleep therapy and increase the quality of my sleep. It was good sleep, but not great. I thought Dr. Díaz would be annoyed at me for continuously scheduling

appointments with her at least once every other month, and sometimes once a month. That became more difficult with each passing month as the number of patients for her increased and the number of sleep medical doctors and sleep technicians decreased. There are times where I have had to wait three months just to get an appointment with Dr. Díaz. Nonetheless, I waited patiently each time. The good thing about having a good reputation with Dr. Díaz was her willingness to provide me with the information I needed to change my own sleep therapy under her guidance. Each appointment brought us closer and closer to identifying the best sleep settings for my BiPAP, the machine I now consider to be my lungs at night as it is what helps me breathe efficiently as I sleep.

In August 2020, I met with Dr. Díaz to readjust my sleep therapy once again. On September 14, 2020, I was happy to report to Dr. Díaz that we finally found the best sleep therapy settings for my BiPAP. The timing was perfect as I would soon become unemployed and no longer have health insurance to continue my visits. It truly was a team effort as she would use my feedback of what my sleep felt like (e.g., inhaling, exhaling, tiredness, energy level, alertness, drowsiness, sleepiness, air pressure, dreaming, number of times I awake, why I wake up at night) to adjust the settings on my BiPAP. Dr. Díaz would adjust settings that would relate closely to what I would describe. I did not describe this earlier, but every CPAP and BiPAP machine collects data from the user that shows activity during a person's sleep. How they determine that data from air pressure is beyond me and I will not elaborate. You can look it up on the Internet. It is fascinating but not relevant. Dr. Díaz used the data along with my feedback to make adjustments to sleep therapy. She would always share her thinking process with me and

make sure I was involved in the decision making. I wish more medical providers were like Dr. Díaz. She has been wonderful in involving me in my own health and treatment.

### **The Medical System**

I had my first sleep medical appointment in the summer of 2016 and my last appointment in September 2020. It took four years, four long years, to find the best sleep therapy for me. In order to get the best sleep, I had to endure four years of medical appointments with several different medical professionals. It was my own choices to seek out other medical professionals (allergy, ENT, neuropsychology) that led to identifying the barriers to why I was not sleeping. This experience has taught me that the medical field is not collaborative when a person's health is not life-threatening. The primary care providers I initially consulted were not interested in considering that basic health prevention (e.g., eating healthy, exercising, getting a full seven to nine hours of sleep, counseling) was not helpful. I made choices to seek out other professionals to address health conditions that resulted in affecting my sleep. No medical provider referred me to other specialists. I self-referred because of Dr. Rose's assessment during a routine dental check. I was fortunate that my health insurance did not restrict that option as previous health insurances have required of me. I had to be my own advocate. Primary care providers only saw an unhealthy obese Latino that had made poor dietary choices. Yeah, sure, blame the tortillas.

Considering this health experience, sleep needs to be a priority during medical visits with primary care providers. It might just be that PCPs are not trained, educated, or equipped to fully understand the severity that comes from sleep deprivation and the health impact it creates. A questionnaire is not sufficient to assess a person's health.



There was one PCP that had a sleep question on a questionnaire during a routine visit.

There was no follow up or questions asked about my sleep health. Primary care needs to prioritize sleep health. If we are unable to sleep well, it negatively impacts all other aspects of health (Walker, 2017). Sleep needs to be prioritized for the wellbeing of everyone's health.

### **Organizations, Learning Environments, and Disability**

Addressing my disabilities and health was difficult, challenging, and painful. This process was nowhere near easy. It might have been easier if that was my only problem in life. It was exacerbated by the conditions placed upon me as an employee and student. The workplace made it clear that having a health condition affect my workload was unacceptable. The learning environment as a student made it clear that my disabilities were not welcomed. Because I no longer fit the box of a desirable employee and student, I was not supported, understood, and believed. In the following section, I will describe the work environment that existed and the treatment I received from coworkers and supervisors as my health declined. Thereafter, I will explore the learning environment and the interactions I faced with faculty members.

### **Organizational Culture and Disabilities**

In this section, I will describe three different working environments. Two working environments were not supportive of my disabilities and health. The third work environment was extremely supportive of my disabilities and health. As mentioned earlier, I will first share the story followed by reflection. In some instances, the story and reflection are intermingled. Given that you now know what I was experiencing with my health, I will describe the interactions I had with coworkers and supervisors while sleep

deprived. These working conditions exacerbated my health conditions through stress, lack of support, hostility, and discrimination. A timeframe at each job correlating to my changing health conditions will be described. Keep in mind, sleep deprivation and all other health conditions are concurrent with the conditions of the work environment and the learning environment. Rather than providing traditional pseudonyms (e.g., Carlos, Drew, Max, Karla), I use job titles for most people referenced. Let's refer to this as non-traditional pseudonyms. This is to take away power to those who chose to be oppressive and discriminatory. One person was supportive and has the first letter in their nontraditional pseudonym capitalized.

#### **Job #1 – Summer 2016 to Winter 2017**

During the early summer of 2016, I held a position as the coordinator of student leadership and engagement within an office that had just hired a new supervisor and two new staff members. I begin at this point in time with this job because things were okay prior to the staff changes even with my declining health. I was already struggling to maintain my job responsibilities, but it was manageable as I had employed four student assistants.

All four of my student assistants were skilled and trained to execute projects with minimal instruction and supervision. As I grew overwhelmed, they provided additional support to reduce my stress and workload. They understood my health and were considerate. Many times, they would ask me if I was okay and if they could bring me coffee or take on further projects. They were a supportive group of students. I will always appreciate their kindness. Unfortunately for me, one graduated and the other decided to transfer to a school closer to his family. It made sense to hire two new students to

maintain the workflow of the busy work environment without having my declining health affect that workflow.

Thinking that I was being responsible, I met with the new supervisor that had been in her role for over a month to discuss hiring two students to continue assisting me as my health declined. With additional support, I could continue to meet my objectives without having my health affect assigned project timelines. After describing the responsibilities of the students that left and reasons to rehire two students, I was met with opposition. The new supervisor did not believe my projects were a necessity to the office or university. As a result, she decided to terminate all my projects, except for marketing, while she decided which new projects to assign. When I asked for clarification as to why my projects were being terminated, she gave me a vague response. It was not the direction the office needed to move towards. She never once took the time to understand my projects, my student assistants, workload, and health concerns. As my health declined, I recognized the need for additional support.

It became clear that everyone was facing a battle with a new supervisor that was not taking the time to understand the programs and projects we held. Because everyone's roles were being altered without explanation, it became a situation of everyone fighting individual battles rather than a collaborative. A good expression to describe it is "every person for themselves." About three months later, I had my first medical appointment with the sleep clinic that confirmed signs for sleep apnea and a sleep study would take place in two months. I thought it was in my best interest to disclose my health conditions to my new supervisor and coworkers for the sake of receiving additional support.

Near the end of a staff meeting, it was my turn to provide updates to the programs and projects I was leading. First, the group was surprised to learn that I was in the process of closing out programs and projects as required from our new supervisor. Second, I took the opportunity to share the early medical diagnosis of having sleep apnea. The majority of my coworkers were aware I was experiencing debilitating health conditions and it was no surprise to them for me to share. It was difficult and arduous to admit there was a two-month waiting period for a sleep study followed by another month to receive the results of the study and treatment. One coworker fully understood as she had a husband who was also diagnosed with sleep apnea and knew it was not an easy process. Another coworker had family members with sleep apnea and showed her support to alleviate my job responsibilities. A third coworker understood from personal experience how difficult a severe health condition made every aspect of life and offered her support. I broke down and cried during the meeting. I had taken every step to avoid having my health impact my work, but I reached a point where I could no longer maintain the same caliber and integrity to my workload. Embarrassed to appear weak and fragile, I felt vulnerable. “I’m done,” I said after sharing my updates. The new supervisor ended the staff meeting shortly after without saying a word to me.

Quickly, I made my way back into my office to get myself together. Within 10 minutes, the new supervisor walked into my office. She recommended I look into the Family and Medical Leave Act (FMLA) to take time off from work. She explained it would be a better approach in the event I depleted sick leave hours and annual leave (vacation/time-off) hours. It would provide me unpaid job protected leave for 12 workweeks during a year (DOL, 2021). She offered help in completing the application if

I determined it would help. She walked away after the brief exchange. This was the first and last time she acknowledged my health conditions. Not once did she ever consider the challenges I was experiencing. Her actions moving forward demonstrated her lack of consideration and support.

In the next two months that follow, my health and work department's organizational culture worsened. The two remaining student employees under my supervision were consistently reassigned on a day-by-day basis to serve as welcome desk attendees. The office administrative assistant previously serving as the welcome desk attendant had resigned from their position. There were four other student employees that could cover hours, but their schedules left gaps in welcome desk coverage. Professional staff also took shifts covering the front desk, but meetings prevented us all from having consistent coverage, thus requiring my two student assistants to provide additional support. Although this situation is understandable, what was not understandable was the hardship on my projects. To resolve the problem, I thought it would be helpful to have their office computers equipped with graphic design software and hardware moved to the welcome desk area so that they may continue to fulfill their responsibilities on my programs and projects. They would be able to attend the welcome desk. Because two student employees had resigned during the summer, there were two other computers in the student office equipped with graphic design software and hardware. They would not have to move their computers back and forth. After proposing this solution to the new supervisor, she declined it. Her reasoning was that she had special projects for them to work on while attending to the welcome desk. My student employees were often left without tasks, and tasks that were assigned were usually filing paperwork. With each

week passing, it became clear that my students were slowly being reassigned away from my remaining projects. I was slowly terminating those remaining projects to take on a new project.

The new project assigned entailed that I digitize a decade's worth of student files into a new computer application and shred the files once scanned. Digitizing meant typing the text on the paper file to the computer application and attaching the scanned document. This can be viewed as data entry. This was disrespectful and humiliating. The projects and programs I previously had assigned entailed developing and implementing a leadership certificate program for undergraduate students, leading a student leadership recognition award program, co-managing the student exchange program, co-leading a student honoree program with the basketball and football programs, collaborating with the ethnic resource centers on campus wide and community events, various campus committees, advising three student organizations, and overseeing social media and marketing for the department. These were all projects and programs I truly enjoyed. Forced to end these projects and programs, the new task was data entry. My projects and programs were manageable with the support of four student assistants as they each had different programs and projects assigned and were trained to work in pairs. Declining health made tasks more difficult without a full team of students. It was feasible with additional support of student employees. A declining health made challenging the new supervisor daunting. The new work assignments were an insult to my abilities and declining health. The job was achievable with the right support. There was one staff meeting in which it became apparent to all 12 full-time staff members and six student

employees that the new supervisor did not take the time to understand my projects, programs, and health.

While speaking about her goals for the office during an all staff (students and professionals) meeting held within the office conference room, the new supervisor began to think aloud about a new program she had in mind. Her half-baked idea was to develop a program focused on engaging students on campus through activities aimed to help them develop their skills by the time they graduated. Specifically, she wanted students to engage with our office in a way that would have students make an impact on the university. I clearly remember saying during the staff meeting something among the lines of, “Are you thinking about having them develop leadership skills, actively participate in community and campus wide events, providing them recognition on campus?” She replied, “Yes, that is exactly it!” She quickly moved to the white board in the conference room to write notes. I felt an eerie chill. In disbelief and shock, all 12 full-time staff members and six students were staring, at me! Their eyes and expressions radiated concern and acknowledgement that the thought I had described was originally my projects and programs she terminated. No one else shared their thoughts about potential programs to the new supervisor.

Once the meeting ended, I quickly returned to my office to drown in my disbelief that the very programs and projects she had terminated were exactly what she was thinking about developing. It reinforced the notion she never once took the time to understand my projects and programs. I will never forget this day. Within two minutes of walking into my office, one of my student employees walked in, flustered and clearly upset about the meeting. “It’s not fair! It’s not fair,” said the student employee.

Exasperated, she sat down in my office and tears began running down her face. Sniffing, she spoke, “That was your idea, and now she’s stealing it, and right in front of all of the other staff too! I can’t believe this...”. Not only was the termination of my projects and programs affecting me, but it was impacting my students. My other student would eventually share their sentiment on the matter. Providing a hug to my student as she cried, I expressed that it was my problem, and it was time for us to find a new employer. In fact, I would help this student find a new job within the next few months, and we remain close friends to this day. While describing to my student the next steps for us, two female coworkers walked by, both visibly upset. Because I was helping my student regain her composure, those two coworkers signaled for me to call them by shaping their right hands as a phone and bringing it close to their right ears. They proceeded by creating heart symbols with their hands and holding the symbol close their chests. I will always appreciate their gestures. They were two of the most supportive coworkers in that office.

While meeting with my two supportive coworkers, we discussed ways to problem-solve our difficult situations with a new supervisor demonstrating a lack of consideration and understanding of the programs and projects we each oversaw. In our collective reflection, we agreed that the new supervisor a) was dictator-like with her tone of voice given she referred to herself as the boss, b) viewed employee hours as a resource to the office and decided we could not spare time to collaborate with other departments, c) her word choices were very demanding, authoritative, and micro-aggressive, and d) her body language showed aggression based on how she would use her hand gestures. For instance, she would often slap the table twice when said would say “right now!” There



were two instances where I received an email asking if I could take on some tasks. Both times I said no because I was overwhelmed. She immediately came over to my office for me to explain why not and would not leave until I said yes. My yes involved having to discard a far more important task she deemed not important. The experiences of my supportive coworkers were similar to mine, with the exception that there was no sympathy or empathy for me. These two coworkers had noted the supervisor displayed preferential treatment toward females. There were instances where other women in the office had mental breakdowns for various reasons and the new supervisor would always make herself available to those women, often rescheduling meetings with others to provide help to those employees. These two coworkers perceived discrimination of gender taking place towards myself and the other male in the office. Preferential treatment was given to women. The thoughts and ideas of the two men were often ignored. Given my declining health, it was perceived the health of women was prioritized while the health of men ignored. There was not a concern when the men were out on sick leave. We could not determine how to prove it to human resources or the EEOC office. There was also the possibility of retaliation towards us, which created a fear of losing our employment and making the work environment more hostile. Our efforts to make this an entire staff conversation without the new supervisor were futile. All other staff members were focused on addressing problems with the new supervisor in their own way. It was very clear all other staff members had no interest in supporting one another. A once friendly office had become a hostile environment with the introduction of one new supervisor. We were baffled. How could it occur?

During each staff meeting and individual meetings with the new supervisor, I made sure to express my diminishing health and the struggles I was enduring. The new supervisor would not offer solutions, support, or acknowledgement. FMLA was not recommended again. She ignored my statements and moved onto work tasks. There was never a statement about how she could best support me or recommendations to seek ADA accommodations. With it came microaggressions from the new supervisor that I needed to be more cooperative and a team player to her initiatives. Microaggressions are subtle or in-direct discrimination towards marginalized people, nonverbal and verbal, often come across as passive aggressive statements, slights, or outright insults (Nittle, 2018; Solórzano and Pérez Huber, 2020). The only kind of acknowledgement she provided was her facial displeasure in my consistent yawning that continued to increase with each day due to sleep apnea. My two supportive coworkers and two student employees would share with me their perspectives that supported my perspective. Our new supervisor was bothered by my uncontrollable yawning and visible exhaustion, failing to offer any kind of help. There was nothing I could do to change my rapidly declining health. Expressing the need for additional support and struggles with sleep apnea were only met with microaggression on doing as told. My input and responses were not welcomed. Conversations were one-sided, a top-down approach. It appeared she had not once heard me explain my health conditions. I did not have the energy or will to challenge the difficult work conditions that were created by this new person.

Eventually, I decided to seek a new career opportunity elsewhere and succeeded. In February 2017, I was offered a new position as a research coordinator in a substance use research center. Like any person would do, I provided a two-week notice informing

the current office of my resignation and new opportunity. The new supervisor replied to my email by stating, “It is unprofessional to provide a two-week notice. It would have been best for you to provide additional time.” There is no policy requiring advance notices for resignations. In-person, the new supervisor stated to me, “I would like to make it clear to you that you will NOT have the option to return to your position if your new position does not pan out for you.” This was a reference to another office employee that had left her position only to request to return after two months because she did not find her new job opportunity to be a right fit. That office employee was allowed to return. I could not return. During a nine-month period, I was the sixth employee to leave. In addition, two student employees accepted job offers elsewhere. The next sub-sections are my reflection.

### **Lost, Confused, and Resilient.**

What is happening? No explanations. How can this be?

No communication. No direct exchanges. I’m lost.

No asked questions? No words. How can we resolve?

No feedback. No thought exchanges. I’m perplexed.

Changes are happening? No feedback. How to understand?

Team isolation. No bonding. A complete separation.

A dictator? No way. An authoritarian?!

This is challenging. No leadership. A micromanagement.

Resisting is difficult. Preventing a meltdown. I must.

Fight, flight, or freeze? No breeze. How to end this?

No alliances. Individual deviances. A war on my own.

Where do I go? No path. How do I make sense?

Eject from here. Any place is better. Follow the horizon.

How is this possible? No answers. Is this real?

Move on. It's not me. I deserve better.

**Employee counseling services.** During the course of these problems with the new supervisor, a coworker encouraged me to seek help from the employee counseling services. I began attending counseling sessions every three weeks to help me cope with the hostile work environment as my own health declined. It was helpful to have someone understand my problems and encourage me to seek support from human resources and the EEOC. The greatest help the counselor provided was assuring me that based on what I shared with him, he believed my side of the story. He was fully aware that the problems I was facing often occurred within the university and was always disappointed to learn how one person with a position of power could create harm to so many employees. Speaking to a counselor kept me grounded in reality, as each day at work seemed unbelievable. In our bi-weekly meetings, I processed the events occurring within the department. It did not matter what approach was taken to resolve issues in the office. None of it worked. The counselor helped me understand the situation as beyond my control. The new supervisor was not fit to be a leader or a manager. Passive aggressive actions did not help create a supportive work environment. I knew it was a result of my sleep apnea, my gender, and first-generation status. My focus needed to be on finding a new opportunity for employment.

**Turning away.** Before I move on to my next employer, there is one particular day that made me understand a quote from the Joker, the clown prince of crime from the

Batman comic books. “It takes one bad day to reduce the sanest man alive to lunacy,” (n.p., Moore & Bolland, 2008). In this comic story, the Joker attempts to mentally break Commissioner Gordon to demonstrate to Batman that the worst day a person can experience pushes them into insanity. A day was experienced where I lost all reasoning and logic. Although I cannot remember what nearly pushed me over the edge, I do recall that the new supervisor sent me an email about a decision she made without discussing it with me regarding my projects, programs, and student employees. I snapped. Standing up from my desk, I walked down the hallway of the office, furious, with the purpose to put the fear of god in her. Determined to show her my brute strength, I approached her door. I stopped. A deep thought and feeling said no. Walking forward, I exited the office. I made my way to a colleague’s office that oversees programs targeted to increase male retention. For the next two hours, Rodney kept me in his office. He provided counsel, guidance, acknowledgement, understanding, support, and love. Someone actually understood what I was going through. Patient and supportive, he shared difficult work experiences like my own, including understanding sleep apnea due to his father having sleep apnea. Rodney knew precisely the conditions I was under from his personal experience. From this day forward, this man continued to monitor me. He scheduled us to exercise together every morning of the work week. Providing inspirational conversations and mindsets to hold me together, he reminded me that being a man of color placed me at a disadvantage no matter what my actions were in each situation. Many Black and Brown men have died at the hands of police for displaying emotions of disagreement, fear, resistance, displeasure, and anger as evident by #BlackLivesMatter. The color of our skin and masculinity is threatening to those outside of our groups. Our conversation reminded

me of times in which I have argued and show my anger, only to be reminded by those around me to calm down before the oppressor escalates the situation due to fear of being taken as the source of the problem. As men of color, we are restrained by society's view of us as threatening and problematic for challenging oppressive structures. It was best to lay low until I could fully heal physically and mentally. Realistically, I was not in a mental capacity to address work problems. Like Batman and Commissioner Gordon, I had to prove that one bad day would not drive me to lunacy. I needed to be better and demonstrate better. Rodney's advice transpired into the learning environment.

### **Job # 2 – Winter 2017 to Winter 2019**

After ensuring my two student employees had found better job opportunities, I accepted a position as a research coordinator within a substance use research center. After receiving a call for a job offer, I received a second call from the administrator (pseudonym) on the research projects with next steps (e.g., documents to complete, start date, salary). After the conversation with the administrator, she stated, "I want to let you know the only reason you got hired is because of [your friend]." "I'll have to thank her," I replied. I thought it was an odd statement and found it unprofessional. I chose to make a note of this interaction. Little did I know, my note would become the beginning of my documentation of problems in another workplace. Please see Appendix E for detailed documentation of the problems that are described in this section. Happy to leave my previous job, I moved forward into what would become another terrible work environment and organizational culture.

During my first day, I received an orientation to the department and work procedures I would have to follow. As the office tour ended, the administrator stated,

“[The Researcher] and I will be your co-supervisors. The Researcher asked me to co-supervise with him.” Not wanting to make a bad impression, I chose not to question the administrator as it was odd to be told I was being co-supervised without the other person present to detail how co-supervision would function. Given that I had just begun my sleep therapy two months earlier and recently left a hostile and unsupportive work environment, I was in no condition to raise concerns. I felt doubt addressing this problem as I wondered if I had PTSD from working in the previous job. To be on the safe side, I shared my difficulties with sleep apnea during the first staff meeting with the administrator, the Researcher, the assistant administrator, and senior researcher. They all seemed supportive initially. As time went on, I was seldom asked how my sleep therapy was going during staff meetings.

Nearly 11 months passed. Any problems that did occur, I chose to ignore. The frequent sleep therapy adjustments, allergies, the nasal surgery, and second sleep study were enough to distract me away from the work environment. My health was a priority. I thought it was best to do my job without addressing problems. By March 2018, my health had improved although now I was waiting for the second sleep study results.

Towards the end of March, there was research data collection that required travel to Texas for a couple of days. During breakfast on the morning before our return, the administrator shared with me and a coworker that the Researcher was a different person years ago and had grown distant without knowing why that was the case. It was uncomfortable and unprofessional to discuss details about one co-supervisor to another co-supervisor. Not wanting to have any problems at work, I pondered what to do and decided to ignore it.

In late April, the administrator asked to meet with me. She wanted to know about my recent behavior, specifically why my facial expressions showed unhappiness during the morning staff meeting. I expressed frustration in the projects not moving forward as scheduled and how the senior researcher often ignored my contributions. She immediately defended the senior researcher's decisions and moved on to blame the Researcher as reasons why her job responsibilities were changed to address the projects. She proceeded by asking if I knew why the Researcher seemed distant. Given that this was the second time I perceived the administrator to fish for information from me about the Researcher, I deflect by stating I had no idea. This was the truth at the time. She ended the conversation by asking that I share my ideas with her as the senior researcher would listen to her.

The following day, I was asked to meet with the senior researcher regarding my facial expressions during the staff meeting. To be clear, the term "facial expressions" was used by both the administrator and senior researcher as the reason to meet with me. Feeling discriminated and offended by their microaggression, this would be a good opportunity to resolve the situation. By addressing the issue, it would provide relief of the frustration (Nittle, 2018; Solórzano & Pérez Huber, 2020). The senior researcher acknowledged that he was asking follow-up questions after meeting with the administrator regarding my behavior. Regarding the projects, I reiterated my point that my suggestions and recommendations are often ignored. The senior researcher proceeded by asking me about my work relationship with the Researcher. Expressing frustration, I explained that the Researcher and I cannot move forward with the projects because of the delays coming from the secondary research team in Colorado and the lack of



communication from their end. Furious, the senior researcher defended the secondary research team and ended the meeting with saying he would resolve things. It was clear to me I was being intimidated and oppressed. A week later during another staff meeting, the administrator raised concerns I had brought to her attention without mentioning that the concerns were from me. The senior researcher stated he will be more vocal with the secondary research team. Oddly, he immediately listened to the administrator despite her lack of involvement with the projects. This was another microaggression demonstrating the administrator carried respect not afforded to me. Staying positive, perhaps things would improve from here on.

Two weeks later in the middle of May 2018, the administrator confronted me about staying late in the office five days earlier. I thought it was odd as I had not shared this information with anyone other than the coworker that stayed with me and the security guard in the building. Expressing that I had stayed to complete an exam for a course after being told it was okay by the security guard, she walked away to ask the building manager (pseudonym) about the situation. She returned relaying that the building manager said it was not okay to stay late to complete homework. She proceeded by stating that she did not care and was okay with me staying after work hours to study. This is where this situation gets odd. She intimidated me, saying that if I said to anyone that she was okay with me staying after work hours, she would deny it. This was unsettling. I wondered, was she trying to set me up for a problem? What was her motive? I pondered whether my actions to confront problems with the research projects were a threat to her status as an administrator. Perhaps sleep deprived “facial expressions” were threatening. Her willingness to defy the building manager’s request demonstrated a lack of ethics,

responsibility, and accountability. Her willingness to deny being okay with me to studying after work hours within the office, if I chose to continue, exhibited betrayal, a lack of support. There was no reason to trust this person. As a first-generation Latino from a Mexican background with disability, if I were to go against anyone's authority in a work setting, there was a high likelihood repercussion would occur due to my background. Society places me at a disadvantage because of the brown color of my skin representing threat in moments of conflict. Whatever her motive, I was no longer comfortable in this organizational culture.

The following day, we were preparing documents for a research project. While preparing the documents, the administrator asked, "Does the Researcher look checked-out to you?" She explained that the Researcher looked unhappy lately. Dumfounded, I state that it is probably due to the senior researcher not sharing the investigator responsibilities. She was quick to defend the senior researcher and blame the Researcher for not "stepping up to the plate" after passing up on several given opportunities. It was clear to me that there were several problems in the background occurring. I had no interest in participating and picking sides. "Please don't involve me in your problems. It is clear there is a problem between you, the Researcher, and the senior researcher. Please leave me out of it." Rather than safeguard myself, it was as if I had asked to be involved in their problems. The conversation ended after my statement and she walked away from helping with the documents. The next day, the administrator made a comment about petty cash I was sorting for a research project. She expressed that if I came up short on money from the project task, I could get rid of any receipts and fix the numbers. She threatened and intimidated by telling me that any missing money would have to come from my own

pocket and to not tell anyone that she told me to do this. At this point it was clear to me that this co-supervisor was highly unethical and not to be trusted. From this point forward, the problems would increase rapidly.

Not knowing what I should do, I decided to speak with my co-supervisor, the Researcher, and share the experiences I was beginning to have with the administrator. He clarified not agreeing to co-supervise and that I was not hired because of my friend's recommendation. We further discussed the issues that were occurring between myself, the administrator, and the senior researcher. He apologized for the experience I was having with these two individuals. Unsure on what action to take, we left the conversation open-ended while we gave ourselves time to reflect.

In June 2018, 11 incidents occurred involving both the administrator and the senior researcher against myself and the Researcher. Any attempts to resolve only escalated tensions each day. I was accused of creating problems at work through mistakes that were placed on me and others not accepting responsibilities or accountability. The administrator once screamed at the Researcher and I for looking at our phones as we attempted to find hotel receipts within our email accounts to identify an unknown charge to the department credit card. This moment led to the senior researcher deciding to forbid electronics during staff meetings. This would not be fully enforced until October. The administrator and senior researcher often retaliated and bullied me for delays in the project such as not providing documents on time. There was an issue for not requesting permission to attend a free conference at the university from the administrator and senior researcher even though they were not my direct supervisor. The assistant administrator became involved and shared with me that university policy only required supervisor

approval, (which the Researcher had provided to me) and was fully aware about the policy. Many issues were raised regarding last minute field data collection in Texas, placing intimidation and retaliation on me for not vetting locations correctly through phone calling, despite not living in Texas and being restricted from traveling to the sites. There were two incidents that occurred at the end of the month that made me fully aware I was being targeted.

In one meeting while discussing establishments to visit for a research study, I mentioned one Spanish-speaking establishment in a primarily White neighborhood. I was asked to remove it and I pushed back saying that I had entered the establishment while speaking Spanish to staff. The senior researcher responded, “You also speak English. We are not including it.” The day following this incident, the Researcher and I had a phone conversation after work hours relating to the meeting he had with the senior researcher regarding my behavior in the staff meeting. The Researcher relayed to me that a) the Researcher shared to the senior researcher how I found his comments to a Spanish-speaking establishment discriminatory from a White man, and b) that I have been going through health changes. According to the Researcher, the senior researcher stated that a) I did not have sleep apnea when I began working for them, and b) I needed to look “happier” during meetings. How the fuck do you look happy at work when you are receiving retaliation, bullying, discrimination, intimidation, and oppression for the way you look and the microaggression you receive? The senior researcher stated to the Researcher, “It looks like he drank a quarter ounce of vinegar.” Given this situation, I filed a complaint at the university’s Equal Employment Opportunity Commission (EEOC) office. Three months after meeting with EEOC to file a formal complaint, they

decided the senior researcher was required to attend a mandatory diversity educational session. This only occurred after I inquired about the result of my complaint in October 2018.

Here is a quick reminder about my health in June 2018. I was finishing a neurological evaluation and undergoing sleep therapy adjustments after getting the results of my second sleep study in March 2018. It is difficult to maintain any kind of positive expressions when you have been deprived of sleep your entire life. It is not easy having a respiratory machine control your breathing while you sleep and not feeling fully rested each morning. It makes me angry that a senior researcher in health communication would make such statements. It was evident to me that the senior researcher had no understanding of health and the impacts it can have on an individual. The research projects granted to address problems in the community were related to health. Despite being exhausted from my health difficulties, I knew it was time to address the organizational culture problems.

In July 2018, there were a total of nine problems that occurred, all similar or continuing from the last month. The month began with a notice that we had lost grant funding for one of the research projects. This would severely impact some of us as that was our source of funding for our positions. I was not surprised. After all, I kept posing questions relating to the project not moving forward because of the secondary research team in Colorado not meeting their deadlines for us to do our half of the work. This was also the case for the other two research projects that remained. During this month, both the administrator and senior researcher teamed up against me, often leaving out my direct supervisor, the Researcher. There was an instance where the senior researcher walked

into my office to confirm I was working on his task. He intentionally chose to walk behind my desk and look at my computer screen. I felt disrespected, offended, and bullied for being questioned on my integrity to fulfill my job responsibilities. It was condescending behavior from the senior researcher. In my university profile, the supervisor listed on record was the administrator and not the Researcher. I brought this to the attention of the building manager and the Researcher. This was odd as this was never discussed with anyone. My work was often under scrutiny because the administrator and senior researcher believed I was the source of creating problems for the research projects. I decided to make a visit to Human Resources (HR), the EEOC office, and employee counseling services. The problems reached a point where I knew I was being discriminated, offended, bullied, retaliated against, intimidated, and oppressed. It helped to have a supportive supervisor and a building manager that served as our HR representative. I was finally taking action that I should have taken in the previous job. There was no way I would allow two more people to discriminate and oppress me given the racial injustice that exists in the United States.

August 2018 had two significant changes and a continuation of problems. My direct supervisor, the Researcher, had a significant problem in a different center he supervised and had to step down as my direct supervisor to oversee the center. This change would not occur immediately, but others decided to do their best to make that the case. The administrator and senior researcher became my unofficial new direct supervisors, although it became a 50% split between them and the Researcher. This was unexpected. This was also odd as the senior researcher was no longer a university employee given that we had lost the grant that employed him through the university. Our

office served as sub-awardees to the other two research grants, which the secondary research team in Colorado served as the primary grant recipient. This meant that the senior researcher was employed by the secondary research team and not the university. How does someone who is not employed by the university supervise a university employee? Given that these two hostile individuals had now gained power over me, they would make it very clear with their actions. Every meeting on my calendar was now questioned each week. The Researcher relayed to me that during a meeting with the senior researcher, my calendar meetings were questioned and wanted to specifically know if I was attending job interviews. The administrator used every individual meeting with me to question the meetings on my calendar. There was one meeting I had listed as private that was questioned by the administrator. I explained that it was a confidential meeting. She proceeded to explain how university policy allowed for employees to attend interviews during work hours. I chose to not disclose the nature of my confidential meeting. Under the guidance of the Researcher, I removed the senior researcher from having access to my calendar. After all, he is no longer a university employee. The meetings on my calendar, all of which were private, were meetings with HR, the EEOC office, and employee counseling services.

Before meeting with HR and EEOC, I met with the director of the research department in which I worked. The director was in the process of resigning and instead decided to have the interim director take my case despite having two more months remaining on her contract as the director. The director and interim director encouraged me to seek the guidance of HR and EEOC. That was their only solution. After a few meetings with HR, it was clear there would be no action taken. The documentation I

created, as recommended by a HR course instructor in Spring 2017 (more in the next section), was labeled a diary by the HR employee I met with. She refused to acknowledge my documentation as evidence, rendering my notes useless. Their take on the organizational culture of this office was that employees needed to resolve their differences. In my view, they would rather protect the university than to support an employee. EEOC took a different approach. Given that I had recently registered my newfound disabilities with their office, they were able to look at my case through the ADAAA. During the month of August 2018, I worked with the department manager and the Researcher to determine the best accommodations to support my learning disabilities. This would also protect me against the administrator and senior researcher as they had often shown a complete disregard for my health.

In September 2018, tensions and hostility continued to increase towards myself and the Researcher. There were always discussions about my calendar and timesheet entries. The administrator was a micromanager and wanted to know every single detail about everything, even if it was not related to her duties. On September 4, I heard the Researcher greet both the senior researcher and the administrator, both of which decided to ignore his kind greeting. This kind of interactions occurred daily. On September 14, the interim director chose to alter one of my accommodations by adding that anytime I chose to use audio recording to take notes, I must follow the office policy of disclosing to staff and faculty that I am audio recording. It violated my request to keep my ADA accommodations private as I feared receiving additional hostility and discrimination. Requesting to see the policy to the Researcher and department manager, it was made clear to me that it was a verbal policy and not written or a university policy. I felt singled



out and targeted by the interim director. This was in part due to the fact that both the Researcher and I had audio recorded conversations with the administrator and senior researcher to demonstrate their bullying, discrimination, hostility, retaliation, and oppression. We had chosen to audio record to prove our case to HR, the director, and interim director. It was made clear that our actions were unacceptable, despite that New Mexico law, “Interference with Communications; exception,” does not prohibit anyone from secretly audio recording a conversation (O’Neill, 2013). On September 26, the department manager, the Researcher, and I met with the ADA coordinator for the EEOC office to discuss ways to maintain confidentiality of my accommodations as well as to learn more about my rights under the ADA. This would become useful knowledge for me in the months ahead.

October 2018 was fairly quiet with high tension and hostility continuing. The senior researcher finally decided to enforce the request for no one to enter the staff meeting with electronic devices. What is interesting about this outcome is that it coincides with the interim director’s notice to not audio record. There seemed to be an exception as the senior researcher and administrators would be the only ones allowed to use their mobile devices. The senior researcher continued to provide directions and tasks while acting as a university employee despite not being on payroll. There were two anonymous complaints made towards me through HR about my use of cologne and an employee being allergic to it. This was odd as I do not use cologne. The Researcher and I determined it was most likely a reference to my air freshener with a lavender scent. This was also odd as everyone in the office had a positive response to my air freshener for being a relaxing calming scent. The air freshener had been in use for two months before I

received complaints. It was clear that someone was seeking to identify a method to retaliate towards me as HR played a role in delivering the complaint to the office manager followed by the Researcher. Although it was a fairly quiet month, my biggest accomplishment was receiving ADA accommodations and having them approved by the ADA coordinator. Please see Appendix F for a list of my accommodations. These accommodations would play a large role in the following month.

As I mentioned in an earlier section, I experienced a concussion in October 2018. This increased the difficulty of dealing with problems at work. My pre-existing depression became amplified. My anxiety also became amplified. My mind was unstable, twisted, and confused. The first two weeks sent me into a panic. Within five days of the concussion, I believed I was experiencing a heart attack or stroke and immediately sought urgent care. The medical doctor assured me that my heart was fine; I was experiencing the symptoms of a concussion. Waking up every workday, I dreaded having to go to a hostile workplace. I held a deep fear to enter an unwelcoming space.

November 2018 would become an extremely difficult month for me, including dealing with a concussion. Issues with my timesheet continued to exist despite that there never were problems with it just months earlier. I was once yelled at by the administrator for delivering a timesheet to the assistant administrator as directed by the Researcher. During a meeting, the administrator, with force, slapped a foot of the Researcher as he sat with his leg crossed over his knee. It was an awkward interaction as the Researcher and administrator were not on speaking terms before the interaction. On November 26, the Researcher would no longer serve as a direct supervisor because he was needed full-time at his center.

The transition from having the Researcher as a supervisor to the administrator was not a welcomed decision for me; most of the problems I was experiencing were stemming from her. The entire situation became a clusterfuck. The department manager was assigned as the administrator's supervisor. The administrator was assigned as my supervisor. My ADA accommodations had to be transferred over to the administrator. A meeting between the ADA coordinator, the administrator, the department manager, and the interim director was held to transition my accommodations. Later in the week, the administrator decided to assign the assistant administrator as the note taker, a role that was originally filled by the Researcher in order to maintain confidentiality. Having a note taker was one of my accommodations. It was not disclosed why there was a need for notetaking to occur. Two days later, the interim director chose to place a moratorium on the supervision of the department manager over the administrator. No reasons were ever provided other than the interim director wanting to try a different approach to help protect me further. I found this to be a bunch of bullshit. The first method was only given two days before being changed. Two days is not enough time to try out the new supervisory chain. I was personally open to trying this supervision chain because the department manager was doing her best to help resolve the problems I was experiencing with the administrator and senior researcher.

The month of November ended with an ADA accommodation violation. I emailed the administrator to update her on a work task that I was assigned. I included in the email the following: "Last, this is a friendly reminder to please send me written instructions on work tasks per my ADA accommodation. It helps me make sure I am completing tasks as requested and don't leave out anything I was supposed to do." Four minutes later, the

administrator replied, “I also appreciate knowing that you need written instructions I was not aware of this.” The administrator clearly violated my ADA accommodation. She had met with EEOC, the department manager, and interim director just three days earlier (November 26) and it is my understanding that all my accommodations were explained one by one to her. On the third day of December, she violated another ADA accommodation. During a staff meeting, the administrator said, “If your door is closed, I assume you are not working.” In my accommodations, I had been granted the ability to work with my door closed to increase my focus. It was difficult working with the administrator and senior researcher often walking by and staring into my office to make sure I was working. It was distracting. I immediately emailed both HR and the EEOC ADA coordinator after each incident.

On December 5<sup>th</sup>, the interim director met with me to discuss the incidents that had occurred in regard to my ADA accommodations. He began the meeting with explaining he was doing his best to protect me in the organizational environment. The interim director acknowledged he was present at the meeting to discuss my ADA accommodations and recognized that those accommodations were violated. As a result, there was a supervisor change. The former director of the department would be taking the place of supervisor given that I would soon be reassigned to a new upcoming research grant project. During the meeting, I expressed how much discrimination I have faced in society as a Latino male due to the color of my skin, accent, disability, and ethnicity. He could never understand my struggles given his privilege as a White male in society. There is nothing he could ever do to make things better other than believe my experiences and do better to address injustice. At a minimum, he acknowledged not

understanding my experiences but wanting to help. His actions demonstrated otherwise. He was slow to respond to my concerns. He favored meeting the needs of the administrator. He was not transparent about addressing the hostility. The remainder of December focused on the supervisor transition to the former department director.

It is now January 2019, and a new year brought with it a new round of problems as well as the continuation of previous problems such as timesheets, my calendar, and my whereabouts. The month began with vague emails with work tasks from the administrator. We exchanged emails and each one continued to include vague instructions from her, not once considering my accommodation request for very specific instructions. During a Monday staff meeting, the administrator challenged my response on not being able to provide a timeline and deadline for a research manuscript that I was involved in writing. She would not back off, even in the email exchanges that had occurred previous to the meeting. Surprisingly, the senior researcher defended my response as candid. That was the only instance in which he provided any kind of defense and support. Unsurprisingly, the administrator backed off due to her longstanding relationship with the senior researcher. Somehow my words were not valid but the senior researcher's words were valid. Heck, even the fact that my wireless printer was not working became a big problem to her because somehow, she and her new employee (pseudonym; hired under her supervision) needed to print from the printer in my office despite the fact that there were several other printers available.

Against my will, I was forced to travel to Texas with the administrator and the new employee to conduct data collection. The hostile work conditions were enough for me not to want to work alongside her. There was no way for me to get out of traveling.

On January 18, the return drive to Albuquerque was vile as we had to share one vehicle. The administrator disclosed information from an email sent by the interim director. She shared with the new employee and I that the department is experiencing budget problems, and that they were considering removal of the security guard on the premises. She wanted our thoughts about it. I text messaged the department manager and asked how that would impact me if I stayed after hours. I shared what the administrator stated. I did not feel comfortable engaging in conversations of any sort with the administrator or my new supervisor, the former director. I would rather ask the department manager. Thirty minutes later, the administrator read an e-mail aloud from the interim director asking her to never disclose confidential information and his disappointment in the administrator's action. Once she finished reading the email, she turned around with anger, screaming at me, "Did you say something?!" I looked up and said no. She yelled again, "Did you say something to someone about the security?" Again, calmly and indifferent I say no. She screamed a third time, asking again if I had said something. Once again, I reply no, providing no emotion. She then turned to the new employee, whom she had asked to drive her personal vehicle, and asked him politely, with a calm and soft tone. He replied, "No". She does not ask him three times. She says, "Then who said something? I only shared it with you two." She resumes doing whatever she was doing on her laptop...which was surfing the Internet and reading emails. It was very clear how aggressive she was towards me in comparison to the new employee. She didn't challenge or question the new employee as she did me. In what circumstance is it ever okay to yell at an employee? Not only was it inappropriate having her scream and yell at me, but she also disclosed confidential information from the interim director. This is disrespectful and

demonstrated that she cannot be trusted with any confidential information. If she is disclosing confidential information the interim director sent out, there is no reason for me to ever trust someone like her when it comes to my privacy and confidential information such as my ADA accommodations and FMLA. This whole instance showed retaliation, bullying, aggression, and hostility towards me. The one last disappointing piece about this event is that when I did report this to the EEOC office, the new employee denied this experience and defended the administrator. I never understood why this new employee chose to side with the administrator and alter the truth of that moment. That would appear to be the case with the former director and her supervision of me.

During February 2019, the former director made it very clear to me that she was not going to believe and support me in anyway. During a bi-weekly meeting, I explain to her the recent problems that had occurred. I shared how I was being tasked with developing standard operating procedures (SOP) for the grants, which was a waste of my time given that in research grants, the procedures are outlined within the research protocol. Every task I followed was literally within the research protocol. I was constantly being blamed for using my smart phone device during staff meetings given that everyone else seemed to have forgotten that the senior researcher had banned the use of electronic devices during meetings. The rule was only being applied to me. The former director defended the administrator each and every time. During another bi-weekly meeting, the former director accused me of not following orders by charging time worked to a grant. I was vaguely told not to charge hours on my timesheet when not working on that grant. I was working on a research manuscript and held a weekly meeting for that specific grant. No one told me not to charge hours for that meeting or the manuscript.

Once again, instructions provided to me were vague and unclear. It was another violation of my ADA accommodations. I do not think it is ethical to lie about working on a project and not charging my time worked to that project. The former director demonstrated that there was no clear communication between the administrator and herself. The former director never once bothered to take time to understand my situation. After all, when I first met with her in August 2018 to report the problems I was having with the administrator and senior researcher, she refused to address it and instead chose to have the future interim director take on the task. Even my complaints about my ADA accommodations not being met were ignored by her. The former director demonstrated her lack of understanding of people in the organizational culture, the hostility that existed, and disability discrimination. To her, I was the source of problems. She never did provide any type of supervision. She was not present at staff meetings. She never provided tasks. She never considered my concerns and problems. Her only goal was to enforce the tasks of the administrator and hold me accountable on behalf of the administrator without once giving me the benefit of the doubt.

**Reflexivity.** Here is my reflection on these experiences. Consider how race and age could play a role in the events that unfolded. The senior researcher, administrator, assistant administrator, former director, and interim director are White and in the ages of early to late 60s. The Researcher and department manager are also White and in the ages of middle to late 40s. The new employee is a White Hispanic in his mid-30s. The HR person is a White Hispanic female in her early 50s. All of the individuals have a white complexion. With the exception of the Researcher and department manager, I firmly believe that my young age (early 30s), brown skin tone (Mexican/Mayan/Latino), and



disability (sleep apnea/learning disabilities/concussion) impacted their views, treatment, and decisions. Not once did someone give me the benefit of the doubt. Both directors and the HR person consistently asked I give the senior researcher and the administrator the benefit of the doubt. The former director never once acknowledged that the senior researcher and administrator could cause problems. The interim director asked me to be patient with him, but he never made any firm decisions and was often forced to make decisions under the direction of the EEOC office. I recognize that if I were the one who had lied, bullied, screamed, intimidated, or even threatened anyone, I would have been dealt with immediately and possibly removed from my position. As a man of color, I cannot show any kind of anger or frustration without fearing that someone will immediately call the police. As I mentioned in the opening of this chapter, I grew up in the city of Compton, California, a place where Black and Brown folks experience police brutality because of the color of our skin. Police brutality continues to occur in society today as is evident by the #BlackLivesMatter movement. I will be racially profiled the moment someone calls the authorities. No one but the Researcher and department manager believed and supported me. These two individuals were not in a position of power to change things. The EEOC office took action only because my ADA accommodations were violated. The HR office never once took action on my case unless EEOC made it clear that there were policy violations due to ADA. Without the protection of the Americans with Disabilities Act Amendment Act, no action would have been taken towards the oppressors. HR and EEOC never once considered my experiences to be acts of racism because no words directed towards my race and ethnicity were made. That is a problem within itself. Someone can easily avoid not using racists terms, but their actions

show otherwise. What does it take for an organization to hold people accountable for creating a hostile work environment? Everything I have shared was reported to the directors, HR, and EEOC. I was never allowed to bring up racism because of the lack of words. Racism can exist in actions taken. My pleas for help were never answered; they were ignored.

In June 2019, the EEOC office released the final report. You can see the final investigation report in Appendix G. It was found that the administrator had violated my ADA accommodations and had retaliated. The report was forwarded to HR to take action. I cannot say what they did for two reasons. First, that information is kept confidential, meaning I do not get to know what actions are taken by HR. Second, the administrator chose to announce her retirement in March 2019. The administrator and senior researcher officially left the university in April 2019. It was unexpected to everyone as the administrator had never once mentioned wanting to retire anytime soon. Both were fully aware that I had initiated an investigation with the EEOC office. My guess is that they knew the administrator would be found guilty. By retiring, she secured her retirement benefits and invalidated any action HR could take. Any efforts to hold the administrator accountable were rendered ineffective. Think about it this way. How can you hold a retired employee accountable for their actions in a case in which that employee was found guilty? The administrator was never held accountable. I believe that demonstrating her inability to respect my ADA accommodations led to her decision to retire as a way to save face and avoid facing accountability. In short, she ran away. The senior researcher's decision to officially leave the university alongside the administrator supported the notion of their codependence as one would always support the other in decision-making. Their

choice to leave was planned as they were able to withdraw the grant funding from the department, causing four employees to become unemployed. One of those four was me. Two of the employees were rehired by them through the other research center we collaborated with on those same research grants. Only one employee truly became unemployed, a casualty. With my success came stories from several present and former employees of the department that had once left due to the issues, much the same as my own, they had experienced with the senior researcher and administrator.

I became an unsung and unrecognized hero in a strange way. No one had been successful at demonstrating the despicable working environment the administrator and senior researcher created through their actions. The former directors never once took action to resolve the problems. The lack of accountability only empowered the actions of the administrator and senior researcher, no matter how wrong their actions were to people. It saddened me to know that I was the first person to be successful in seeking justice for the discrimination, racism, bullying, intimidation, retaliation, oppression, and offenses the administrator and senior researcher bestowed upon me. Many of these former and current employees helped acknowledge my views and perceptions that I was a victim. I cannot share their experiences as they are not my own. However, what I can say is that my experiences do reflect similarities to their experiences. Their only option was to find other employment opportunities. No person should experience what I experienced. No person should be allowed to create a hostile work environment. Any efforts to address the problems were never successful. Only I was successful at demonstrating their cruel actions, and only through the use of the ADA.

**Won't give it.** In his comedy stand up special, Trevor Noah (2018) explains that while jay walking on a street in Chicago, a man in a pickup truck shouted a racial slur at him. Noah's reaction is to joyfully shout that racial slur back to the man with a smile. Confused, the man swerves and nearly crashes his pickup truck. Noah reflects, "I'll never give a racist person the pleasure of seeing my pain. It may be painful, it may be hurtful, but I won't give them the pleasure of seeing my pain." If we allow a racist, discriminator, oppressor, offender, bully, intimidator, retaliator, and hostile individual to see the pain their actions cause us, it only makes them believe that their actions and words have power to control. Not reacting to their racism might not make them stop or reflect, but it will confuse them. It will frustrate them. It will infuriate them. It will make them try again. They will never receive the satisfaction of seeing our pain.

Noah's words represent the belief I have to live by every day of my life. I cannot allow a racist, discriminator, oppressor, offender, bully, intimidator, retaliator, hostile individual see the pain they cause me. These people, I believe them to be demons. In each instance, I had to withhold emotions of anger, frustration, pain, and disbelief. With instinct, I knew my best decision was withholding my emotions. Giving them a sign of those emotions is a win for them. Each and every day, the demons continued to find ways to create torture. They wanted to mentally break me. I had to prove that I could not be broken and rise above the occasion. I had to demonstrate I was different. Not once did I give these demons one moment to have the satisfaction of giving up on my approach to hold them accountable. I never provided them with any hints that I would drop my pursuit of accountability. My resistance only made them continue their attacks without success of breaking me. Had I not launched an investigation, those two individuals may

have never left the department suddenly and unexpectedly. The university may have not held the administrator accountable, but I am sure she will never forget the reason and conditions under which she left the university. That is a victory the department directors will never acknowledge was a result of my pursuit for social justice.

**March 2019.** Dumb luck occurred beginning March. Recall the Researcher stepping down as my supervisor to take care of his center. Turns out, an employee resigned at his center, creating an opening. Because I was an employee of the department, I was able to be reassigned given that it was also a grant funded position. Without this opportunity, I would have been left unemployed by mid-April. The Researcher and I rejoiced for an opportunity to work together without the two toxic individuals, the senior researcher and administrator. This would provide both of us a fresh start and focus on a center that was experiencing grant related challenges.

### **Job #3 – Spring 2019 to Fall 2020: A New Hope**

By mid-March, I began working with a new team in serious need of positive leadership. The previous manager had created problems that led to his forced resignation as he was found guilty in an investigation by the EEOC department. It seems like a trend for this department, doesn't it? The Researcher had acquired the role of manager while I took the role of project coordinator. Much like in my previous role, the grant objectives were not being met due to staff turnover relating to the previous manager as well as the grant required tasks. There were five employees: a Hispanic woman in her early 30s serving as a technical assistant, a White woman in her early 40s serving as a graphic designer, a Native American/Hispanic woman in her early 50s serving as the administrator, a Native American male in his early 30s serving as a program coordinator,

and a Native American/Black woman in her early 20s serving as our student assistant. The technical assistant, program coordinator, and graphic designer had been in their roles for over a year with all others being new hires. Because the center is a component of the department, I was familiar with everyone except the student employee, as she had been recently hired before my arrival. In this experience, I share with you the story and reflection intertwined.

The first few months were a steep learning curve with understanding the grant requirements, the challenges the staff had confronted with meeting the grant objectives, working with the state grantors, and addressing the concerns of a local external evaluation team. This required that I take the time to listen to the experience of the staff to identify approaches to remove the barriers. Given that the Researcher was also taking the time to understand the grant requirements and objectives, we trusted the technical assistant in her guidance and knowledge to develop solutions to barriers. Conversations with the staff provided insight to the problems created by the former manager, a White male in the age range of early 60s, which reflected similarities to my own challenges with the senior researcher and administrator in job #2, and the new supervisor in job #1. The similarities in our work experiences allowed all of us in the office to bond as we sought ways to heal and move forward.

The initial bonding provided the Researcher and I with an opportunity to take a different approach: positive psychology. Coffee breaks, lunch meetings at restaurants, pastries on Fridays, team building activities, and flexible work schedules improved the office dynamics. In my ADA accommodations, I had the option to schedule flexibility due to my sleep apnea. The Researcher had a greater understanding of sleep health and

decided to provide everyone in the office the same flexibility. This action removed any need to have to disclose my disabilities or justify my unanticipated schedule changes. Eventually I did open up and share my disabilities, receiving positive support from everyone. In fact, one coworker disclosed having ADHD, allowing us to relate and find comfort in knowing someone else understood our unique challenges. Another coworker disclosed her husband having sleep apnea. She understood my sleep struggles. As time progressed, the office dynamics were transformed.

“You are all my supervisors. You tell me what to do. I’m just here to help you,” the Researcher would often remind us. He broke the idea that he was our supervisor and shifted his power over to us. We each had our own individual projects under various grants. He instilled within us confidence and support that we were subject matter experts in our projects. We collaborated to reduce our workloads and simplify tasks that were once made complicated by previous staff members no longer working together in the center. We often took our lunch breaks together to discuss life outside the office, increasing our bonding with each interaction. We began considering new research ideas for grant applications that would focus on everyone’s interests and strengths. The Researcher’s approach to create a positive organizational culture drastically shifted a once toxic and hostile work environment. In our time together as a team, there was never a problem among staff.

The only problems that occurred were coming from grantors within the state of New Mexico when it came to changing our project objectives. The grantors perceived objective changing to be a sign of problems and would often treat us with hostility and aggression. We were able to navigate these challenges as a group and push back politely

to avoid having our grant removed. Other than that group, we all enjoyed working with each other. We had trust, confidence, and faith in each other. We showed each other compassion, empathy, and support.

Unfortunate events took place within the next year and a half. We lost our coordinator within five months due to not having his grant renewed. He was reassigned within the department but would no longer work within our center. The graphic designer resigned within nine months because her partner was being relocated for work. It made our small team feel smaller. A group of seven became a group of five. During this time, we wrote and submitted eight grant applications. We were awarded two small grants, neither of which was enough to employ a single person. The funds were enough to execute participant recruitment, data collection, and analysis. One by one, we received notices from each remaining grant submission thanking us for our application and encouraging us to reapply again in the future.

In September 2020, the technical assistant and I became unemployed; the student assistant had her work hours reduced. The center administrator was able to shift her effort to other grants to avoid losing work hours within the department while still providing support to the Researcher. The last grant application we submitted returned as a rejection. We received positive responses and scores on the grant applications. We were less than 10 points away from perfect scores on two grant applications. We truly did our best despite the technical assistant and my lack of grant writing experience prior to submitting all grant applications. We sure did gain considerable experience in grant writing. There was not a lack of effort from anyone providing support on the grant applications. We gave a year and half of our best work.



Unlike previous jobs, we all experienced grief. We enjoyed the team dynamics and the positive organizational culture created from our efforts. I never woke up dreading having to work that day. We all agreed of the positive impact we felt from not experiencing discrimination, disrespect, and lack of support. If we were having a negative mental health day, we provided encouragement and time off to each other. Everyone was empowered. We all were given the ability to excel and lead without fear of repercussions. Any mistakes became learning opportunities for improvement and growth, which no one ever viewed as concerning. Mistakes were always insightful for us all. Disagreements were always welcomed because they were used to understand as many perspectives as possible for the sake of developing strong grant applications and meeting our grant objectives. We all took the time to understand each other's views without judgment. Thinking outside the box was always highly encouraged as it led to some amazing events and activities to meet our grant objectives. We all agreed that the one thing lacking was additional time for us to continue working together once our grant funding ended. This truly was one of the best work environments any of us have experienced. It taught us that is possible to be happy and have work-life balance under positive leadership and management alongside coworkers and a supervisor supporting it.

**Health and a positive organizational culture.** Throughout this positive work environment, I continued to undergo sleep therapy adjustments and concussion side effects. As I mentioned earlier, my concussion healed in April 2019, just about one month after beginning this job. It was a great improvement, but along with it came the return of my ADHD. Therefore, I had to seek ways to re-train myself to manage my ADHD. Having the technical assistant disclose having ADHD helped alleviate the

pressure of not being understood. We had many great conversations about our ADHD and the various techniques that help us address it, as well as the advantages of having ADHD. As for my sleep health, once I shared it with everyone in the office, the graphic designer disclosed that her husband's sleep apnea. She understood my struggles and provided encouragement that I would find the correct sleep therapy adjustment I needed. She helped normalize my experience by sharing the experiences of her partner, showing me that my health would improve. Knowing that my coworkers understood my various disabilities and that my supervisor was willing to accommodate me to the best of his capability provided me with something unexpected.

Stress, depression, anxiety, fear, PTSD, and trauma began to fade away with each passing month in my new role. I no longer worried about having someone looking for ways to torture me and create problems because they felt like reminding me that I was somehow inferior to them. In the first three months, I did experience PTSD and trauma. I sometimes awoke in the morning feeling afraid to work. I reminded myself I was in a new place. The slight feeling of experiencing a disagreement or problem at work made me think the situation would escalate. We were all experiencing these exact feelings. The warm and friendly smiles we gave each other helped alleviate tension. I often asked my coworkers for permission to modify grant activities before executing them. They reminded me that it was my job to determine those things and do as I thought it was best. We did our best to change those conditions by empowering one another. With time, we created a positive organizational culture. Their empathy and compassion allowed me to really focus my attention to improving my disabilities. Reducing or eliminating the stress, depression, anxiety, fear, PTSD, and trauma helped improve my overall health and

allowed me to be a successful person and employee. This is what a work environment should be like for everyone. Direct communication, honesty, goal-setting, and trust with one another helped us all focus on our job without any toxicity of oppression and injustice.

### **Health, Work, and School**

So far to this point, I have described my health conditions (e.g., sleep apnea, ADHD, concussion), the difficulties of two organizational cultures, and the positivity of one organizational culture. As my health unfolded and challenges of each job occurred, I was attending courses to complete a graduate degree that will grant me a doctorate. Even in the classroom, I was being discriminated and unsupported by faculty due to my health. In the following section, I will describe the learning environment of higher education as a graduate student experiencing severe sleep apnea and other disabilities.

#### **An Unsupportive Learning Environment in Higher Education**

Wanting to occupy my free time, I chose to do something that would propel my career forward. In fall 2014, I enrolled in graduate courses out of boredom of being new in an unfamiliar city and state. In the fall of 2015, I began a doctoral graduate program based on the first two courses I completed. Unexpectedly, I did not believe I would experience discrimination, insults, and unsupportive behavior from educators that refer to themselves as faculty and professors. There would be no way to brace myself for what was to occur in my educational experience as a graduate student at a university. Nothing in the toolbox of my experience would prepare me for the changes in my health and the difficulties of functioning sleep deprived.

From summer 2014 to summer 2016, my sleep apnea began to unravel itself. I was fully unaware that the changes in my health were indicating something severe. After all, medical professionals often told me there was nothing wrong with me based on a basic blood exam. Choosing to enroll full-time as a student while working full-time as a professional, I thought I could manage the workload. After all, I had managed to complete a bachelor's degree and a master's degree while working full-time and part-time. It was no easy task. I knew it was doable. I did not have family, friends, or a partner to distract me or require my time. My view was that I had all the time in the world without any concerns. Feeling prepared, I began my journey to complete another degree while working full-time. What could possibly go wrong? Turns out, a lot did go wrong.

#### **Fall 2015 to Summer 2016**

My first year working full-time and attending courses full-time was a breeze. The courses I completed felt easy and applicable to my career. There were some disagreements with faculty over content being taught not being applicable to toxic and hostile work environments and instructional design not being a one-size-fits-all model for all learners. It provided good discussions and debates in the classroom. Taking what I was learning, I would apply it in my full-time job to test the effectiveness of the content in the courses. Some stuff worked. Some stuff did not work. Not being in a position of leadership or management within my job always seemed to be a barrier that professors would, at times, reject by stating there was something I was not doing correctly. The overall experience in the program was good, but not great. I always have believed that the best learning in life comes from our own personal experiences in the fields we are interested in pursuing as careers.

**Vacation restoration.** Always seeking opportunities for growth and development, I was fortunate to be awarded an opportunity to travel. A scholarship made it possible to travel to an international conference focused on educational technology in the United Kingdom. With this opportunity in hand, I chose to take vacation time. At one point, I traveled to Switzerland to visit friends. June 2016 would teach me a valuable experience about my sleep health.

Concerned I might keep my friends up all night with loud snoring, I apologized ahead of time the day I arrived in their Switzerland home. The four days I stayed with them provided me with some of the best sleep I had ever had. I vividly remember thinking to myself that the humidity felt refreshing to my lungs. I felt extremely happy. Surely, the jovial experiences were responsible for that. Following the morning of the first night, I asked my friends if I had kept them up at night with my loud snoring. Being light sleepers, they did not hear me snore. Perhaps it was the great hospitality they were providing. It was the first time I had visited friends across the globe. I was unaware I had sleep apnea at this point in time and would learn of that in two months upon my return to the United States.

Upon exiting the airplane after landing in New Mexico, my breathing became restricted. The first two weeks I believed to be experiencing jetlag. The feeling of jetlag never did go away. At the end of August 2016, I met with Dr. Rose, the dentist that would first identify that I had sleep apnea. I was in disbelief. Feeling amazing out in Switzerland and my return to New Mexico just made me feel depleted.

Reflecting upon my recent travel after being identified with sleep apnea justified the potential for sleep apnea. Diet, exercise, and sleeping habits were no different in

either country. The two contributing factors to experiencing amazing sleep were being at a lower altitude and higher humidity. Naturally, upon my return to the United States, I would go to sleep thinking of my time in Switzerland and wishing I could feel that way each and every day. Those four days in Switzerland were like an experiment to my sleep patterns, justifying my need for sleep.

### **Fall 2016**

At this point in my role as a graduate student, I was fully aware I had a sleep apnea and was awaiting a sleep clinic appointment. Knowing my condition did not change a thing for me. I continued to do as before. Keeping myself together was becoming messy. The sleep deprivation began ravaging my mental state. I was no longer able to hide the conditions brought forth from sleep deprivation. I feared facing stigmas of being a male Latino that underperformed. Adding a disability to my identity made all things more challenging. Past experiences as a student inform me there will be no empathy or sympathy towards my declining health. In other institutions of education, very few faculty members have taken interest in helping a person of my background. These past life events taught me that I needed to prove I was an overachiever and not an underachiever. The prior educational experiences made me believe that I had to work harder than anyone else and withhold any information that would suggest I was struggling.

Sometime in the first or second week of the semester, I was in one of three courses late in the evening. The students and the faculty member were all sitting around a large conference room table. Whatever the activity was, everyone had to speak and participate. As I sat there waiting for my opportunity to jump in, I felt a strange sensation

running through my body. Looking down, I notice my right-hand trembling. Looking around the classroom, my heart began to race alongside my mind. The trembling began spreading across my body. I felt terrified. What was going on? “Has everyone had a chance to speak?” asked the instructor, a White female possibly in the age of late 30s or early 40s. The pseudonym for this instructor will be “faculty 1”. As before, I remove traditional pseudonyms to remove power from these individuals. I tried hiding and avoiding speaking before being singled out by a few peers in the classroom. The trembling would fade in and out of my body for the remainder of the class that evening.

This same feeling continued to occur within that same course and at times within the other two courses. That trembling feeling felt like anxiety and panic combined. That evening was the first instance that forced me to accept a decline in my overall performance and my inability to hide the impact of sleep apnea. I was determined to push forward. I was losing control of my focus to maintain an appearance of who I no longer was. For the first time, I was afraid of the impact sleep apnea would have in my life. If I could no longer control my appearance for fear of stigmas, what was I to do next?

During the third week of the semester on September 2nd, faculty 1 emails me: “I wanted to check in on you. I know you said you have been having sleep apnea, but you seemed so unlike your usual self. Anything I can help with?”

I replied:

“Thanks for checking in on me. My sleep apnea triggers my hypertension and insomnia. It makes me feel paranoid and anxious during the day. I've only had 3 to 5 hours of sleep each night. It progressively got worse throughout the week and yesterday was the worst. I

took the day off from work to readjust today. I just moved to a new place and I think the air conditioner is affecting me. I slept without it last night and I got a better sleep. I'm hoping I can readjust this weekend. I'm probably going to see a medical specialist soon to get a sleep study.”

She responds:

“That's rough. I had insomnia for a year and a half and slept biphasically (hour at dawn, hour at dusk) for about 6 months of that. I really feel for you. Again, if there is anything I can do, just ask. And take good care of yourself.”

At first, I was relieved that someone actually understood me after I chose to disclose after class my experience with my initial sleep apnea diagnosis. This disclosure led to the email responses you see above. This encouraged me to share with the other faculty what I was going through. Everyone appeared to be supportive. I slowly began sharing it with peers who asked if I was okay after noticing changes to my usual participation displayed in the previous academic year. Around this time, I had also chosen to share with my coworkers and that new supervisor in job #1 the conditions of my health. I thought it was best to be honest and straightforward, believing people would show me compassion and empathy.

Determined to find every method to get around the limitations of sleep apnea, I visited faculty 1 for guidance on new ways to study. I was experiencing difficulties recalling information from the assigned readings in all my courses. It was as if I had never read anything. I was beginning to have challenges understanding assignments.



During this meeting with faculty 1, she provided notetaking techniques such as writing notes within the book or using sticky notes, as well as writing down my thoughts after reading a paragraph. This was something I was already doing but was not effective.

Insisting I continue, faculty 1 focused on sharing her experience with insomnia and how she was able to find times where she was more awake and alert. I listened. I thanked her for help and left.

After a few more meetings with her to help me identify new study techniques, I stopped seeking support. As I reflected, I became angry. Insomnia and sleep apnea are completely different. They may have similarities in causing a person to feel tired, sleepy, irritable, difficulty paying attention and remembering. However, insomnia allows a person to get some sleep, even if it is a few hours. With sleep apnea, I am not sleeping. As I would later find out, I was waking up every two minutes to an obstruction in my breathing. Think of it this way: I was only sleeping two minutes at a time. Insomnia and sleep apnea can be relatable, but strongly differ in this way. Faculty 1 had made the assumption she understood exactly what I was going through. She believed I could identify times I could best study and focus during the day or night. With a work schedule of forty hours or more a week, such a task was not realistic. If she could do it, I could do it was the message she kept pushing upon me. These interactions led me to never return to faculty 1 for help.

The other faculty members in the other two courses did not offer much help. Under the health conditions experienced, I could not think of what would help me. Looking back, no one person made recommendations for seeking academic support or the disability resource center. Not one person took the time to further understand my

condition to help identify new learning and studying strategies. However, they all stated they would be considerate and lenient in grading my assignments with the understanding that my abilities were hampered due to my health. One faculty member did provide a recommendation to visit the university hospital sleep center doctor. These faculty were also White, two females and a male over the ages of 50. As the semester progressed, I continued to put my best effort, even if that was just remembering one thing from the readings to create the illusion I was reading. I felt terrible participating in group activities and assignments as I did not have the energy to give it my best three times a week in the evening after leaving a hostile and toxic work environment.

Any hope to have my first sleep study and treatment plan before the middle of the semester faded away as I quickly learned the challenges of not being able to find an earlier date. By mid-October, I had my first sleep clinic appointment that led to a sleep study in early December. There was nothing I could do to change that. I pushed forward with every bit of energy I could muster.

**Complications between work and school.** There are some pieces of information that impacted my role as a graduate student by means of the new supervisor in job #1. Given that some of the employees in the office were also graduate students seeking to advance within their careers, the new supervisor decided that effective January 2017, employees would no longer be able to attend courses that interfered with the business hours of 8 a.m. to 5 p.m., Monday through Friday. She was not willing to allow employees to continue modifying their schedules to make up for any worktime missed as a result of attending a course. “I need you all here!” she proclaimed in a staff meeting. In addition, she expected us to answer our phones and emails while in class. We had to

always prioritize work because we were exempt employees, meaning we had to continue working until the job was done even if it required working beyond 40 hours a week or eight hours a day. In fact, when the Fair Labor Standards Act (FLSA) rules changed, she was not happy because it meant most of the staff had to only work 40 hours a week instead of the salary exemption that allowed her to overwork us until the work is complete. I was reprimanded for not answering my phone or email during class time. The pressure of being a full-time employee and full-time graduate student proved to be daunting and intimidating. I felt myself sinking into the abyss. I often wondered if I had died and entered purgatory. The balance I once held between graduate student and employee became non-existent. Without a position of power, there was nothing I could do. Even if I were to report the problems at work, what would occur? I lacked evidence to address the issues.

### **Spring 2017**

During the beginning of the year, I received my sleep therapy equipment and was hopeful my life would improve quickly within the first two weeks of treatment. I was severely wrong. It was only the beginning to a larger health problem as I described earlier in this chapter. Optimistic, I enrolled again in three courses believing my performance would improve to my previous caliber.

Two of the courses I enrolled in were taught by an Asian male in the age range of mid 40s to early 50s and the other course was taught by a White male over the age of 50 within the public administration department. The Asian male will be referred to as faculty 2. Faculty 2 was serving as my program advisor during this time. Within the first few weeks of the semester, I found myself struggling once again. Determined, I kept putting

my best effort for the next three weeks. Although there was some improvement to my sleep during this time, I was not fully operational. Difficulties with remembering, concentrating, thinking, and staying awake continued to persist. Contemplating between dropping out of my courses and quitting the program, I felt conflicted. There was something occurring that I could not determine. Interactions with my peers revealed a new perspective changing my own views nearly half-way through the semester.

Considering dropping out of the courses and program, I spoke with a few peers after a quantitative research methods class about my situation with sleep health. “I’m not understanding a single thing in each of faculty 2’s courses. My sleep apnea is severely affecting me.” To their surprise, one of the peers responded. “I don’t have sleep apnea, or any health conditions, and I am struggling to understand the course material.” The other two agreed with that statement. Another peer overheard our conversation and agreed. With five out of 10 students in the course sharing the same sentiment, we wondered about the others in the course. The five of us were also enrolled in the other course with the same faculty member. Turns out, we were not alone.

Those of us with close ties to the other five students in the quantitative research methods course reached out to them to get their input about the course content. In the group, one student had significant experience conducting quantitative methods and was annoyed with faculty 2 for often relying upon him to help him explain course content. This student had also attempted to substitute the course for an advanced course and had been denied. As a group, we were all displeased. We agreed to bring the issue of not understanding the course content to faculty 2.

In the next class session, we were met with push back from faculty 2. Collectively, we detailed the challenges in not being able to understand the “R” software and explanations of quantitative methods. At one point, faculty 2 made the comment that we needed to spend time outside of class learning how to use the “R” software. Annoyed at hearing that, I responded that he should take the time to understand “R” before teaching it to us. He would often spend time in class attempting to figure out how to execute functions and request help from the one student that fully understood it. As students, we would often sit quietly for five to 10 minutes patiently waiting for faculty 2 to explain the next step. After an hour discussion, faculty 2 expressed doing better to teach the course material. We all moved on with his lesson plan for the evening. This led to changes to the class.

A few of the students, including myself, were unsatisfied with faculty 2’s response to our concerns. One student withdrew from the course. Another student and I chose to take incompletes in the course. After being made aware by a peer, I withdrew from the other course because it was not fulfilling a program requirement as I had already taken a course in a previous semester that fulfilled the program requirement. This made me aware that faculty 2, my program advisor, was not being diligent in advising. I recognized sleep apnea and my Latino identities were not contributing to the difficulty of the course content. Initially, I believed my identity to impact my learning. It was not the case. This realization was empowering. The students sharing similar and identical thoughts lifted the burden I felt of not being a good student. Clearly, the instructor was the source of problems. Meanwhile in the third course, the situation was opposite.

With sleep apnea comes a lot of frequent yawning, which most people will interpret as a disrespectful sign of boredom. Because I did not know the instructor teaching human resource management for the public administration department, I had decided to share with him my health condition so that he would not feel offended or disrespected. The instructor was fully understanding and asked me to see him as I needed help and he would provide me support. He assured me his goal was to make the course content as easy as possible to learn. In addition, the instructor made an announcement to the entire class about understanding that late evening courses are challenging when we have full-time jobs, full-time student schedules, and other commitments. He encouraged everyone to feel comfortable to bring food or snacks, stand up and stretch, and do anything else to help us stay engaged and awake. He kept his word. I sought him out twice for help during the semester. Each time, he found ways to help me comprehend the course material. I found him to be very accommodating, successfully completing the course. Even partially sleep deprived I was able to learn plenty through this instructor. My learning did not feel hindered in any way. In fact, his impact provided me the tools that I would later need to address the problems in job #2 such as creating documentation to report problems. During class, he often expressed his frustration with HR departments overprotecting the employer and not the employee. In some way, this was foreshadowing the problems I would soon confront in job #2. This was what a learning environment should be like for students with disabilities. The instructor always asked questions about his teaching and how to improve it during class. He sought feedback. This instructor was a huge contrast to my interactions with faculty within my program of study.

Towards the end of the semester, I received a response to my annual review submission required of students to submit to their advisors in March. See appendix H for a copy of the annual review letter received. The response was very disheartening. Here is my reflection. As difficult as it was for me, I had shared my sleep health struggles with five faculty members. In summary, the letter describes that the “quality of your assignments have not been at a high level”. I also did “not put in enough effort”. According to them, I was “disengaged in some activities”. What the fuck? Did they not understand how severe my sleep health was to begin with? What did I have to do to help the faculty understand the severity of health conditions? An instructor in a public administrator program was fully understanding and supportive without requiring a full explanation of my health severity. By contrast, the faculty in my program of study were the complete opposite. How is the feedback in the annual review process aimed to help me improve? In fact, I had met with the advisor a week or two before receiving the letter to discuss what I would need to complete the course during the summer. I even chose to email him a letter from my sleep medical doctor early in the semester because I felt he did not believe my health condition. See Appendix I for the medical letter. Faculty 2 would often avoid having conversations with me about my health as I attempted to convey the challenges to my learning and being sleep deprived as I sought help after and before class. His response, “Just do your best”. Oh, I’m sorry. I did not realize I was not doing my best. Well, fuck you. How were my actions to seek help before or after class not indicative of requesting additional support to ensure my success? How are faculty within a program focused on organizational development, instructional design, and learning sciences not able to understand how health can impact the learning of a person?

How were they not able to identify learning approaches to help a sleep deprived individual? You can argue they are not equipped to know everything. I do not disagree. Many of the faculty behave and act as if they do know everything. Argue that.

It makes me furious to remember the spring 2017 semester. It was clear that faculty 2 was willing to blame students for not learning the course content. Students cannot be blamed for not learning when the instructor cannot teach in a way that is clear, concise, and easy to comprehend. There was no universal design for instruction and learning taking place in any course taught in the program. In two semesters, not one faculty member considered recommending the use of the disability resource center. I did my best to hide away the visibility of my sleep deprivation but there were days where that was not possible with excessive yawning. Visiting the faculty during their office hours was not sufficient to justify efforts to succeed academically. Under a sleep-deprived condition, there are limitations to functioning, which include metabolism, learning, and mental stability (Walker, 2017). Faculty disregarded the impacts of my health relating to learning.

### **Fall 2017**

Continuing to struggle with sleep health, I chose to reduce my course load from three to two courses as a way to reduce stress and find a new balance. In a new job requiring travel and evening work, it made sense to focus on adjusting. The recent problems with faculty convinced me to take a course in health disparities.

As before, I explained to the faculty member, which will be referred to as faculty 3, my health conditions with sleep apnea. With my explanation, I provided details about excessive yawning, difficulties with thinking, and my low energy level. She, a Turkish



woman in the age range of late 30s, appeared to fully understand. After all, she was teaching a health disparities course. In this semester, I underwent nasal surgery to improve my breathing as an effort to improve my sleep health.

I returned to the course two weeks after surgery and requested to join the course remotely through video to minimize absences from the course. My near-death experience during the recovery period of my surgery was enough to traumatize me for the next few months. Concentrating during the class time was difficult. The surgery was successful, but it required that my sleep settings be altered. The previous sleep therapy settings on my BPAP machine were no longer helpful. As a result, my sleep worsened.

With all this at bay, I kept putting my best effort forward. During a November class session, I was attempting to describe one of the assigned readings. I could not find the right words to describe what I had in mind. Determined, I kept seeking words as I spoke. Interrupted suddenly, faculty 3 exclaims, “You’re digressing! We need to move on and get back on track.” From this point forward, I noticed small microaggressions towards my difficulties in processing my thoughts aloud in every class session. I began reducing my participation in the course. It was already difficult functioning and having problems at work. Any thoughts of addressing the incidents were disregarded because faculty 3 served as a research project member on the research grants that I was assigned to in job #2 as a research coordinator. I did not want to create a problem that would negatively impact our work group dynamics. I felt too tired to want to address the microaggressions.

In late November, two peers in the course approached me after a class. They both acknowledged that they had noticed faculty 3 interrupt me many times in class and

offered their support if I chose to address it. They could tell I was struggling and shared their empathy towards my health condition. I was grateful for this encounter. Sometimes, I wondered if I misinterpreted and misread the actions of others. These two peers gave me their support. It made me trust myself and my perspective on faculty 3's responses to my health.

In the other course, a qualitative research methods course, the outcome with my learning was the opposite. The faculty member, a Latina in the age of late 40s, was extremely supportive. Initially, I believed it was because we both shared a Mexican heritage and experience living in Los Angeles. I never felt hindered in my learning and comfort in the course. If I remember correctly, a few of my peers often sought my assistance as I demonstrated a greater understanding of the course content. Their actions instilled confidence in my learning abilities during sleep deprived conditions. Once, I was frequently yawning in class after returning from surgery. I felt terrible and apologized. The faculty member asked me not to worry and acknowledged it was just late in the day. Her actions made a big difference in my learning. I was not afraid to be discriminated for my health and identity. Learning was peaceful. Addressing health was a problem that was understood by her. A year after this course, I read her obituary. She was battling cancer and lost the fight. Her kindness, understanding of health, encouragement, and support stemmed from her own personal experience with health problems. As I reflect, it makes me realize she was understanding of her own health and did her best to demonstrate it to students to make an accepting learning environment that did not exclude health.

## **Spring 2018**

Since my sleep apnea weakened my health and abilities, this semester was rather quiet. With one course and an internship, there were no problems that arose. If there were, I ignored them as I was dealing with problems at job #2. Once again, there was an annual review process and a packet to submit. I had chosen to change advisors due to faculty 2's indifference towards me. The new advisor never provided a response to my annual review submission. In fact, I was asked to submit it three times. It was apparent the advisor had forgotten three times that I did submit it on time as requested. I did not care to ask for a response. I had bigger problems to worry about with my health and problems at work.

## **Fall 2018**

During the early summer, I received a neurological assessment that identified ADHD and memory retrieval difficulties as my learning disabilities. With the support and motivation from a friend with dyslexia and ADHD, I decided to register as a student with disabilities with the campus's Accessibility Resource Center before the fall semester. As a component of my accommodations, I received a Livescribe Echo Smartpen. This smartpen records audio and utilizes paper with microdot codes to remember where within the paper the audio was recorded. In case I stopped writing, the pen would continue recording audio until I turned off the feature. Amazed by this computerized pen, I felt excited to begin another semester with an educational tool for my academic success.

With problems beginning to worsen at work and my health about to take a decline, I did not expect to find another faculty member at another department that would make concerning comments about my disabilities. Enrolled in a research methods course

under the communications department, the faculty member, an Asian person in the age range of late 30s, will be referred to as faculty 4. Faculty 4 received accommodation letters from my friend and I prior to the second week of the course. During the class discussion, a controversial topic was brought up. A student asked faculty 4 what they thought. Their response, “We can’t have that discussion right now! You never know who might be recording.” They looked at us during their response. Confused, the student made the statement, “But you always make controversial comments.” The class session continued as normal. My friend and I discussed this moment after class. It made us feel uncomfortable that faculty 4 made a comment about being recorded by us. A tool aimed to help us was perceived as a barrier to faculty 4’s ability to openly speak to a class of students. We thought this would be a one-time event.

During the semester, there were several instances in which faculty 4 made comments that singled out my learning disabilities. When faculty 4 was asked to share their perspectives on various subjects, they would remind students that they could be recorded. Because it was a class of about 10 students, it easily became noticeable that my friend and I were using smart pens. The pens are bulky with a tiny digital screen. We felt obligated to turn off the sound the pens would make when selecting audio recording options. Right before the course drop deadline, my friend decided to leave the course due to faculty 4’s comments. Choosing not to find another course due to the difficulties in finding faculty understanding of learning disabilities, I remained in the course. Six weeks before the end of the semester, I experienced a concussion in October.

It took a while to understand the limitations of having a concussion, but it was quickly apparent that faculty 4 had no interest in providing any flexibility. I was

reminded by faculty 4 about their no more than two absences class policy and expectation for participation. During a class, I was required to deliver a presentation on one of the course readings along with developing discussion questions. Critiques about my discussion questions being “weak” were made by a few students and faculty 4. One student made a comment about questions sounding like something you would read in a standardized test. I was ridiculed. It did not matter to anyone that I had shared prior to presenting that I was undergoing the effects of a concussion. “It doesn’t seem like you understood the reading,” said faculty 4 that evening. Despite this, I continued to push forward. Things were different in the other course I enrolled into.

The other course, a dissertation seminar, was under the sociocultural studies department with a male faculty member of Asian background in the age range of mid 30s. This is one of the most supportive faculty members I encountered. He was very considerate of my health. When my concussion occurred, he encouraged me to focus on improving my health and prioritize it. “Don’t worry about your assignments. I’ll grade you on the progress you have already made. Focus on your last assignment and do what you can.” His encouragement only made me work harder as I did not want to take advantage of his kindness. During one class, the bright lights in the classroom were affecting my vision and creating headaches. He noticed. He came over to me and asked me to put my head down and close my eyes for a while. He proceeded to tell me to go home once I felt able to drive safely. The students in this course were all very understanding and kind. In fact, everyone in that course was dealing with various life challenges, including health. A student who is deaf and hard of hearing provided me with the most encouragement after my concussion. His recommendation was for me to make

peace with my health. The kindness and support from everyone in this course reduced the pressure of working hard and motivated me to instead focus on working efficiently. I did not feel stressed. This faculty member even went as far as to ask me what he could further do to be supportive to me. He was candid in his request for feedback to improve as an instructor. I felt comfortable to not hide a concussion and sleep apnea as I did in the other course with faculty 4. In this reflection, there was a clear contrast between these two instructors. It was obvious some faculty did not care about student health while others did care and went out of their way to be supportive. It was positive experiences with some faculty that support the notion that the higher education learning environment is not inclusive where there are more faculty willing to ignore disability and health than those willing to be accommodating without any medical documentation.

### **Spring 2019**

By completing the last two courses in fall 2018, I had officially completed my course requirements for the doctoral program and now had the task of tackling the dissertation requirement. The problems with job #2 were coming to an end as I was now entering job #3. My sleep health, although not the greatest, was beginning to improve and my concussion woes slowly faded. I was now focused on determining the contents of my dissertation until I was reminded there was another annual review of doctoral students in the program.

With the last two years being a negative experience, I chose to not submit the required annual review application. In its place, I decided to write a letter describing my disappointment in the process. You can see Appendix J, Annual Review Submission, to

see the letter I submitted. I will summarize some of the points I made. In my letter, I stated:

“This again...ugh. That was my first thought upon seeing the email regarding the annual review process. I wasn’t the only individual to feel this way but I am also the only one willing to address the problem directly. I don’t fear any of you as my peers do. They are afraid of having any sort of conflict affect their career paths and degree attainment... In the first year, I received negative feedback regarding my performance without any follow up or plan for improvement. This was also the same year in which my health declined significantly, bringing me close to death. I shared my health problems and my struggles, placing myself in a very vulnerable position, to which I received no guidance or support... What are the learning outcomes from this process for the student, the faculty advisor, and the program? How does this process help a full-time professional with personal and professional development? How does it help a student who has already completed all course work and has limited interactions with the OILS faculty with the exception of their faculty advisor?... Simply saying that other doctoral programs also conduct an annual review, or “common practice,” is not sufficient or an appropriate response. It’s a cop-out response. It makes the response seem like it was not well-researched. Is there any research supporting the annual review process as an effective tool?... If you’re thinking about just sending me a letter acknowledging receipt of this and telling me you’re working on things, don’t bother replying. Words are meaningless unless they are supported with positive action. You are all researchers. Study the problem.”

Just reading the letter makes my anger and disappointment in the program resurface. I was discriminated too many times by faculty. No student should ever experience discrimination in a learning environment. None of my peers in the program were willing to speak up. I was alone in my cause to challenge the system in place that provide no meaningful learning. For once, I chose to take action against the injustice I experienced and represent those who were afraid to speak up. Remaining silent in the previous semesters only forged my resilience, courage, voice, and social justice mindset. I knew better than any graduate student that if any faculty member chose to retaliate towards me, I would use every resource available to me to expose the problems to the news media community and university administrators. Besides, great social justice leaders such as

Cesar Chávez, El-Hajj Malik El-Shabazz (Malcom X), Stephen Biko, Dolores Huerta, Elie Wiesel, Harvey Milk, and many more have done so much to challenge oppressive structures in society. If I aspire to be like them, I needed to confront the oppression and discrimination in a graduate program.

After submitting the letter in March, I would not receive a response until June. It took three months for the newly promoted director, faculty 2, to respond. You can see Appendix K for his response. To summarize his letter, he apologized for not following up after the first annual review. He thought it was best to leave me alone. He acknowledged that the faculty discussed and reviewed the doctoral annual review process.

“Unfortunately, we have not been able to finalize a better process, yet.” No decisions were made. “My hope is that the discussion will continue in Fall and a significant change will happen in 2020”. This was exactly the outcome I knew would occur. This response was a reminder of why no doctoral student wanted to speak out against the process.

In March 2020 and March 2021, there has been no doctoral annual review process. No email communication or announcement was made regarding this outcome. It appears the process was removed. No doctoral student in the program, other than the few friends I have in the program, will ever know that this occurred due to my lone protest.

### **Fall 2019**

As any student will know, there are always hurdles to jump in the process of graduating and meeting program requirements. In the process of writing a dissertation, a student has to first complete a comprehensive examination, or comp exam for short. The comp exam begins with a writing component focusing on the areas of study the dissertation will address through questions provided by your selected faculty committee.



Here is the twist. You only have a few days to answer the questions and submit them for review. After the committee reviews the writing submission, an oral exam takes place to test your verbal and recall knowledge. That is the basics of what a comp exam entails. I share this as the following experience involves this process.

During the week of September 19, I fell ill prior to the start of answering the comprehensive exam questions. Aware that my illness would impact performance, I sought medical care hoping to receive medication. The PCP determined the flu was responsible for illness. There were no medications, and I received a recommendation to rest, hydrate, and eat chicken soup. Concerned, I requested and received a medical note to share with the dissertation committee (see Appendix L). I quickly shared it with the committee. I was offered to reschedule. Because questions had already been provided to me, I felt doing so would create problems such as questioning my integrity, doubting my illness, or giving me an unfair advantage. With four days of writing, my health worsened. With fevers, chills, coughing, body aches, headaches, and exhaustion, I painfully read and wrote to answer the committee's questions.

On October 15, I met with my dissertation committee to discuss the written component of the comprehensive examination during the oral exam component. I had hope they would be understanding of my illness while writing. As usual, I was wrong. Before walking into the meeting, I was fully aware difficult questions would be asked. Expected were questions regarding the writing responses provided to them. Unexpected were the remarks and comments two of the three faculty members would make.

In the smartpen I received as part of my accommodations, there is an audio recording of the two-hour meeting with the committee. As much as I want to listen to the

audio file for accurate quotes, I cannot stomach revisiting the painful experience. Anger does not express the feeling in my core. Disbelief and baffling are not sufficient words. In that two-hour frame, all I saw were two oppressive individuals filled with privilege establishing their power. Their actions were uncalled and had no purpose but to offend, intimidate, and belittle my efforts. All three faculty members were previous instructors. One is a White male, possibly in the age range of fifty. He will be referred to as faculty 5. The other is faculty 4, which I mentioned in the previous semester. The only reason I requested faculty 4 to participate was due to my interest in using autoethnography as a research method and not being able to identify another faculty outside of the program as required by the graduate studies department. Two faculty previously approached rejected my request, one due to health and eventually passing away to cancer, and the other not being able to accept additional students. Despite my experience with faculty 4, I had chosen to provide them the benefit of the doubt.

The comprehensive examination oral exam process is identical to an interview where the committee provides question and you answer them, except the questions are based on your writing and their own thoughts. It includes follow up questions to your responses if the committee chooses. When the oral exam began, I started by establishing a foundation for myself to address my disabilities (e.g., sleep apnea). With my learning disabilities amplifying my forgetfulness and increasing with anxiety, I set out large index cards with keywords such as oppression, learning disabilities, anxiety, PTSD, mental health, toxic masculinity, discrimination, workplace hostility, bullying, and many more terms as a way to help my recall abilities. As I sat the index cards folded as table tents on the conference table, I explained briefly how these terms impact learning environments

and workplace culture. The remainder of the two hours demonstrated to me that faculty 4 and 5 did not hear a word I said.

During the oral exam, there were questions where it was difficult for me to understand what was being asked and concepts I could not succinctly describe. The frustration of not being able to answer questions because my anxiety mixed with learning disabilities and some sleep deprivation made it difficult to focus, concentrate, recall, and process. Not one person in the committee made any attempts to help me calm down and feel comfortable. Instead, only pressure was given.

Rather than being supportive, faculty 4 and 5 attacked my efforts. “It doesn’t seem like you studied and know the material.” “You only responded to some questions.” These were statements by faculty 5. “You might not be prepared to move forward,” said faculty 4. Each statement made me lose respect for them and interest in giving it my best effort. It was clear they wanted this process to feel challenging and difficult. Keep in mind, all three committee members were fully aware of my disabilities. In fact, all three of them expressed having an understanding of disabilities through personal experiences either to them or someone in their family. Their actions proved otherwise.

“Autoethnography is not about you,” said faculty 4. This was odd. In the course they taught, they made the students read an autoethnographic article they submitted for publication. It was very much about their Asian and gay identity and how society responds to it in the dating scene. If you are confused, go back and revisit the autoethnographic sections in Chapter 3. At one point, faculty 4 asked me to explain the context of my dissertation. I was confused as I had previously stated that it took place within higher education, specifically the classroom (learning environment) and workplace

(work environment). What more did this person want me to explain? After a minute or so of my silence, I asked, “What do you mean?” They simplified, “Where does it take place?” “I thought I already explained that before.” They responded, “Okay, I’m done being an asshole,” and laughed. At the end of answering questions and being insulted for two hours, I was notified that I passed with the condition I make revisions to my writing. The oral exam is complete. Right before walking away, faculty 5 says, “Now that it is all over, you can go home and cry like most students.” My immediate response without any thinking was, “I don’t cry to White people.” Someone please explain to me why this hurt his feelings? He walked away without replying, with his head sadly looking down, similar to Charlie Brown from the Peanuts comic strips and cartoon. Why in the fuck would any faculty member tell a student to go home and cry? The third faculty member sat quietly as faculty 4 and 5 made their attacks. This whole process has me convinced it is academic hazing. How is this experience meant to help me academically? This was an exercise of their power as faculty.

After several months, I chose to submit a complaint to the EEOC office. An audio recording, a verbal explanation, and one witness was provided to the EEOC office for evidence. The EEOC claimed there was insufficient evidence and too much time had passed since the incident occurred for them to take action (see Appendix M). It makes me wonder, how much evidence is needed to hold a person, two in this case, accountable for their actions of injustice? How are the statements faculty 4 and 5 made conducive to learning and improving my research? It is not conducive to learning. My identity was discriminated. Their behavior modeled injustice. It was not criticism. Their words were insults to my intelligence. They ignored my disabilities through their choice of words.

This is not a learning environment. This is an oppressive learning environment. It was opportunity for them to execute their power upon me to remind me of my place as a student, and not an equal. Their behavior is unacceptable and a demonstration of what really happens during a dissertation process.

### **Spring 2021**

Since then, I changed my committee and have designed this research study in a way that best suits me. As a person identifying with disability, I must seek accommodations for every aspect of the learning environment. I cannot trust someone thinking about how to best accommodate my unique learning and to remember it. To disclose disabilities to a faculty member does not grant me accommodations. This within itself is a problem of academia not incorporating universal design and learning into the curriculum, including the process of a dissertation (Skrtic, 1991; Dowrick et al., 2005; Marshak et al., 2010; Davis, 2011; Lewis & Sullivan, 2012; Potter, 2014). There are no alternate formats provided because there is an idea it might compromise the academic rigor (Murray et al., 2008; Skinner, 2007).

The last two components of a dissertation are a hearing and a defense. The dissertation hearing is a presentation of the first three chapters. The dissertation defense is a presentation of a completed dissertation to earn the title of Doctor of Philosophy, or Doctor of “any other field of study.” During my dissertation hearing, the committee opted to have me “pass with minor revisions.” Here’s my problem with that phrase. I was told there were three options: pass as is, pass with revisions, and fail. The term revision signifies there are changes to make to my writing. Merriam-Webster (n.d.b) dictionary defines revise as “a printing proof that incorporates changes marked in a previous proof”.

It was explained to me that they, as a committee, had made suggestions for me to consider making, if I chose. There are very minor changes, such as punctuation, sentence structure, grammar, and points to elaborate. All other statements made on my writing are suggestions. By Merriam-Webster's definition, suggest means "to mention or imply as a possibility" (n.d.c). It does not alter my writing in any way. This makes me ask one question, in order to "pass as is", did I require perfect writing without any sorts of mistakes, revisions, and suggestions from them? There were no criteria or rubric defining what I would need to meet "pass as is." Perfection should not be a benchmark for demonstrating learning. This implies it was a matter of opinion and belief. It is as Skrtic (1991) states, "Things are done in certain ways simply because they have always been done that way" (p. 176). Just because something is not broken does not mean it cannot be improved upon. Consider how a person with disabilities may experience this process. With ADHD and memory retrieval difficulties, I am aware there will be things I forget. There will be things I thought about and forgot to address. I will begin an idea and not complete it as I jump to the next idea. I sometimes get stuck thinking about how to best describe a thought, preventing my progression or choosing to skip ahead, often forgetting to return. Sometimes, I go on tangents during an explanation in hopes it will help me remember what I have forgotten. This all happens in speech and in writing. There are several ways to improve the dissertation process to make it inclusive for all people. The stigmas and stereotypes towards disability creates a fear of discrimination for not being a high achiever (Evans et al., 2017; Loisel & Côté, 2013; Goffman, 1963; Olkin, 2012; Shannon et al., 2019). The fear of discrimination is a barrier to learning.

There is something wrong with the concept of dissertation defense. The dissertation is a component that higher education has not significantly changed since the 1960s, representing the prevention of change (Boyd & Crowson, 1981; Weick, 1985; Skrtic, 1991). “Organization, with all of its characteristic paraphernalia – committees, departments, hierarchies, codes, standards – often manages to choke the last bit of life out of an enterprise, frustrate almost ever tendency toward originality and imagination, and militate against decision and responsibility” (Rudolph, 1990, p. 440). There are many ways to improve the dissertation defense process to make it inclusive for all learners (Davis, 2011). If I was continuing to experience anxiety or panic, the process does not change for me. ADHD and memory retrieval cannot be accommodated effectively when the expectation of the committee is to provide rapid responses. Accommodations may be helpful, but they do not fully address my unique learning needs (Black, Weinberg, & Brodwin, 2015). “Defense” implies there is an attack, or offense, causing me to defend. This represents a war, a fight, a debate, a disagreement, or a battle. This concept should not exist within a learning environment. With a committee of three to four faculty members, the lone student is at a disadvantage by being outnumbered. If the intention of this process is to demonstrate mastery of research methods and research literature, a more appropriate and positive term should be selected that moves away from the negativity of the term defense. A dissertation presentation, dissertation bequest, doctoral inauguration, or doctoral induction are all more positive and meaningful concepts. Learning should not be rigorous, negative, or oppressive. Learning should inspire, motivate, encourage, include, and promote innovation (Rudolph, 1990).

## **Changing Archaic Education**

This is difficult to remember.

I want to keep memories buried,  
out of existence.

To change the way things are  
is to share the experiences of injustice.

The aim to bring attention  
to problems  
for the goal of improving the process  
within academic programs everywhere  
is met with resistance,  
archaic procedures,  
and antiquated professors.

This oppressive manifestation  
of learning, teaching, and education  
can change.

Problems cannot be kept in darkness.

Our might for change  
will be the light to catharsis.

Without students,  
there are no teachers.

There is no learning environment.

Cruelty has no place



in what should be enlightenment.

Silence is painful.

Voices and actions are stronger.

To change oppressive structures  
requires confrontation.

For positive change,

we must unlearn,

innovate,

and do the unthinkable.

Speak your truth,

be authentic,

take a meaningful pause.

Words for the wise.

### **Reflexivity: Concerns of the Organizational Culture of Learning & Work**

#### **Environments**

Looking back at my educational and employment journey, how was it possible for a sleep deprived, learning disabled, chockful with negative mental health, first-generation Latino from migrant parents able to successfully complete courses and withstand a toxic higher education environment while on the verge of death at different points in time? It does not make any sense. Academic failure and resignation of employment should have occurred. Why did faculty members or employers not provide support? Stepping out of the program and resigning from work to focus on my wellbeing was the most logical

option. Yet, it never once occurred to me or any individual, including peers. What got me through the most challenging health problems in higher education?

In a sleep deprived condition, the health changes stemming from it altered my entire being. I refused to let it succeed in ruining my life. Each and every day, life was dim and dark. With heavy burden of failing health, one step forward, even if small, was the goal to reach. The lack of support and opposition convinced me of the expectations for failure of my brown face. Reminders of the stigmas, oppression, stereotypes, discrimination, and lack of equity and inclusion for minorities like myself empowered me to demonstrate my resilience, my uncanny ability to succeed despite the obstacles of academia and my own health conditions. I would be lying if I said I did this alone.

A few peers in the graduate program, some colleagues, one student employee, one Researcher, one medical assistant, my traveling family, and some friends provided motivation, encouragement, momentum, incitation, support, and empowerment. On the verge of quitting and resigning several times as a graduate student and employee, they refused to abandon and lose hope on my capabilities. They listened. I cried. They acknowledged the visible exhaustion in my face and posture. They reminded me of the toxic masculinity that supports the notion that men should be strong and emotionless. They insisted I challenge toxic masculinity. They motivated me to challenge the oppression and stigma bestowed upon people with disabilities. They incited the need for positive Latino role models in society, especially those confronting disabilities and health challenges. As one of my traveling family members said to me, “This is the plight of champions.” Another traveling family member said, “Take a meaningful pause.” In their wisdom, they reminded me of the importance to take time to enjoy doing absolutely

nothing to allow my entire being to rest and heal. These people refused to give up on me. I could not give up on myself. Without these wonderful humans in my life, the outcome of my creative autoethnographic *testimonio* would differ. I am sure I would have quit many years ago.

If the work environment and learning environment would have done more to help someone with my conditions, I would not have anything to write about. Because of my failure to comply with the organizational culture of learning and work, I am labeled as the problem. The problems of higher education's organizational culture demonstrate a resistance to change. It is not accepting and accommodating of people with disabilities. Why do students need to seek accommodations? All teachers should have learning plans that are inclusive of all learners. Learning does not occur one way. Perhaps it is teachers, professors, instructors, and faculty members that experience a teaching disability. Why is it students are always viewed as the problem when they do not obey and respond well to a person's teaching?

There is an animated series, *Rick and Morty* by Roiland and Harmon (2013), that I enjoy watching. In the first season pilot, Jerry questions Rick for having Morty skip school to go out on "high concept sci-fi rigmarole" adventures. Rick believes that Morty will learn more by being out in the universe. Rick, the grandfather to Morty, explains to his father-in-law, Jerry, his views on education:

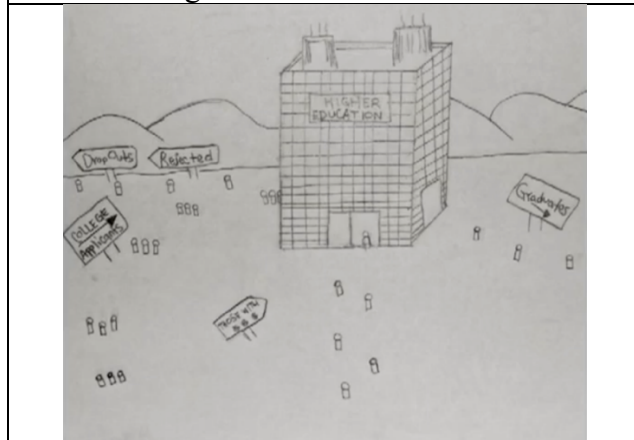
I'll tell you how I feel about school, Jerry. It's a waste of time. A bunch of people, running around bumping into each other. Guy up front says two plus two, people in the back say four. Then the bell rings. They give you a carton of milk and a piece of paper that says you can take a dump or something. It's not a place for smart people, Jerry. I know that's not a popular opinion. It's my two cents on the issue. (3:33)

First, this is hilarious to me. Second, there is much truth in this statement. Rick is specifically referring to K-12 education, but I believe it applies to higher education's organizational culture as well. In the learning environment and workplace, I was required to obey and listen to those with hierarchical positions and power. This is represented in Rick's statement about the guy up front, the bell ringing, and the piece of paper. If I drifted from following the curriculum or work tasks, I am at fault. My experiences with faculty 1 through 5, the new supervisor, the administrator, and senior researcher demonstrate the organizational culture's influence of overpowering those within positions of leadership, management, and tenure. Nothing I said to this group of people could ever change their minds, even when it was regarding my own wellbeing. To do anything, I needed their approval. If I did not behave like other students, I was not dedicating myself to learning, or not paying attention. I learned about disabilities, discrimination, injustice, organizational culture, workplace problems (e.g., bullying, intimidation, oppression), human resources, ineffective teaching and learning, research and grant writing, effective workplace leadership and management, and so many other things from personal experience, not the teachings of faculty members in a classroom setting. Even this research study, or dissertation, has demonstrated my own capabilities in learning by reading books and research articles with application of personal experiences without the need of being inside a classroom. Faculty members and employers did teach me ineffective teaching practices, how to haze a student/employee, how not to support a student/employee, how to discriminate a student/employee, how to offend a student/employee, how to misjudge a student/employee, how to ignore the disabilities of a student/employee, how to disregard the health of a student/employee, and how to

oppress a student/employee. From this perspective, higher education is a waste of time and is not a place for smart people. From another perspective, there are some good staff and faculty within universities and colleges willing to take the time to be supportive to a student, including health. There is not many of there. There is not enough good staff and faculty available in positions of leadership and management. We need champions to change a system that refuses to change. The top of the organization needs a culture change by placing staff and faculty willing and capable to make higher education a place for learning (Denison, 1990; Kotter & Heskett, 2001; Senge, 2006). We need a better higher education system.

Image 6.

Still from Higher Education in 2011



As I reflect, I am reminded of a short animation I developed in 2011. Ten years ago, I enrolled in an animation course and this was the product for an assignment. There is a still below (Image 6). There are many college applicants to higher education, many are rejected or drop out, some graduate, and anyone with wealth, not just students, is able to walk in and out through the front door. The higher education building is intentionally meant to look like a business-factory. It is a shame this is still what higher education

appears to be 10 years later after my initial reflection of my experiences. After being a student and or employee at four different universities, the conditions for employees and students are the same. You can view it on YouTube (<https://www.youtube.com/watch?v=OnSVoggHAX0>). People get territorial and defensive of the systems they work for because, “This is the way it has been done before.” With my disabilities, I realize higher education is not welcoming of people’s health. The focus is always on getting the job at hand complete and the classroom assignments complete as required. Difference, the diversity of learning, is not welcomed. If faculty and staff would have done more to support me throughout my health difficulties, this would all be a different story. There would be no story to share. This short, animated clip offended faculty, graduate students, and undergraduate students. It led to good discussions with those I shared it with, including the faculty member who taught me how to animate and that felt attacked by this clip. Higher education, based on my experiences, benefits those who buy into the system as long as they do not question how things are done within it. You do as you are told, just like any business organization. As a coworker jokingly said many times about the organizational culture of higher education, “do as I say, not as I do.”

### **Reclaiming Disability and Mental Health as a Professional and Human**

The last five years of my life have been difficult and challenging as I navigated understanding my disabilities, mental health, and general health as a first-generation Mexican American male navigating the treacherous organizational culture of higher education. Holding the oppressors, discriminators, offenders, bullies, and hostile individuals accountable is not easy when you do not have a position of authority as a

leader or manager. Recognizing and accepting this thought is not easy. The best next thing to do was educate those around me and those willing to hear my experiences as a way to improve our communities.

In late 2018, there was a conversation with an individual that led to a wonderful opportunity to educate others on mental health and disability. This opportunity was not sought out, it happened by chance. The interaction with this individual became larger discussions warranting a platform. This person believed my truth without once questioning it. What follows is performance autoethnography.

The performative autoethnography takes place in a webinar series named *Consejos y Consuelos* (Advice and Consolation) provided by the National Association for Student Personal Administrator's (NASPA) Latinx/a/o Knowledge Community (LKC). This performative autoethnography required that I be vulnerable, reflexive, intersectional, connect the "we" and "I," and address injustices, ethics, and healing through a performance of my experiences and embodiment of emotions (Alcoff, 1991; Tierney, 1998; Madison, 1999; Pezzullo, 2003; Calafell, 2013; McIntosh & Hobson, 2013). It was not an ordinary or traditional webinar. This was personal. I was asked to present on the topic of mental health in the Latinx/a/o community using my personal experiences to best connect and engage with my audience. My life was on display and used a conveyor to connect myself to our community and society in an effort to change the views on mental health. Mental health is not an easy topic to discuss, especially when it involves your own past experiences addressing mental health. It required looking at myself as person, professional, student, and member of the LKC. Allowing myself to be vulnerable would be the most difficult component, but I hoped it would allow others to reflect and consider

their own intersectionality. The goal was to normalize negative mental health and focus on advocacy and support for individuals experiencing difficult mental health. This performative autoethnography allowed me to reflect on what did help me become my current self. This required looking at what helped dismantle the trauma and oppression bestowed upon me. This is apparent in the recommendations I provide during the performance. This took place on April 5, 2019 (see Image 7 below). This opportunity flourished after speaking with a colleague about the challenges of being a male and the toxic masculinity in regard to mental health. He served as the leadership committee chair and believed I was equipped to make a difference in the webinar series. This opportunity was well received and was the final motivation I needed to write my research study on disabilities. This is transcribed from the video recording of the webinar.

### **We Don't Talk About that Here: Mental Health Issues in the Latinx Community**

Nestor (Host): Welcome everybody to *Consejos y Consuelos numero once*. That's number eleven to my non-Spanish speaking friends. We are excited to bring you this bi-weekly installment of our signature leadership development program that has continued to just rocket in terms of growing an audience and being really good for the community. As always, we are going to ask everybody to remain muted until our presenter has finished speaking. Then we are going to go ahead and open it up to the community for questions. The chat will be live the entire time so if you have questions, links, just want to give props to the statement that was made, you want to create a hashtag, feel free to do all that stuff. That's really cool and we encourage it. This is a safe space. So, there's no judgment happening here. This is really about us getting information from members of our community, and having them wow us with their brilliance and lived professional



experiences, in some cases some personal anecdotes that help make our journey through this field more navigable.

It is my pleasure at this time to introduce to you our speaker for today. *Señor* Leonel. I'm going to go ahead and read his bio to you.

Leonel Díaz, Jr., pronounced Lee-Oh-Nel, is a project coordinator at The University of New Mexico. He's earned a master's in education in Postsecondary Administration and Student Affairs from the University of Southern California and a Bachelor of Arts in Digital Arts from the University of California, Santa Cruz. He is currently pursuing a Ph.D. in Organization, Information, and Learning Sciences. *Wepa* [go for it, yay, or a cheer]/ His academic and professional background is interdisciplinary: fine arts, digital arts, social media, academic advisement, student leadership, academic support, marketing, organizational development, and social justice. That's a résumé! Leonel enjoys learning several disciplines to find ways to merge ideas, bridge gaps, problem solve, and develop new perspectives. He began his career as a photographer and digital media artist, only to follow his interest in helping mentor and support college students. On his spare time, Leonel enjoys exploring the outdoors to photograph and paint. Leonel is from COMPTON, CALIFORNIA, and uses his success to change the negative stereotypes and perceptions of his hometown. Ladies and gentlemen, it is my great honor to present to you a good friend and *colega* [colleague], somebody I am incredibly proud of, *Don* Leonel Díaz Jr!

Self: Thank you! Thank you for the introduction. That bio sounded more exciting from you than it did coming from me. Thank you! To begin this, I'll start with saying this

is my story, my truth, and my perspective on an experience that I've had. I will provide a trigger warning. I might bring stuff up that may trigger some of you.

I'll do my best to avoid anything that might trigger someone. In my own experience, I have found triggers to be a good thing. My initial reaction isn't always positive, but I have used it as an opportunity to ask myself why it triggers me. I do my best towards making peace with the memory through accepting it as a moment in my past that I cannot change. I can change how I think about it in the present. I'll elaborate upon this through my story. I'll start with the beginning of my story. In 2014, had you asked me about mental health, my answer would have been different than the one I am providing today.

My thoughts about mental health were that it was all based on our thinking and a creation of own imagination. I saw it as people not having a strong mindset. As my mom says, "*Solo hablas porque tienes boca*," or "You only speak because you have a mouth." What was waiting for me in the near future would test this line of thinking.

In summer 2014, I moved to New Mexico for a new job. The change of environment eventually brought forward a series of conditions I was unaware I had. The change in altitude and humidity set off a chain of events. California is very humid. New Mexico is very dry. In California, I was at sea level. Up here, I'm about a mile high. The altitude change and humidity were enough to start something called sleep apnea. Sleep apnea is trouble with your breathing during your sleep. For me, it was more of an obstruction in my breathing rather than my brain not sending the correct breathing patterns. So, when I moved here in 2014, it was summer. When you move, you just think it's the transition much like going to college for the first time. That's how I viewed it as

at first. I thought it was normal to experience difficulties in sleeping, anxiety, time zone change, being in a new job environment, the culture here. I did not think much of it.

In mid 2015, I started feeling excessively tired, beat, depressed, anxious, overwhelmed, began gaining weight (even with exercising regularly and healthy eating habits), hypertension destabilized, angrier, moody, and so much more. I almost went full vegan, and I was gaining weight. It was a signal something was wrong with me. I started going to doctor checkups, figuring out what's wrong with me. Every doctor would tell me to lose weight, which I was like, I'm already doing that. That's not solving my problem. I kept pushing forward. Was it stress from work and school? Was I home sick? I brushed it off as it's not a big deal.

Come 2016, it started to get worse. My functionality of every day, it was just hard. I couldn't function the same way. I'd tell myself I wasn't doing my best and I wasn't trying. I'm not working hard enough. I need to change my habits. I need to give up the tortillas and bread. I need to stop eating carne adovada. Which if you haven't been here, it is amazing and delicious. It took me a while before figuring out my condition wasn't doing with my own being. Something was triggered by the change in climate. It was the sleep apnea. The lack of humidity would dry my throat more, thus shutting my throat. It would cause disruptions in my sleep. I was waking up every two minutes. I was not sleeping at all. I got diagnosed sometime mid 2016 around September and it wasn't until October that I had a sleep study to figure out what was happening in my sleep. It was obstructions. Every two minutes I was waking up. There was no sleep happening. At this point, I have already been sleep deprived for two years without treatment.

Eventually, at the beginning of 2017, I get a BPAP. It's a breathing machine that I have to sleep with. That's the only way I can get sleep. Even at that point, it was not enough. I was still tired. I was feeling a little better but not enough. The weight gain stopped because I was getting some sleep. Some restoration was happening, but not enough. Turns out, the anatomy in my nose called turbinates, three little fins inside our nose, were too large.

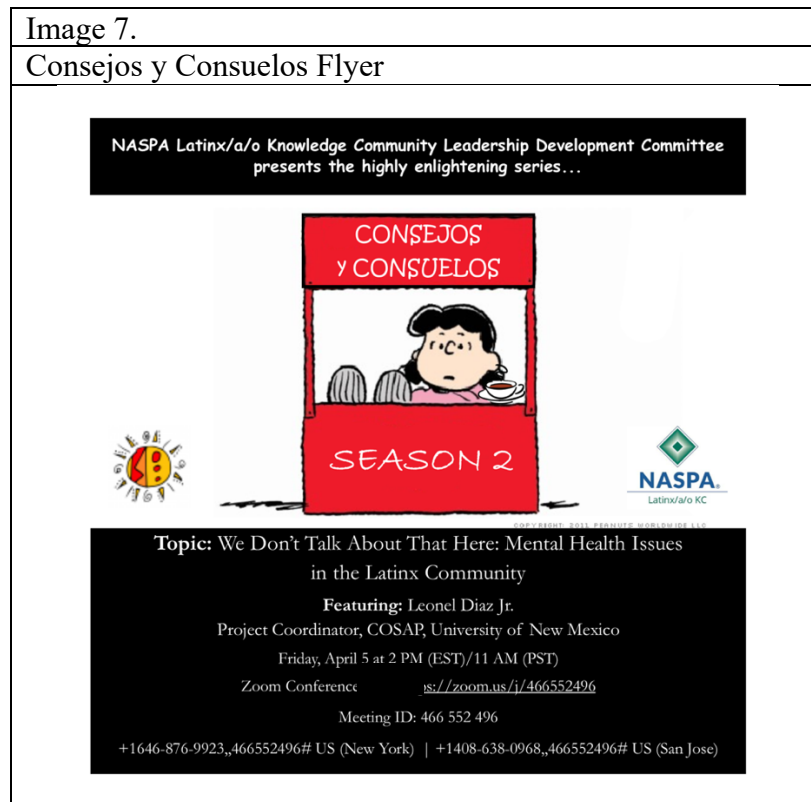
In 2017, I had nasal surgery. Nothing I can do to change my anatomy that I was born with. The sleep therapy wasn't very effective and led to this event. I just wasn't getting enough oxygen since I'm a nose breather and not a mouth breather.

In early 2018, I had a second sleep study due to the nasal surgery. The change in nose anatomy changed my breathing and sleeping. I'm starting to feel better, but still heavily tired.

In mid 2018, I found out I have two learning disabilities: ADHD (which I already was aware and knew how to take care of) and memory retrieval issues. It made some sense to me. With sleep apnea, I felt my memory wasn't functioning and a second learning disability was contributing to it. That was new to me. The ADHD was interfering with my sleep. I was placed temporarily on insomnia/ADHD medication to help shut my brain off during the night. I also learned I had allergies to dust mites, which are everywhere! If you have a heating or AC unit, it's in those machines. There's no way to get rid of it. So now I know allergies were contributing to making me feel sick for the several years, which was not a part of my sleep issues. It was contributing to my mental health because I was feeling sick. I was feeling tired. I wasn't sleeping. My body wasn't metabolizing. I had a series of issues all contributing to the same problem of mental

health. With ADHD medication, allergy medication, and my sleep being taken care of, I am beginning to feel great. After a month, I had two to three amazing weeks of sleep. I was feeling great where I felt better than ever. This would end quickly.

In late 2018, I had a mild concussion. I'm out again. I went back to square one. At this point in time, I am still recovering from that concussion. In my fast-paced thinking and moving, I became careless and hit my head against a pole at the park near my home. It subdued the ADHD, which recently has decided to return within the last three weeks. It also damaged my right eye's vision. I wasn't aware of this until two months ago.



I tell you all that because one thing I had in common during that whole time is that I had a VIP [very important person] front row seat to experience mental health from a work setting, student setting, and personal setting.

At work, my colleagues didn't believe I had mental health problems. They would see me and say, "You look fine! Nothing is wrong with you." I went to my professors to express that I am struggling, I'm not sleeping, I don't know what to do, I'm trying to stay on top of homework and projects, I'm having a hard time keeping up. Their response? "Just do your best." Come an annual review later, I got grilled for not being a great student during an annual review process. I was told I wasn't attentive in class, my writing wasn't at a graduate level, and class participation was minimal. They tore me apart as a graduate student, despite explaining my mental health. In class, I looked functional. I looked fine. It looked like I just didn't want to contribute or participate. At work, rather than saying let's work on a plan to loosen up your workload, I got more work added to it. I had three student employees. I lost two of them. Why? Because I didn't need that many student employees with me despite my mental health and sleep apnea.

In my personal life, I had friends asking why I was disengaged or why I didn't want to be their friend anymore. They believed it was intentional. This was despite explaining that I wasn't sleeping, the depression was getting difficult to deal with, the anxiety was difficult to deal with. Gaining weight, despite eating healthy and exercising, was self-defeating. It was hard because I was pushing myself through all that. I was doing my best. My best wasn't enough. Reflecting back, it really tore me apart. I was trying to compensate for myself and lack of abilities to be a functional human. My environment wasn't supporting me. It wasn't helping. It was making it worse. That was really difficult.

In this entire process, no one believed me. Just because on the outside I looked fine, on the inside I wasn't. There wasn't a part of me that was functional. I don't know how many times a week I would think about wanting to end my life. I didn't feel I was

contributing to society. I wasn't helpful to anyone. I felt like I was a waste of space. It was really hard to deal with. Wanting to share what I was experiencing to people was difficult because prior experiences dictated if I shared just a little bit, they would say I was just fine. "You're just making it up in your head." This goes back to what I started with.

When I first thought about mental health before all of this, I thought it was all in the mind. I got a taste of what that was like. As my mom says, you shouldn't say things because they might come back to bite you in the ass, came around. At that point, I realized I had to make some changes. I needed to think about what was going to help me move forward. There is nothing I could have done differently during that time. As much as I reflect and tell myself, "I wish I would have done A, B, or C." Realistically, there was no way I could have done A, B, or C. I was at bare minimum. I was trying to survive. I was just trying to get through the day. I was trying to do my job. I was trying to keep up with being a student, you know. I didn't want to leave New Mexico and return to my family because to me, that was running away. There were a lot of things I had to deal with: my own stigmas, people's stigmas of myself and their own perceptions of mental health. I had to deal with my own goals in life. I was trying to make sure I succeeded yet trying to meet those goals, trying to survive and function, it was a lot. Realistically, at this point in time, doing all those things, it does not feel like a lot right now. At that point in time, it was more than I could handle.

All that turned me into a mental health advocate. When we think about mental health, most of us quickly think of negative things like suicide, depression, and anxiety. When you look at the media, it's the same thing. We only see the negative side of mental

health. We only hear about it when someone complete suicide or has a mental breakdown. We hear about this with Kanye [West] or students at universities committing suicide for whatever reason. We know it is out there. That is all we hear is the negative side of mental health.

In my process, I realized, as much as I am on the negative side, there was a part of me that was pushing for the positive side. I wanted to be better. It's a missing piece in the conversation: positive mental health. Because mental health is us, our mind, our brain, that also means there is a positive side to it. I bring this because to continue moving forward, we have to move back and forth between the two. Just reflecting on my last five years, sometimes I don't know how I managed to function to get through all that. I do know what did help stay afloat and continue moving forward.

During that time, I have met with four mental health professionals. I met with a neuropsychologist that assessed my learning disabilities. I met with a psychologist that is a sleep doctor. She has an MD/PhD. Just getting feedback from her was helpful. I met with the counseling services here on campus. Recently, I started meeting with a private practice counselor outside of work because I used up my free counseling sessions at work. The one thing all four of them have had in common that has been said to me is, "How have you made it this far given your situation? Most people in your situation wouldn't have been able to make it this far. What allowed you to get there?" When I think about it, there were a lot of things I had to go through. One was accepting the fact that I had mental health problems: depression, anxiety, panic, metabolism stopped working. Being happy was difficult. Feeling love was difficult. Feeling like I belonged somewhere was difficult. Even just the idea of fitting in, was difficult. My self-esteem



took a hit. Even at this point in time I am still pushing my self-esteem. I'm telling myself, reminding myself, I am really good at a lot of things. I have to re-enable myself to feel that way again. Friendships, and having people understand my situation, I have become a little more aggressive in talking about mental health because I realize people are quick to dismiss it. They are quick to ignore it. I just transitioned from a hostile work environment and my current supervisor said, "You know you have PTSD, right? You shake a little bit during work. You are still lacking confidence. You know, you are in a safe space now. You are in a better situation." He keeps doing health checks on me on a regular basis, even though his office is right across from mine. He still calls me from his other office on campus and checks up on me. That's another piece of this conversation is work environment. I transitioned to two jobs during that time. Neither job was supportive to me. Neither supervisor nor boss truly acknowledged my mental health. They just dismissed it. One of them at one point said, "You didn't have sleep apnea when you started working here." To which I looked back and said, "I have always had sleep apnea and I said that in the first week of this job." Which to me, made me realize again, the moment you start looking well, people assume you are fine, and everything is well taken care of. That's the thing about mental health. It's not a one-day recovery plan. It's not a couple hours session with counseling. It's not going on a good time with your friends. It's not going to fix everything. It has taken me so much time to repair different aspects of myself. Sometimes they are all tangled up in different areas of my memories. I still get triggered, consistently. Sometimes I talk to people and then I remember something. It's hard to look back and realize there's moments, memories I don't have. I wasn't there. I may have been there physically but mentally, my brain was not close. I don't know how

many times I have had a friend tell me, “You were there!” You said this. You said that. I look at them confused. I don’t remember any of that. Are you sure about me? “Yes, you did. You did such a great job that day.” It made me realize, sometimes in our mental health, we are quick to push ourselves to be better, to move forward. Sometimes, that is damaging. I took so much damage just pushing myself, trying to become my best. Realizing that what I thought was good for me, was also bad for me. Realistically, I don’t know what would have been better. That’s not important. As Latinos, as the Latinx community, we get caught up on, “I wish I could have done this. I wish I could have done that. I know I should have spoken up and said this.” When I look back at my healing, there is no changing the past. I can only change my present. My present will change my future. That’s the line of thinking I have now.

As much as I look back and wish things would have been better, or taken different approaches, it’s unrealistic. That’s very hard for me to accept sometimes because there are so many different things, I wish I could have done to advocate better for myself and my mental health on campus. I wish I would have addressed it sooner, gone to the office of civil rights to address the discrimination I was facing in class, at work, and in my surroundings around campus. I don’t know how many times I was discriminated. As a social justice advocate, it makes me angry this was the experience I had. I advise the student veterans here at campus. They have PTSD, anxiety attacks, and panic attacks. They have come complaining to me about their professors in class saying they are disrupting class. They are experiencing PTSD and trying to help themselves, each other at times. Yet, it is seen as disruptive. It is not something specific towards one group or another. It’s just the whole concept of mental health. When we think about it, everyone is

just judging you based on how you look on the outside. It's not about what is inside.

None of us do a good job at portraying what's in the inside. We try to have a happy space to do our jobs. At the same time, for me, it was damaging to bottle so much of that in my life.

This whole experience led me to my dissertation topic: mental health. How that affects us in a work culture, work environment, and how that affects our learning. My learning, there's things I don't remember. I remember textbooks; I don't understand them. I remember readings; I don't understand them. I remember pushing myself so hard to get through class. Getting a grade, I realize, wow! I worked so hard, and it doesn't reflect my efforts. It was based on the scale of everyone's performance. We can really quickly defeat ourselves in the process. In my reflection of what helped me move forward, what helped me stay afloat, there's a couple things people did for me and what I did for myself.

- 1.) I had a very small group of friends that would allow me to vent, would look after me, would encourage me, would tell me it was okay for me to not to be at my best, reminded me that I needed rest, would give me the hugs I needed to feel cared for, and remind me to be patient with myself. Those hugs made me feel love because I didn't feel that for myself. There were friends who asked me to call them if I needed anything. That was one of the most important pieces. Anna, who is here in our session, was my student employee at that time. I don't know how many times she put her neck out for me. "It's my fault. I didn't finish the task he assigned me." Even though I never assigned that to her. She would take the hit for

me from my supervisor. She was just a student. I felt so wrong for that. At the same time, I couldn't function to really do it on my own. Anna was really the first of friends that would stick out for me, to tell me it was okay. "How are you feeling today? Can I get you anything? Can I get you coffee? Can I get you some lunch?" I didn't want to eat sometimes because I was gaining weight. Again, that problem was repetitive no matter what angle I was looking at it. I was always defeating myself from one angle to the next because I wasn't happy. Some friends would tell me, "Let's grab a beer. That's all you need. Let's relax, just talk about life." That was really helpful. It was a brief healing moment. I needed something to get me out of my environment that would help me forget about my health issues. Having a tribe to be there for me, to be my voice, to defend me, that was instrumental to my health success. That would be the first thing to point. Surround yourself with people that will help you, will take the time to listen and understand. Eventually, what I learned from this group of friends is that all of them have had mental health issues or had experienced mental health issues whether it was anxiety, depression, or PTSD. They all had experience. It allowed them to be really great friends because they understood firsthand what that was like. Find yourself a tribe that will be there for you when you need them.

- 2.) The second thing I would say is do things that bring you joy. I had such a hard time finding joy that eventually I started defaulting to things I know I really liked. I like playing video games. If I spent four hours playing video games and that's what made me happy, I would be okay with that. I would try not to tell myself I just wasted time. Realistically, there was nothing else I could do. If I would try to

read a book, it was like never reading the book. I would be five pages in and not really remember one thing I read. I didn't understand a single thing. I started writing short stories of my spontaneous adventures with a friend. I like creative writing. It was an outlet. I used it. I'm an artist. I started painting for the first time in several years. I started printing out my photography rather than taking photography. It's all over my home now. I don't have any in my office because of the cement walls. I have no way to nail them. I'd have them in here too. I want to bring them in. Just doing things that release the creative side of myself helped me in my own process. It was something I needed to do for myself. Find things that you like to do for yourself. If it is getting a manicure, pedicure, massage, do it! Don't hold yourself back. For me, I kept holding myself back. The more I did it, the more I felt better. Maybe I wasn't doing my job. Maybe I wasn't being a good student. That wasn't as important as my health.

- 3.) The third thing I would point out is that you have to accept your limits each day. Your best today is different from your best yesterday and tomorrow. Your best changes. That's the thing. We are all consistently changing. I had to learn how to be patient. How to be loving to myself. How to be okay that, you know, what I got done today, even if it was just getting out of bed and making it to work. That was better than staying in bed and not making it to work. If I managed to cook, even it was *sopa huevona*, or top ramen, cup of noodles or whatever you call it. If that's what I made that day, I needed to be glad I did that because most days I couldn't do anything. I didn't want to cook or eat. Taking pride in those little

accomplishments, that makes such a difference for me. Through all that I had to learn to be patient and just love myself.

- 4.) The fourth thing I would say is, there is mental health first aid training available. I took it several years ago. Never did I intend to use it on myself. I used it on students beforehand. Making sure I am doing active listening and being able to refer them to other people because I was just the first stop to a series of events for them. It was hard to do it to myself. Do take training out there. I took mine from [mentalhealthfirstaid.org](https://www.mentalhealthfirstaid.org). The cost is about \$50. It's not that expensive. That training came in to keep me afloat because every day I would remind myself there was no need to commit suicide. There's no need for me to think I'm useless. This is just a small phase and I'm going to get out of it. It was really having that training that helped me change my mindset. Else, I don't know what would have happened to me had I not had that training. It really kept me from harming myself. I was already harming myself by defeating myself through my own thoughts. The last thing I needed was to take physical actions towards myself. It's serious too. It's hard to change your thinking when you are tired and defeated. You need people to help you with it. You can't do it on your own. I'm very individualistic. I grew up as the oldest in my family and have learned to always be the leader of the household. Naturally, I'm always going to find ways to take care of myself, but given my circumstances, I had to learn that I needed to accept help. It was okay to receive help. It was okay for my friends to buy me lunch and or get me lunch. It was okay for my friends to pick me up from work and take me home, help me with my homework, or summarize the readings for me because I couldn't

understand them, that it was okay to get all that help. I would self-defeat myself in thinking I needed the help. Realistically, we all need help. We always need help from someone. It's always easier having someone there for you. Take the time to get help and that includes getting counseling. I've been going to counseling for two years. I just started seeing a new counselor because I used up my UNM free counseling sessions. It helps me a lot to have someone to reflect with and think things out loud to, finding strategies of what I can do for myself now and next time, and knowing what to do with my friends if they ever need my help. Again, mental health training, going to counseling, even having these conversations out loud and being okay with saying, "I'm having anxiety, a panic attack today," that's the first step. Acknowledge it and accept it. That's what made my process difficult. It took me a long time to get there.

- 5.) Last, try new things. In this whole process, I actively sought new things because I just got tired of feeling I was in a routine every day. Complaining, not wanting to get out of bed, dragging myself to work, having new things in my week or in the month was refreshing. I started going to Yoga. I stopped due to my concussion a few months ago. At that time, it helped my body stretch in ways I didn't know I could stretch. I found muscles I didn't know existed in my body. [laughs] It was really good for me to change my exercise routine. I took meditation courses to learn how to quiet my mind and just be okay with silence. I felt if something wasn't happening in my mind, there was something wrong with me. Silence is a good thing. We need silence. Our minds are so active. Because my mind has ADHD, I have thirty voices running every second, even now as I am talking.

There are so many things I want to say, I'm trying to stay focused with one voice. The meditation helped me a lot with that. I started half-marathon running training again. It gives me something to work towards. I haven't made it past five miles, but at least I'm at five miles, even if I have to walk the last two miles. That's more progress than a year ago where I could barely walk a mile. I also increased my creative writing. I enjoy writing. It helps me tell a story. I like telling stories. I added it to my routine. Trying new things really helped me. Routine is good. Diversifying our routine, it helps you with making progress for yourself.

- 6.) Last thing I want to share before we open it for discussion. For my birthday a couple of months ago, a friend gave me an aloe plant. She gave it to me because I told her I have a tendency for killing plants. They never survive past a year. She gave me an aloe plant because she said it was really resistant and it would teach me that there are things I can grow. Being that I am terrible at it, I started watering it every day. That's my problem. I forget to water plants. I over watered it. I nearly killed the damn plant. I showed it to her a couple weeks ago, not knowing what to do. I was afraid to lose the plant. She told me to leave it alone and not water it. I was asked to just leave it in the sun. Just yesterday, preparing for this, I was looking at the plant and I realized, we are all like plants. Some plants like more sun. Some plants need a lot of water. Some plants need very little water or no water. Some plants need to be in humid environments. Some plants thrive in the cold.

That's our mental health. We are all different. We are all so different. I can't provide you all with strategies of what you have to do to keep yourself healthy. You have



to find your balance. Finding what's going to keep you healthy. Extroverts, they love being in loud scenes all the time. I'm an introvert. Conferences scare me but I love catching up with my colleagues. I have to find a balance of knowing how much to engage and disengage during a conference. That aloe plant has taught me so much. At the moment, I have about 12 plants I am growing. I have to rotate which I give most water to, which I don't give water to, which ones I put out in the sun more often, which ones I put away in the shade more often. Some plants are needier than others. That's how we all are. Some of us have very different needs. That's okay. We have to find that balance for ourselves and determine, how much do we need of what? For me, I just needed a group of friends to be there with me, hold my hand, and get through it. There's no way I could do it on my own. Our mental health is the same. We need to find a balance. That's where I'll end and open up to discussion.

Nestor (Host): I'll jump in here as we get ready to open up. I think that the chat has been incredibly lively with lots of support, lots of people sharing their stories, and so I'll reiterate what I said at the beginning of announcements. This is incredibly brave step that Leonel has taken. This conversation has been a long time coming. We talk a lot about self-care. I see it on Twitter. I see it on Instagram. Some of the regions [NASPA sub-groups] have been posting things to remind us of self-care. But actually practicing it, completely different. Self-care is not necessary only, at least that is what I am hearing, the things that you do can protect your space in your mind and health, but also the people that you bring into your life that will do so for you as well. The thing that I hear from Leonel is that other people coming in and providing reminders, check-ins, sometimes a kick in the butt. You know, I've been blessed I have been part of *Consejos* [*y Consuelos*],

there's threads. I remember, both Dr. [name] and Dr. [name] talked about your board of directors. This sounds like that to me. Leonel is saying have your board of directors. These are not only people that will help you navigate your career moving forward, but also to make sure you get there safely. I feel like, thank you for that. Folks, this is the time to talk to the man who brought this to our attention. Please. Jump in. I'll call on people.

### **Discussion.**

Audience member 1: This was such a timely event for me to listen and hear. I have a friend. We aren't close geographically. We keep in touch via Marco Polo, which is a video messaging app. I get to see her here and there, but necessarily see, connect with her in-person. As she has described, she's in a dark place. She has reached out to her doctors and such, in getting help. I have this question: How can I help? I don't want to smother here with "How are you doing? How are you doing? How are you doing?" I also don't want to seem or appear to be distant. That was more like a comment and appreciation for your transparency and your candor. Also, maybe ask, actually, how would you suggest someone who is not able to connect with people in-person. What advice would you give?

Self: That's a great question. I'm from California and I have friends scattered across the nation. What they did for me was ask me. What is it you need? What can I do for you? Some of them would call me once a month and say, "I'm thinking about. I saw this at the store," or, "I was working on this, and I remembered this great conversation I had with you." What I notice from these moments is that they would use it, not to tell me, "How are you doing? How are you feeling?" It was to remind me. This is how great you are.

This is what you have accomplished. This is how you have impacted my life. I think that's an aspect of positive mental health. Getting that positive reinforcement from people saying this is how you have helped me. "I just want to say thank you for having this great conversation with me." I just had a friend not long ago do that. That's what helps sometimes. Just reminding the person of who they are, not what they are in that moment. We become something when we are tired or depressed but, that other side of us is still there. It's hidden. We put it away. We forget that's who we are. Just providing those friendly happy memories, to me, was such a big deal. It was part of my healing process. That's my recommendation. Help remind that person of what they have accomplished and how far along they have come. For me, it was hard to remember that. I was looking at where I was and where I was stuck, not where I've been and where I'm going next.

Audience member 1: I appreciate that! Thank you so much!

Nestor (Host): Thank you [Audience member 1's name] for sharing and asking. I think in today's day in age, even with all the ways we are connected, I think we are more disconnected than we realize. Reaching out and having those conversations are more important than a comment on a thread, like on an Instagram post. I'm old school. [Audience member name] raises the question about our fears of our professional reputations taking a hit. I've been in the field long enough to hear the stories about meltdowns, if we are going to use that word as an example, that people had. Folks have stepped away from the field due to having to work around some of these issues. I don't have an answer. I would be scared if people might judge me. It sounds like Leonel was

lucky to find supervisors and folks that were supportive of him during the time.

Although, there was that example of folks not acknowledging what was going on.

Self: I think at our universities we need to find support groups. We have to find teams that understand what we are going through because the colleagues that did help me here, they are the ones I don't work within the office, or offices I don't work with. There are offices and units that have had experiencing the same thing. In some way, I built a little coalition here for myself that was a combination of students and staff. That's what helped me get through, just being open with these conversations. If you are facing discrimination on your mental health, use the civil rights office. Bring it to their attention. We shouldn't be judged based on anxiety or depression. Those things should be included in the workplace. We don't have these conversations. Most of the time, it's, "Here's your load for the month. Get it done. How you get it done, I don't care." There's a lot of life events that happen. These are conversations that need to happen more often on campus. We focus on the student, but again, based on the comments [Zoom chat], we don't focus on the employee. We don't focus on faculty. We don't focus on the staff. We need to change that culture. It's going to take some time to change that culture. It's not going to happen overnight. That's why I am writing my dissertation on my mental health. It's autoethnography about me. I realize I don't want to tell other people's mental health stories. I don't want to interview students or staff about their mental health. I want to tell my story. Why is my voice not that important under a research circumstance?

Autoethnography is a delivery method for me. It's an ongoing struggle we have to get through. We need to change the stigma about negative mental health to positive mental

health. We have to find ways to be happy at work and find a balance of workload. Those are things that are changing because of budget cuts, changes in staff. Then there's the whole spectrum of diversity that takes place with these conversations. For some cultures, it's hard to talk about it. In my Latino community, I remember growing up, my parents. There was this homeless guy that would walk by with a shopping cart. He was the *loquito*, the crazy dude. Looking back, that dude probably had some mental health problems. That's how we acknowledge mental health. If you have a problem, you are probably crazy. We really have to change that stigma. It's everywhere. In our homes. In our families. In our communities. At work. It's everywhere. We need to become advocates for ourselves and push towards that.

Nestor (Host): That's a wonderful jumping off point. It's something that has popped up in the thread. I think the genesis of this conversation, when you and I talked about well before, we don't talk about it at work. We don't necessarily talk about it with our friends. We absolutely don't talk about it in our families. I think some of us have that cousin, that *tio* [uncle], or that *tia* [auntie], or even a parent that has been struggling through some of these issues and we acted like everything was okay. We ignore that there's a problem. That sets up the stage for us to view it through a stigmatized lens. I started the thread by asking, "How many of us didn't get diagnosed because our parents couldn't afford proper care?" We didn't learn about these things until we were adults. Now we are trying to battle through some of these things while helping students that are coming to us increasingly in distress. It's a volatile kind of workplace, where you have students in distress. You have staff in distress who are increasingly being overburdened with work

because job descriptions keep getting bigger and bigger. I'm yet to see a job description get smaller and retain the same pay scale and not result in some reorganization to get rid of somebody. That's a different conversation for another day. We don't create that space to talk about it. If we do, do we feel safe enough to do that? Or are our colleagues going to say, "*Ese loquito* [that crazy guy], we don't want to work with him." It's almost like a no-win situation. I don't know that we are going to come to an answer here. Definitely, even having a conversation is a good place. At least that is what I am getting from you guys. Tell me if I am wrong.

Audience member 2: Can I share?

Self: Yes!

Audience member 2: Hi! I agree 100%. I was diagnosed with anxiety when I was in Florida. The first three months were the worst. Then I decided to go to therapy. I made it known in my office. I'm going to therapy! It created this conversation about therapy. My boss started talking to me and she was like, "Do you mind giving me a referral?" It just became a fun conversation. I do think sometimes there is that. I also think too, for people going through anything, it's never on that person to say I'm going to share. If it is a private thing they wish to keep private, and something for themselves, I do think that is important. I think what helped with me, was going, "Okay, I'm going to get this help that I need." Then, when I started going, I was like, everyone should go to therapy. Then I sounded like that person. It's very true. When you said the family part, I was actually just

talking to my dad about this last night. He said to me, “You know that thing you were talking to me about, the anxiety? I realize I had that my whole life. There were some days I would wake up and I’m just tired. I don’t want to do anything.” I was like, “You see!” [laughs] So, it’s very fun, that this is so relevant in our family. Our parents may not be aware either.

Self: Yeah. It is true. It wasn’t until a year ago that I shared it with my family what I was going through because I kept it away from them. I didn’t want to worry them because I was out here and they are so far away. I focused on my initial surrounding. You got to do it where you feel the most comfort. Start there and eventually grow from that. Had I been asked to do this a year ago, I would have said no. I wouldn’t have brought up the topic. A year later, I feel confident. The more I talk about it, the more I acknowledge it, the more I heal. It works both ways. I don’t shy away from it. If there are moments where I feel uncomfortable to talk about it and it happens, I mention, “I’m not comfortable right now.” It ends there. We have to find that balance. Our balance changes. I used to think balance was about staying in the same spot at all times. I realized over time your balance is always changing. You have to kind of move with it. Acknowledge that movement. We always think that things stay in one place. It’s not. The more I take care of plants I realize how much they do move towards the sun, or how much water will damage them, or how much more water I need to add. They wilt. That’s how we are. Sometimes we are going to need more people, have those outings more often, sometimes we are going to need more time to ourselves because that is what we need in that moment. It really starts with having conversations and having comfort and building from there. The more I’ve talked

about it, the more my friends have opened up about mental health. There are more conversations I've had about mental health, only continue to inspire me, encourage me, that I am on the right path. It changed my career interests too. I think we need more people in this arena. It's what motivates me to be an advocate, do the research, and push forward it by having this conversation with NASPA LKC. We need to do more of this. We need to start with our communities and surroundings, expand from there.

Nestor (Host): I got to say. This is probably one of the richer threaded conversations that we have ever had. I find myself typing into [the chat box] as questions come up. It is just awesome to see a topic resound and hit on so many levels. I'm happy that we are all here. I just wish there were more people in this conversation because I know this thing cuts both ways. We sit, as I look around the room and see the different levels of experience. There are certainly middle managers. There are certainly newer professionals. This stuff hits VPs [vice presidents]. This stuff hits provosts. This hits the presidents of colleges. This is in the board of trustees. It is certainly in the flesh and fabric of our students' daily lives where some of them are dealing with more things than I know I ever had to deal with as a student. There's more obstacles and impediments now than there were. Or maybe we just didn't talk about it then. I don't know. It's quite possible. I love how rich this is and this may end up having to be one of those *Consejos* that ends up getting a part two because we have to revisit it. Do we trigger ourselves as [audience member 2] asked? My worry is that I'm going to trigger somebody else and not have the capacity to help. But I do know from my training that it's okay to know that sometimes you can't help and get people to the places where you can. That's where those referrals come in. That's



where knowing who the staff are your campuses are. It's also important to be the person who takes the student or your colleague and deliver them to that space rather than just send them on their own. I want to thank [audience member] for giving us the term self-maintenance because that is a beautiful term that allows us to say, "You don't need to know what it I am doing. You just need to know there's some technical upgrades that are going on right now. That's all you need to concern yourself with." Leonel, as we come up on time, because I want to honor and respect the space we have created for this. Some people are going to go. I know you gave us your top six things. I love personally being okay with silence. I know that most of us in this field feel if we are not doing something, then something is wrong. I struggle with that all the time. I love also, find your balance, your last talking point, which was however that looks. Video games for four hours or playing video games for seven. I get it. Bring us home. Take us to a happy ending place with some final thoughts.

Self: Sure! As we end, where I am going with all this, I have chosen to write a dissertation on this. It heals me. It tells my story. I like to tell stories. Why not combine the two? It's easier for research. I don't have to go out and interview people. That's a thing. It's okay to do easier things. Because those easy things are things that heal us at times. It's things that make us feel good. We challenge ourselves consistently. Whether it is getting work done for that day because of deadlines to meet or we decided by the end of the month to lose ten pounds and we're not getting there. It's okay to not meet those goals. You have to tell yourself it's okay to not met your expectations. Your priority is you. Who is going to care more about you than you? At the end of the day, you have to

do you. Do what's best for you. If you want to take a nap, take a nap. If you want to go get drunk, go get drunk. Whatever it is for yourself, if it makes you feel better, do it! I don't know how many times I have told myself that I don't want to go drinking because it makes me feel tired. Now that I am better, that's just an idea. I've increased my drinking every so often now. I feel good because it makes me feel like who I was. I would drink every so often, and it was okay. I work in substance abuse prevention. I can talk about it from side of just be responsible. Just do the things that make you feel happy. If it is just making cookies, fine. For me lately, it has been growing plants, killing plants, making new plants, putting new seeds. That's life. We learn from our mistakes; we learn from our errors. We use that opportunity to be better. It's always work in progress. Whatever you do today that helped you, it might not be the same thing that helps you tomorrow. Just keep that in mind. It's why I say you need to do new things every so often. You need to change your mindset to change your perspective. I have a need to want to grow things lately and plants is a good outlet for me. Take care of yourself. Do what makes you happy. Always remember that. For me, it was hard to remember that when I was sleep deprived and wasn't functioning. I was just sad all the time. I felt that was what I needed to do, to feel sad for myself. It was the things that made me happy that allowed me to heal. Do that for yourself. The other thing I have been doing lately is sitting outside in the patio to look at the sunset. That's what makes me feel good. I've been out there reading a book now. I added a glass of wine to the process now. I now added watering my plants after doing all that. Do the little things that will bring a smile to your day. We need that rest. It's okay not to do anything for anyone but yourself. Your priority is you.

Nestor (Host): Leonel, you have been incredibly gracious. Supremely honest, genuine, and authentic. These are all things that come up in the chat as people have shared. I know I appreciate you. In reading the thread, everyone else truly appreciates you being vulnerable in the space because it is going to help people move forward and have a conversation about something that, for too long, has not seen the light of day. To use your plant analogy, we are a community of people that will be living, breathing, growing, parts of us will die, parts of us will sprout, but this reality of that care, that maintenance, is certainly a thread that we have to follow. I know that conversations you and I have had are very rewarding. Full disclosure, Leonel and I spoke at NASPA in the midst of one of the socials. It was like only the two of us in that space having a conversation. It was a beautiful moment of extrovert, introvert sharing. I'm very happy that we were able to get that because it brought us here to this space. It was a very necessary conversation. Whatever fears you had going into this, I hope you see that you killed it brother! You did a good thing here. I'm very proud of you. I'm very humbled by you as well. Thank you so very much. For everybody else: it's Friday. And maybe the sun is going to come, maybe not. I don't know. What you should do is go catch a sunset somewhere, crack open a glass of wine, and maybe bring a bottle of water with you and pour it on some plants on your way to bed or something like that. It sounds like a good way to end the day... Take a page from Leonel. Check up on somebody.

### **The Pandemic**

Upon hearing that COVID-19 had entered the United States the week of March 9, 2020, I did not expect the situation to last more than four or five months. At best, I thought it would only be a matter of three months before society resumed to its regularly

scheduled programming. That previous line includes sarcasm. Prevention measures and the seriousness of the virus further divided the society of this country. This is the spectrum I would place responses from people: some people took every preventative measure, others put minimum effort in prevention, and others chose not to take any preventative measure. The remaining people are scattered in between this spectrum. To me, this reflects society's division over the importance and seriousness of health. Regardless of our beliefs, the pandemic has impacted everyone to different extents, from major to minor.

Within my own life, I did not need anyone to be impacted by COVID-19 to take the threat of death and severe illness serious. The many years of deteriorated health resulting from untreated sleep apnea is enough for me to always prioritize good health and positive mental wellbeing. This is not true for many people in my life. Some of these people have made comments such as, "If I die, I die," "We have to move on," "These are times to be with family," and "We can't live scared." Two of my cousins attempted to visit me two months after being infected with COVID-19 and refused to get tested before gathering. They believed they were no longer contagious and were safe based on misunderstanding the CDC's guidelines. They believed they were no longer contagious two weeks after the first day of symptoms and did not require to be retested due to antibodies showing positive results in testing for up to three months. I rejected. Clearly upset, one of them replied, "It's been more than a month! Come on dawg!" Some friends in my life have attempted to invite me to eat at restaurants and others invite me to gatherings with over five people. Providing safe alternatives, they were often

disappointed in my rejection. These actions speak volumes. It provides a reflection of society at large.

In one year, I did not expect the following to occur due to COVID-19: a friend's father passed away, my mother's cousin and a friend passed away, my father's sister was infected, nine cousins infected each other, my best friend's family of four were severely infected with his father requiring hospitalization, and many other friends' family members have been infected. In two separate instances, my housemate and a cousin notified me they had come into contact with someone infected with COVID-19. I had to get tested and quarantine as a result of their interactions. My few cousins in New Mexico continue to travel to California to visit family, demonstrating no lesson learned from catching COVID-19. Each time, I fear becoming infected and dying alone while quarantined in my bedroom.

Unrelated to COVID-19, a friend passed away due to liver failure, I ended a toxic relationship, and I got injured twice in one day. I disabled myself from sitting for nearly two weeks and healing the injuries required three months of therapy. Attending a socially distant funeral was difficult for everyone, and even more difficult to not be able to hug my friend's family. In addition, I have not seen my family as they have vulnerable health conditions. The few friends I do spend time with are through social distancing. Other than my housemate, I only visit one friend without social distancing as we both trust each other's prevention skills.

These outcomes in my life have taken a toll on my mental wellbeing. I'm an introvert by nature. The isolation has become difficult. I distrust friends and family not being safe during this pandemic. People refusing to wear a face mask in public settings

such as parks and hiking trails upset me. I am hyper aware of ensuring I sanitize my hands after going to the grocery store or running any other errand. I am tired of living under a pandemic society. Despite this feeling, I would rather be alone, alive, and healthy if it means I will get to live longer and one day safely see my family and friends again. In some ways, it has increased communication with family and friends as we are not able to physically see each other. Playing video games online with friends has become my new social activity as we are able to verbally speak with each other. I walk and run daily to relieve stress, maintain physical activity, and get sunshine. Even after being vaccinated against COVID-19, I still take every precaution to stay healthy. I have managed to find coping strategies to counter the isolation.

I often reflect: If I am able to withstand this pandemic to my best ability, what are others experiencing that are unable to withstand it? My guess is that some people will be severely impacted by various traumas, others will resume to normality, and others will remain wary. For those who have lost loved ones, life will never be the same. Time will tell us the results of this pandemic once it is resolved correctly.

### **Anchors**

A month or two prior to the pandemic, I spoke with a cashier I frequently interacted with at the nearby grocery store. One day, she had tied her hair into a ponytail, revealing a tattoo on the right side of her neck. I asked to see it. With excitement, she turned and leaned towards me so that I could get a good look at it. In black ink, a boat is under full sail with an anchor dragging behind it below water. Curious, I asked her to explain the meaning behind her tattoo. She joyfully explained we all have experiences in life that try to stop us and drag us down; we must remember to sail forward towards our

dreams and what we love. Additionally, she shared it was inspired by a lyric in a song by her favorite heavy metal band. She then opened up and shared some of the life difficulties she had experienced in life and the mental health challenges it brought. Her experiences motivated her to pursue a career in mental health counseling for teenagers. Her tattoo was a reminder for her to continue to move forward in life because there will always be something that attempts to hold us back from accomplishing our dreams. I smiled. I thanked her for sharing her personal life and encouraged her to never give up on her dreams. “We need more people like you in this world.” As I quickly reflected and prepared to leave, I share: “You know, anchors can be removed or brought back into the boat. We don’t have to let things drag us down.” “Oh! I didn’t think of that.” We laughed and wished each other a good day. These are the lyrics to the song, *Chelsea Smile*, from her favorite band, Bring Me The Horizon (2008):

We all carry these things inside that no one else can see.  
They hold us down like anchors.  
They drown us out at sea. (2:34)

## CHAPTER 5

### INTERSECTIONALITY WITHIN ORGANIZATIONAL CULTURE OF HIGHER EDUCATION

In reflection, there are dark and light moments when representing the balance of my own intersectionality. Several times required a complete stop of writing to disengage from the dark, painful memories of the past, while at moments I had to push myself through the torture of trauma and sorrow. To re-center, memories of support, encouragement, comradery, motivation, and love allowed safe passage to the present. These positive memories served as anchors to guide my return. In this process, anchors holding back my growth and ability to write were removed to allow healing to continue. These anchors are “re-collections of disseminated identities” (p. 198) that Fisher (1986) described regarding autoethnography. The writing journey was treacherous. It was the first time I explored memories of stigmas, discrimination, oppression, hostility, bullying, and racism, best represented by term injustices, under a healthier state of mind and body. Even with a stronger, healthier state of mind and body, nightmares, back spasms, and anger wounded my being each day. Creative autoethnographic *testimonio* is not an easy process.

Chapter four explains the difficulties and challenges experienced because of the changes in my health triggered by sleep apnea. Resolving health issues was not a quick and easy journey. The organizational culture of the work and learning environments exacerbated the outcomes of one disability, unnecessarily expanding negative health conditions through a lack of support. Three different conditions are difficult to navigate when two of those conditions are working against one condition. The one condition is the

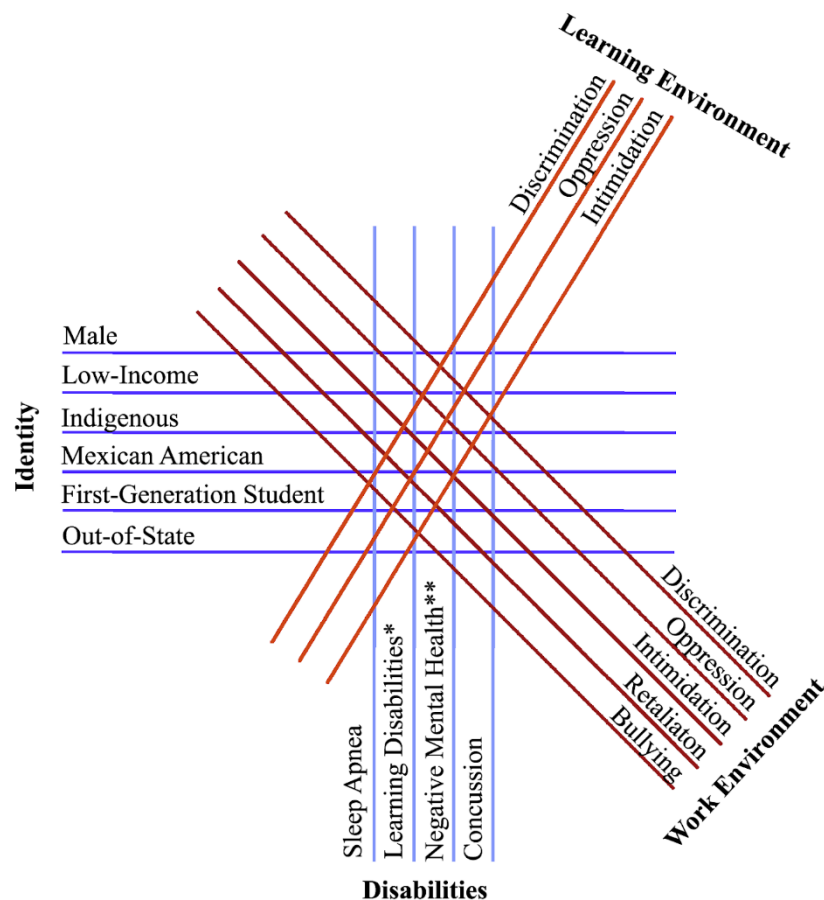


health disparity of disabilities, and the other two conditions are the organizational culture of 1) the work environment and 2) the learning environment of higher education. This does not include events of everyday life outside of higher education impacting my health in positive and negative ways. There were many various elements occurring simultaneously at every phase of my downfall and recovery. The best way to describe it is visually.

Figure 4, Leonel's Intersectionality (diagram below), represents the intersection of my identity, health conditions, the learning environment, and the work environment. My identity is color-coded purple, which includes my gender, race, socioeconomic status, and other aspects of my identity. Disabilities are color-coded blue and are inclusive of all the health conditions I experienced. The work environment is color-coded red; the learning environment is color-coded orange; both include the injustices I confronted. The diagram is a summary and a representation of my experiences. The lines intersect with each other. It is messy and confusing. Chapter four was intentionally written linearly, one experience at a time. This was done to avoid confusion and allow for a deeper understanding of health, the work environment, and the learning environment. The intersecting power relations of organizational culture, specifically work and learning environments of higher education, demonstrates the power divisions of ability, gender, age, and class (Hill Collins, 2019). In all instances, I was the youngest, most dark skinned, most disabled, and earned the least income. Never was I in a position of power within the hierarchies of higher education. There was always a disadvantage in all aspects of my experiences.

Intersectionality allowed for a natural use of *testimonio* and autoethnography. With *testimonio*, I provided my eye-witness experiences (Warren, 1997). Autoethnography allowed me to be vulnerable (Tierney, 1998), authentic (Reed-Denahay, 1997), and confrontational to the “dissonance within” myself (Herzfeld, 1997). With the support of ars poetica (Cox, 2011; Faulkner, 2007, Griffiths, 2018) and reflexivity (Madison, 1993; Tierney, 1998), I conveyed memories through reflective creativity and performance autoethnography (Alcoff, 1991; Calafell, 2013). Using intersectionality to analyze the oppressive system of higher education, I theorize my experiences (Hill Collins, 2019).

**Figure 2. Leonel’s Intersectionality**



\*includes ADHD and memory retrieval difficulties

**\*\*includes depression, anxiety, panic attacks, PTSD, and trauma**

### **Analysis: The Obstacle Course**

Beginning with health, there was the frustration of not being able to identify the source of the changes in my health. It never once occurred how lack of sleep could alter my physical and mental health. Most people had never heard of sleep apnea as I shared my condition. The unknowledgeable medical doctors prolonged identification of sleep apnea by refusing to further understand my diminishing health. It is difficult to receive help and identify help without knowledge of sleep apnea. This was the first obstacle to resolving health issues. The next obstacle became accepting disability.

It was not until a few years after being diagnosed with sleep apnea that I would recognize it as a disability. Resolving my sleep issues was not an easy process when the primary source of wellbeing, sleep, was compromised by obstructed breathing, allergies, a deviated septum, and eventually ADHD. Managing my roles as a student, employee, consultant, friend, son, brother, advisor, mentor, volunteer, and member of society were difficult. The lack of energy and ability to function were understood by those who have been impacted by difficult life experiences of the body and mind. There were some who claimed to understand but clearly did not believe, care, or accept my conditions were getting worse. This second obstacle leads to my third obstacle.

Identity development is important for a first-generation Mexican American experiencing disability for the first time. Identity development added an additional layer to a complex experience. How does having disabilities impact my future? How does it limit my life? How do I compensate for and manage my disabilities? These were the

questions I asked myself frequently. This was made difficult by the influence of the fourth obstacle.

The fourth obstacle was the unexpected resistance as I reached out for help. Although there are no concrete answers as to why people behaved the way they did, there are some thoughts I have about what I experienced. The truth is, I will never truly know. Shame on them. The only positive side is that their actions led to this research study exposing the oppressive organizational culture of higher education.

These obstacles contain several thoughts and ideas. What follows are thoughts about why some people help or don't help, race, masculinity, identity development, and social justice.

### **Conditions One, Two, and Three**

Being a Mexican American, with a low socioeconomic status, as well as an out-of-state first-generation student and employee, overall life experiences have taught me two conditions relating to my identity. The first condition is if I am struggling, withdrawing, distancing, separating, and underperforming, there will be people attempting to mentor, advise, and guide me onto a better path. Someone will try to “save” me because of my identity. I cannot explain every reason why those people will attempt to do everything they can to change the course of my life. Some have expressed seeing a part of themselves within me because of our shared identities of being Latinos and/or first-generation students and employees. These individuals recognize the inequalities and injustices placed upon those of us labeled as minorities, people of color, or marginalized. Those people, I appreciate. I think others were trying to be “saviors” to make themselves feel better about their roles within academia. There were not any commonalities within

our identities. Their level of interest was specific to one subject, such as a course, or a project at work. For this condition to occur, it requires a resistance on my end to not want any help. Some of the reasons for not wanting help related to not wanting to appear weak, wanting to overcome obstacles alone, and to not be in debt to anyone. Those people lack establishing a connection that is relatable. A person's reasons to provide help have to be clear, concise, honest, and intrinsic. Some people are genuinely wanting to help. It is okay to ask for help and give help. This leads to the second condition.

If I am struggling, underperforming, or incapable, asking for help will help me improve and make changes. People who have a shared identity to my own will genuinely understand and provide support. The second condition: People who do not have a shared identity to my own and cannot relate to my own experiences will refuse to provide support. For this condition to occur, I have to be confident, vulnerable, trustworthy, and strong. This is strange. Within the organizational culture of higher education, I implemented the second condition with the hope that people would provide me support and guidance. This was not effective because there was a lack of people in positions of power who shared a similar identity to my own. People in positions of power are those with titles of dean, director, administrator, professor, and any position above a manager role. This led to the oppressive, discriminatory, hostile experiences within the work and learning environments. I never allowed myself to appear weak if I could hide it. The concealment of my deteriorating health was successful as very few people attempted to provide me with support simply because I did not appear fragile, weak, incompetent, or defenseless. I resisted failing and sought help, only to be met with resistance. This was not true for everyone in my surroundings.

The third condition is the opposite of condition two. People who do have a shared identity and can relate to my own experiences will offer help. People of all backgrounds, except those with positions of power, did not hesitate to offer help. Peers, student employees, coworkers, and colleagues provided help. Many of them were quick to note the changes in my behavior. Before learning of sleep apnea, some people would ask me if everything was okay in my life, expressing concern and willingness to provide help. One coworker often reminded me, “Always prioritize your health. Work will never go away.” Other people would offer me lunch, coffee, motivational quotes, evening cocktails, and hugs. Some of these people recommended I seek counseling services. Despite my best efforts to conceal the pain of my health condition, many could see through the illusion. I did not shy away from seeking these individuals out when I confronted the worst of days. Phone calls, text messaging, emails, and face-to-face meetings occurred for the purpose of help. These people recognized how an unknown, and eventually known, health condition impacted every aspect of my life. How could those in positions of power not see it? Did my race/ethnicity have something to do with their decision to ignore?

### **Race and Oppression**

Sometimes, wondering if I am creating experiences that never occurred, I remind myself that oppressive and discriminatory actions aim to create dissonance within the self. The other person is determined on enforcing their views as the only true reality (Hardiman & Jackson, 1997). It reminds me of a quote by Rony (1996) describing race as never being scientifically validated:

After thousands of skulls had been measured and endless statistical analysis performed, no one could agree on what race was or how to measure it. If “race” could not be scientifically proven, however, the narrative of racial difference with its evolutionary premise proved ideologically powerful. (p. 30)

In short, race does not exist scientifically, but we, as humans, gave it a narrative through describing difference to define skin color. Surely, there also must be many similarities, yet that is not important to society as we continue to see incidents relating to #BlackLivesMatter, #StopAsianHate, and #Immigration. Oppression on the basis of race, the color of our skin, continues to exist.

In my experiences, oppression due to my disabilities and race took place in a work setting and learning environment, with employers and faculty making both unconscious and conscious decisions to oppress. As Hardiman, Jackson, and Griffin (2013) state, oppression has three dimensions (context, application, and consciousness) that help describe the circumstances to oppressive experiences. Oppression can take place at any location in any setting whether it is done knowingly or unknowingly. As a Latino experiencing disabilities, the workplace and learning environments established barriers. Asking for help directly did not change the circumstance. Explaining my disabilities did not change their choices. The choices of the employers and faculty to ignore my requests for help were conscious decisions. If they did not know how to help, why wouldn't they be direct and state it? Some clearly chose to ignore me. Others chose to make the circumstance difficult. What if I was in condition one instead of condition two, as previously defined? Would they have tried to be "saviors" to make themselves feel empowered and establish their dominance? No person should have to reach a point of desolation and despair for others to provide any level of help. I often wonder if the circumstances would have been different if these individuals had a similar identity to my own. Better yet, what if my identity was similar to theirs? Some of those people may

have treated me different. However, most of them might have taken the same actions, regardless of identity similarities.

In my personal experiences described in chapter four, I often wonder how my story would have played out if I were a White male. There is no doubt there would be differences in treatment. There is no evidence one “race” is superior to the others or that “race” makes anyone inferior. Rony (1996) makes it very clear that race could not be measured or validated through science. It is an ideologically fabricated concept to describe difference. Rony makes it clear that notions of race are utilized to describe non-white people. No string of words was ever said to me regarding my race. However, their actions established power and dominance in an act of superiority, placing inferiority upon my brown face. I was always treated differently. The concerns brought forth were never taken seriously, often ignored, often downplayed as if the injustices were nonexistent. Any concerns and problems shared to those in positions of power, even with providing evidence, were deemed unimportant. Their expectation of me was to accept the others as they are, pretending it as a conflict of personality. There was a refusal of accepting race, disability, and gender as reasons others would discriminate and oppress. It was easier for those in positions of power to ignore, justify, or pretend the issues in the workplace and learning environment were non-existent to avoid the difficulty of confronting injustice. In addition to race, gender contributed to the injustices by those in positions of power that viewed me as being sensitive.

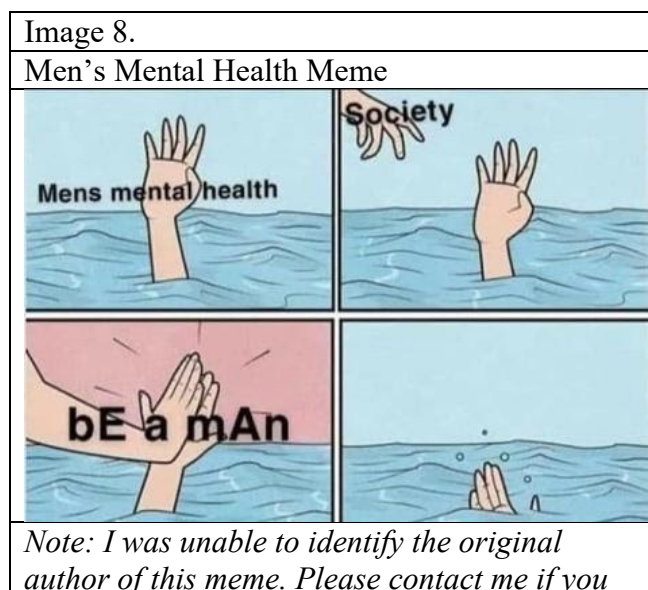
### **Masculinity and Disability**

With society’s push towards ending the patriarchy’s privilege, as made evident through the much needed #MeToo movement, masculinity must be reexamined,



reevaluated, and redefined. People who make unwarranted physical and verbal advancements towards others must be held accountable. What about the people who reinforce or instill the notion of toxic masculinity, also referred to as hegemonic masculinity? By toxic and hegemonic masculinity, I am referring to the definition of aggressive male behavior, which includes the notion of men being tough, unemotional, rugged, aggressive, and enduring of hardships (Mirandé, 1997; Barrett, 2001; Whitehead et al., 2013; Whitehead, 2009). Were these people in positions of power supporting toxic masculinity?

The actions of the new supervisor, administrator, senior researcher, former director, interim director, and faculty reflect support of toxic/hegemonic masculinity. None of them demonstrated empathy, sympathy, compassion, or support towards my disabilities. I came across a meme in the forum, r/malementalhealth, of the social media platform, Reddit. Below is image 8, men's mental health meme. The meme accurately portrays the reaction of the organizational culture of higher education upon disclosure of requiring help as my disabilities unfolded. The people who did help were not in a



*know as I want to give credit to the creator of the meme.*

position to change my circumstances in the work or learning environments. Some of them did do their best to keep me afloat, much like my former student employees, peers, former coworkers, the department manager, and the Researcher. In my situation, I was being very open, vulnerable, transparent, and honest about how my health conditions were impacting every aspect of my life. This behavior is the opposite of hegemonic masculinity.

Challenging the toxic/hegemonic masculinity, I recognized needing help and sought it. Alongside this recognition, there was limited knowledge on how to cope with declining health. This led me to do the only thing I knew: to be strong, enduring, and vocal. There was no medication or treatment prior to the sleep study. There is no treatment for a concussion. Even when I did receive treatment for sleep apnea, it did not improve my health immediately. A concussion requires time to heal. Because I chose to be strong, enduring, and vocal, did this make others believe it was okay to support notions of hegemonic masculinity? Were they thinking I had to “be a man” and “suck it up?” Did they not believe I was struggling to function? Others without a position of power believed every word I said and acknowledged the visibility and embodiment of my struggles. These people noticed the changes in my appearance and behavior. Condition three was met. What made those with a position of power not believe me?

During the process of writing this research study, I often dreamed about the trauma I experienced. In February 2021, I had a dream in which I met with a former friend, a person who does not believe mental health exists. I only saw half of her body. Her other half was in the darkness. Upon waking, I reflected. It reminded me of the one of

Batman's villains, Harvey Dent, also known as Two-Face. Dent's mental health condition can be best described as dissociative identity disorder, although the comic books often referred to his condition as multiple personality disorder (Langley, 2012). This thought process led me to a realization. When it comes to mental health, people only see the side of you they choose to see. People are not interested in getting to know the whole person. In the case of Harvey Dent, most characters in Gotham city refer to him as Two-Face, while Batman usually refers to him as Harvey. Batman does this to remind Dent of his good side with the hope to help him. In my personal experiences, my declining health was ignored and used against me. Those in positions of power held no intention to provide any support. They were displeased with my change in behavior. It came in the form of statements that I was not paying attention, not cooperating, not studying, or working hard enough. Much like Harvey Dent/Two-Face, those in positions of power saw the side of me that was most convenient to them.

### **Disability Discrimination**

Never asking anyone to feel sorry for my disabilities, the help I sought was accommodations required to allow a continuation of learning and work. It is not difficult to help an individual. People in the positions of power made it appear providing help would cause some kind of hardship. They all refused to understand. I believe they held stigmas of my identity. They most likely saw a disabled male, first-generation Mexican American that could not be helped. They were declining to accept and integrate my disabilities because of stigmas (McCaughey & Strohmer, 2005; Goffman, 1963; Hayashi & May, 2011; Olkin, 2012; Shannon et al., 2009). Did I appear to be dependent and emotionally unstable, leading to their refusal to provide accommodations (McCaughey &

Strohmer, 2005)? Their stigmas on disabilities probably led those in positions of power to make learning and working difficult in the hopes I would leave.

Here is a quick recap of the experiences I held. In job #1, I believe the new supervisor chose to push me out of the office by eliminating projects and programs that had been assigned to me. This was not the case with any other employee in that office. In job #2, my accommodations were blatantly ignored. The senior researcher and administrator were set on being hostile and retaliated when I challenged their unethical behavior. With faculty 1 through 5, their actions never included attempts to empower or support my learning. Faculty 1 made attempts, but often she would make assumptions her guidance should help if I tried harder. All faculty refused to acknowledge and accept me as a person with disabilities. It reminds me of the social justice model of disability. The model describes how discrimination, oppression, and prejudice is woven and embedded into social institutions and individual consciousness, supporting ableism (Bell, 2013; Evans et al., 2017; Griffin et al., 2007). The interesting thing to some of these people in positions of power was them trying to relate to me using their experiences with short-term disabilities. Their mindset was, if they could overcome a short-term disability, I could overcome long-term. Get the fuck out of here with that! My disabilities are not short-term or long-term, they are permanent. They all held discriminatory beliefs on disability. It is acceptable to not know how to help someone. There is no disputing lack of knowledge. At a minimum, one of these people in positions of power could have reached out to others and identified resources. Out of the nine people in positions of power, seven of them are researchers. They should be well equipped to investigate resources at a

university. If this is how they responded to me, imagine other employees and students who may have reached out to them for help.

No person should experience discrimination, oppression, and hostility because they advocate for their disabilities and speak up against unethical behavior. Navigating the organizational culture of higher education demonstrated a lack of knowledge, education, and resources by staff, administrators, and faculty. Some people might say it is the responsibility of the individual to seek out resources. I agree that this is possible, depending on the health circumstances an individual is confronting. In my specific case, the sleep deprivation had dampened many of my abilities. My only focus was surviving and blending in to not draw attention because of the early onset of discrimination in job #1 and with faculty 1 and 2. Unable to think clearly, finding resources never crossed my mind. Sleep deprivation impacts every aspect of a person's health. As for those helping me to the best of their capabilities, they also did not think of referring me to university resources other than employee counseling. These people were unfamiliar with the office of civil rights providing accommodations to employees. Human resources was brought to my attention; however, it was followed by comments of how unhelpful HR could be in most circumstances. They were not wrong. The passing of the Americans with Disabilities Act was a monumental recognition of disabilities within the United States thanks to the hard work of disability activists, advocates, and warriors. There is much more work to accomplish within the disability area. The current policies and laws are not effective when confronting discrimination. There should be no tolerance towards discrimination of any kind. It is already hard enough to be an individual experiencing disability for the first time, let alone facing discrimination alongside it.

## **First-Generation Latino Disability Identity**

Before recognizing and accepting disabilities as part of my identity, I felt broken and defective. Not knowing what was wrong with me was the most difficult aspect of the process. I just wanted a solution to improve my life. With my status as a first-generation Latino, navigating school is a challenge. Learning to be a professional is a challenge. Adding a disability into my identity was difficult. Adding several disabilities into my identity was terrifying. Sleep apnea, learning disabilities (e.g., ADHD, memory retrieval), and negative mental health was a storm. Disabilities have never been discussed within my family or with my friends prior to developing sleep apnea. There was no one I could ask for guidance, assistance, recommendations, advice, or help. Disabilities are kept quiet. Many health conditions are disabilities, and they are not viewed as such. Cancer, depression, COVID-19, anxiety, surgeries, and wearing glasses to improve vision are unrecognized disabilities. My guess is the stigmas associated to disabilities causes certain health conditions to be unrecognized as disabilities. People are probably afraid of being stigmatized because it would somehow make them a less complete person. It was not until I began to disclose my disabilities that others began to share their own with me. It reminds me of Goffman's (1963) research on how people with stigmas live a double life, often making efforts to hide their stigmas. It makes me angry. We continue to live in a society that values perfection. It reminds me of a conversation I had with a student ten years ago.

The student, a first-generation Latina with negative mental health, kept being harsh on herself because she wanted to be perfect in every aspect of her life: school, work, friends, family, and so on. She put her best efforts forward to hide or remove her

imperfections. One day, she felt defeated after experiencing a difficult week. In providing compassion, I said, “Perfection doesn’t mean having everything in perfect condition. It should mean being happy and appreciative of what you do have.” After a moment of silence, she responds, “That’s meaningful and deep.” “I know. I probably got it from movie or something.” “You just ruined the moment.” “Good.” From this point forward, she began to excel and became accepting of the hurdles life brings. There is an unwritten and unspoken pressure to be our absolute best as a person of color. Adding disabilities into the mix creates problems best described through an identity model.

In chapter two, I explained the Howland & Gibavac (2010) model of identity development in a person with learning disabilities (table 1 in chapter two). The model helps understand my own process with other disabilities not related to learning. Social systems helped ease my transition into accepting my newfound disabilities. The social systems were the people who chose to disclose their disabilities to me. These people were of all backgrounds: Latinx/a/o, White, Black, Asian, Native American, non-binary, men, women, religious, non-religious, spiritual, moderate, liberal, conservative, etc. It helped quickly normalize my disabilities through social acceptance. Disability affects everyone, regardless of background. The colleagues who disclosed having a relative with sleep apnea provided reinforcement of not being alone in my struggles and understanding that treatment for sleep apnea can take several therapy adjustments. All these people provided support that led to my own acceptance. These people shared advice and guidance of what worked for them or their relatives. For those observing my work or classroom interactions with those in positions of power, they acknowledged the discrimination, oppression, and hostility occurring. Sometimes, I questioned perceiving situations with

those in positions of power incorrectly. Having someone else observe the interactions reinforced my perspective of being correct. Those moments empowered me to trust my instincts and intuition when there was no one available to observe moments of injustice. Support and acceptance were influential variables in helping adjust to a life with disabilities. However, there were other aspects of my identity that I began to question.

Understanding my own disabilities required reevaluation of some aspects of my identity. My intelligence, cultural, gender, physical, and belief identities changed to integrate my disability identity. Initially, disabilities made me feel incomplete, lacking, insufficient, defective, broken, and missing. The interactions I held with those in positions of power made me feel disgusting and inhuman. Those people chose not to help or believe me. I felt dumb, incompetent, a weak man, physically incapable, and a poor representation of Mexican American identity. We live in an American society that views anyone not White/Caucasian as inferior. How was I to demonstrate otherwise if I could not perform the bare minimum of life (e.g., be a good student, be a good employee, be a contributing member of society)? All I could do was focus on myself and work towards improvement. This was difficult to accept without the two counselors and two psychologists I met with. These individuals provided guidance and reassurance that my disabilities did not change any aspect of who I was before the onset of severe sleep apnea. Friends and colleagues often did the same.

As my health improved, it became easier to accept my disabilities. Rather than living a double life as Goffman (1963) describes, I chose to merge my lives as one. Disclosing my disabilities was daunting, but it also empowered my choices. To listen and recognize how often people (e.g., friends, family, colleagues, coworkers, students) are



discriminated based on disabilities only fueled my anger. With this anger available, I accepted myself. Before the year 2015, I lived life with unknown disabilities and was successful, despite always working harder to compensate for lack of accommodations and knowledge on managing my own disabilities. The key difference was becoming sleep deprived. The conditions that once prevented sleep apnea from severely impacting my health changed the day I moved from California to New Mexico. There was no way I could prepare for that change. Patience was required to heal properly. Healing cannot be rushed. The momentum of wanting to return to normalcy changed. I did not want to be go back to a “normal” life. At some point in my healing process, I realized understanding my disabilities would allow me to identify new methods for growth and development. The change in views of my own disabilities is identity development as described by Howland & Gibavic (2010). Experiencing grief, relief, resistance, and alienation was difficult and messy. Once I reached a point of redefinition of my overall identity, it has become an ongoing resolution process. Anytime I hit an invisible learning wall, rather than becoming frustrated, I think creatively of ways to eliminate the wall to avoid repetition. The process of accepting disabilities, albeit difficult, gave me a newfound perspective.

Discrimination and oppression continue to exist upon those who experience disabilities. It is even harder for communities and groups of people that do not talk about disabilities. Experiencing disabilities alongside discrimination and oppressive actions of non-disabled people transformed me into an advocate and a disability activist. Now that I know the actions of oppressive and discriminatory people in positions of power, I can take steps towards challenging them.

## **Establishing Social Justice**

It is unfortunate that people with positions of power within the organizational culture of higher education chose to make unjust decisions towards a Latino first-generation student and employee facing several disabilities. Their choices were prejudicial and ignorant as shown through their discriminatory and oppressive actions, mirroring the social justice model of disability (Bell, 2013; Evans et al., 2017; Griffin et al., 2007). My focus here is on the educational mission of the model, which seeks to educate about disability oppression and the structures and policies supporting oppression and discrimination (MacKinnon, Broido, & Wilson, 2004). Universal design for learning and instruction must be implemented into every aspect of higher education (Boothe et al., 2018; Evans et al., 2017; Grier-Reed & Williams-Wengerd, 2018; Hackman & Rauscher, 2004; Higbee & Goff, 2008; Lewis & Sullivan, 2012; McGuire & Scott, 2006; Scott, McGuire, & Foley, 2003; Orr & Hammig, 2009; Scott, McGuire, & Shaw, 2003; Spooner et al., 2007; Smith & Buchannan, 2012; Walker, 2017). If universities truly seek to support diverse students and employees, removing barriers through universal design must occur. Universal design needs to be supported through policy changes and a shift in organizational culture. Given my experience with disabilities, a universally designed work and learning environment would have made my experience positive. Briefly returning to figure 4 (my intersectionality), the problems of the work environment and learning environment, along with some negative mental health conditions, would have not occurred. I envision that a supportive organizational culture would have made experiencing disabilities an easier transition. It might have allowed me to focus only on sleep apnea. With universal design, there would be no need to request accommodations

and provide evidence to validate my requests for the learning environment and work environment. Here is a twist. We cannot change the views and choices of people who decide to create injustice. There would be no acceptance of unjust actions. A human resource office and civil rights office would be quicker in their investigations and support those filing complaints. For human resources, this would require not to protect the university and those in positions of power such as directors, deans, and faculty. It would, instead, protect the employee. In addition, those who do not possess knowledge on disabilities would be required to attend a disability justice course. A one-hour training or workshop would be insufficient. If lack of knowledge is contributing to the problem, then education on disabilities will help those who genuinely lack knowledge and wish to improve and be supportive to people with disabilities. Not everyone is intent on being unjust to people with disabilities. Disability education must be implemented now. This ideal scenario will never occur as long as there are more people in positions of power defending the way things are currently than there are people pushing for change. My experience is just one of many in existence. People experiencing disability injustice need to be empowered, inspired, and encouraged to take action for change. We are capable. Equity must prevail. Change is inevitable. *\*Snap!\**

### **Disability in Mainstream Films and T.V.**

With the COVID-19 pandemic restricting social life outside the home, it has allowed me to spend additional time watching films and television series. I have a hunch this has been true for others. I have taken an interest in paying attention to how disabilities are portrayed. In some films and TV shows, it is brief, while in others it is more extensive and embedded into the narrative of a character. This is important when

we think about inclusivity and equity as it leads to representation of identity (Rony, 1996; Boylorn, 2008). Stated earlier, it will allow me to “zoom backward and forward, inward and outward” (Ellis, 2004, p. 37). To connect with pop culture characters helps establish a connection and reduce stigmatization of disability. It lessens the isolation of going through a disability. Relatability is important in reducing stigmas. It makes you realize you are not alone, and others might be going through something similar. What follows are some examples.

In the television series, *Malcolm in the Middle* (Boomer et al., 2005), episode 15 of season six, “Chad’s Sleepover,” Dewey invites his school friend Chad over for a sleepover. While being dropped off, Chad’s parents demonstrate their fear of their own child. They give Hal, Dewey’s father, restraints and a harness to tie down Chad at bedtime. Throughout the day, Chad runs around the home obsessively reorganizing every item by color, alphabetically, type, and shape. It is clear that Chad has obsessive-compulsive disorder (OCD). At the end of the episode, Chad’s parents return to give him his bedtime pill. As Hal enters a room to get Chad, he finds him with a hatchet, ripping clothing with more than one color to organize the now rags by color. Dewey is afraid, expecting his father to become upset. Instead, Hal grabs an encyclopedia book, grabs a red pen, opens the book, and assigns Chad the task of filling in every circle created by letters, numbers, and symbols. Visible, the book has a page already marked as an example. As Hal, Chad, and Dewey return to the front door, Chad’s mother asks, “Has he been okay?” Hal responds, “I think people pre-judge Chad sometimes. He’s a good kid.” After the interaction, Dewey asks Hal, “How crazy are you?” With a smile, Hal responds, “Let’s just say that’s my third set of encyclopedias.” Seems like Hal also has OCD.

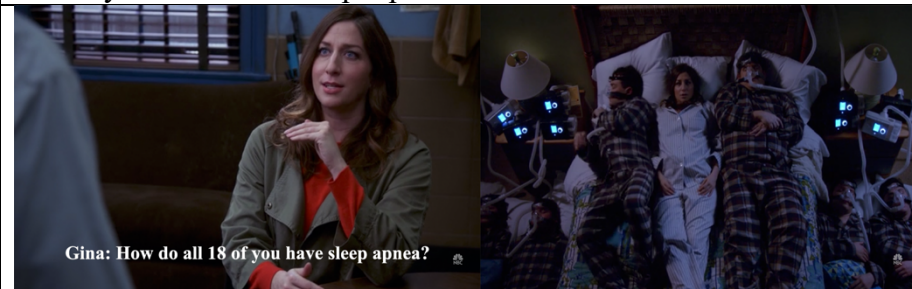
The TV series, *Shameless* (Hissrich et al., 2011 – 2021), is set in a low-income neighborhood of Chicago, focusing on a White family raised without a responsible parent. The entire series focuses on a variety of disabilities: depression, bi-polar disorder, agoraphobia (fear of places and situations that might cause panic, helplessness, or embarrassment), anxiety, postpartum depression, oppositional defiant disorder, narcissism, alcohol abuse, drug abuse, intellectual disability, Down syndrome, and many more. Some of the characters develop their disabilities while others are identifying ways or struggling to manage their disabilities. Physical and mental disabilities intersect during everyday life events. This series is not promoted as a show about disabilities, but rather as one about a low-income family and their friends experiencing hardships such as paying rent and utilities, looking for work, addressing work problems, managing relationships, dating, attending school, being a first-generation college student, becoming a legal guardian to your siblings, socializing, and life's unexpected events.

A TV comedy series about police detectives, *Brooklyn Nine-Nine* (Lawton & Del Tredici, 2017) has an episode briefly focusing on a very specific disability. In season four, episode 18, "Chasing Amy," two of the characters, which are dating, are having a discussion over a contested family heirloom. Boyle, a detective, explains to Gina, an office administrator, how his cousin is attesting a will left by an aunt. Boyle is concerned they will be removed from the family for destroying the heirloom. Gina is indifferent and happy to be removed from the family. As Boyle explains what will happen if they are removed from the family, Gina expresses, "How do all 18 of you have sleep apnea?" You can see image 9 below for a screenshot of the scene. Although this moment is brief, it brings awareness to sleep apnea and might make people do an online search for "what is

sleep apnea?” A film briefly referencing sleep apnea is Jumanji: The Next Level (Johnson et al, 2019). Eddie, played by Danny DeVito, is shown using a CPAP or BPAP while sleeping. He shows a dislike for the machine.

Image 9.

Brooklyn Nine-Nine Sleep Apnea Scene



*Note.*

The Falcon and the Winter Soldier TV series (Feige, 2021) focuses on two heroes and members of the Avengers as they navigate the world after being returned to life by the infinity gauntlet. In the early episodes of the series, we see Bucky, the Winter Soldier, attending counseling sessions to address PTSD. In episode two, “The Star-Spangled Man,” we see the main characters forced into a couple’s therapy session to resolve their differences. Bucky and Sam, the Falcon, are at odds with each other and are not allowed to leave the session until they speak their truth to each other. In a previous Marvel film, Captain America: Winter Solider (2014) Sam is introduced as a combat veteran working as a PTSD counselor. He offers his services to Steve Rodgers/Captain America.

In the Good Doctor (Shore & Gordon, 2017) TV show, episode one of season one represents the discrimination and unethical treatment a young man with savant autism receives. Shaun Murphy experiences backlash about being hired as a medical doctor due to the stigmas of autism and concerns on how he might behave and treat patients. People

advocate on his behalf pointing to discrimination in the workplace. Murphy's memories reveal the difficulties he has encountered such as bullying and oppression.

In the film *Godzilla vs. Kong* (Tull et al., 2021), a young girl named Jia is played by Kaylee Hottle. Jia is able to communicate with King Kong through sign language. Outside of her role, Kaylee Hottle is deaf. In season two of the TV series, *Titans* (Ortiz et al., 2018 – Present), Chella Man plays the role of Jericho, who uses sign language to communicate. Outside of this role, Chella Man is deaf and a disability activist.

*Joker* (Phillips et al, 2019), a film based on the origin story of Batman's greatest adversary, takes a different view on the rise of the clown prince of crime. Arthur Fleck's life is explored prior to becoming the Joker. Arthur's life reflects the societal conditions of Gotham city: poverty, lack of health care services, violence, hostility, oppression, and discrimination. Arthur is often a victim, being bullied, ridiculed, misunderstood, and mistreated. The social services agency loses funding, causing Arthur to lose access to counseling and medication. With each negative interaction, Arthur becomes bold in taking matters into his own hands. He eventually begins to commit murders. Arthur's experiences lead him to becoming the Joker.

Mainstream films and television shows, or cinema, have the capability to change society's perspective on disabilities and reduce stigmas. Cinema can emit a negative portrayal of diversity, but when done correctly, it can be a powerful mechanism to change views on any given subject (Rony, 1996; Boylorn, 2008). Cinema must continue to move away from using binary identities (Boylorn, 2008). To watch disabilities included in films and TV shows helps normalize and accept my own disabilities. Although brief, to see sleep apnea represented in a TV show and film relieved the feeling of loneliness. It made

me feel included and accepted. It provided an opportunity to laugh at myself. I often worry what it would be like for someone to sleep in a room with me, and *Brooklyn Nine-Nine* captures my own exaggerated perception. Danny DeVito's reaction to wearing a CPAP/BPAP machine captured my own initial responses to treatment. Bucky's resistance to counseling, the oppression and discrimination Arthur and Shaun confront, and the acceptance Chad, Jericho, and Jia receive mirror many of my personal experiences with disability. Representation is important for empowering people. It helps challenge stigmas associated to disability. It creates awareness and normalizes disability. Since the onset of disabilities, I have been more aware of spotting disability in films and TV shows.

Disability identity is a minority identity that many people will experience at some point in their lives, whether it is short-term, long-term, or permanent (Seibers, 2008). Disability does not discriminate. People choose to discriminate what they do not understand and perceive to be "normal" based on pre-existing stigmas enforced by society at large (Goffman, 1963). The unknown frightens people. Changes of the body and mind are not easy to accept and understand when it alters our lives. Representing disability in mainstream films and television shows will not alone resolve issues in society. However, it is an important step forward. It helped me cope with my own disabilities. It gave me a perspective of the good and bad in society outside of my own experiences. It served as motivation for me to write my own research as a creative autoethnographic testimony. This is why representation matters. If it encouraged and helped normalize my experience, imagine what could be possible with an increased representation of disability identity.



## **Self-Empowerment: Becoming an Educated Gangsta**

During my journey of exploring disabilities, I sought ways to empower myself through actions, interactions, and conversations. Being open about my disabilities led to new ideas, new perspectives, opportunities, and new insight. Allowing myself to be vulnerable did allow others to do the same and entrust me with their own experiences, whether direct experiences or a lack of knowledge. The first step to self-empowerment began by redefining past experiences.

### **The New, Current Self**

Becoming who I am now was shaped by various events that occurred alongside confrontations of injustice in the workplace and learning environment. These moments were not planned; they occurred organically over time. The more I shared my unjust experiences, the more others would relate, provide support, create safe spaces, and remind me of my greatness. Each interaction empowered my identity. It reframed views of myself. Over time, these experiences helped deconstruct the oppressive conditions placed upon me by the oppressors. As I gained momentum in my identity redevelopment, the perspective of myself became empowered. Deep down inside my mind, I acknowledged a will to overcome the obstacles of doubt and fear. I recognized not being able to return to a past version of myself and resume being my best. There was a better path. It was transforming myself to a better, improved version in the present. Changing my outlook of hoping for better days to living better days in the present was the thought change I required. With the many injustices confronted, I refused to live a life with trauma, depression, anxiety, and sleep deprivation. I sought guidance from people I knew would understand the unjust experiences placed upon marginalized and minoritized

people. These were friends and colleagues that also challenge the oppressive structures of our society. I surrounded myself with people who would empower, encourage, motivate, embolden, and inspire. My empowerment came from other people willing to help me in my healing and journey. The following five topics have left a positive impact on my life. These are the moments and interactions that helped me become who I am now. They all redefined and strengthened my identity.

**The Former Self.** In conversations with a fellow tribe member, we often discuss our former self and current self. This should not be confused with the Christmas ghosts of past, present, and future. That is a joke and irrelevant. Brandon, a Black male from Detroit, has identity similarities of being first-generation and growing up in an urban environment plagued by injustices on marginalized and minoritized people. When Brandon and I speak of our pasts, Brandon phrases our pasts as versions of our former self. We believe each day we create a new self. The prior day becomes our former self. These conversations provided a new perspective on letting go of the past. History cannot be changed, but we can learn from the past. We can create new decisions each day. When I think of my past experiences with disabilities, workplace discrimination, and learning environment discrimination, I see it as experiences of my former self. My former self experienced trauma, depression, sleep deprivation, oppression, discrimination, and many more unfortunate conditions. It is not who I am in the present. The past teaches us how to be better in the future, and we need to be that future today. This perspective of looking at my past as a former self led to reshaping present thoughts as steps towards a new self.

**Disability Training.** A training on disabilities was held on May 27, 2020 (see image 10 below). This opportunity arose from a substance use prevention training I

attended in which my assignment was returned with corrections for not following instructions. Upset, I discussed with the instructor the lack of clarity in the assignment.

Image 10.

Disability Training Email Promotion

**NOTE: Both trainings will be offered remotely, in a one-day, web-based format.**

**Upcoming Trainings**

**Disabilities: Understanding the Diversity of Learning**

**May 27, 2020**  
Remote, Web-based, 1-Day

The World Health Organization estimates that 15% (over a billion) of the world population has a disability. In the United States, 61 million adults and 17% of children ages 3 – 17 have a disability. In New Mexico, the 2017 Behavioral Risk Factor Surveillance System (BRFSS) identified 26.5% of the adult population identifies with having a disability. Disabilities go beyond affecting people physically, whether it is short-term or long-term. Learning disabilities create a difference in the way an individual processes and comprehends information. Because learning disabilities are “invisible,” it is easy to exclude this population in our work. There are several methods to being dismissive and inclusive in the way we deliver trainings, instructions, presentations, visual aids, and programs. This training will help preventionists understand the various aspects of disability and how to be inclusive in their prevention practice and workplace approaches. Participants will learn about disability policy, understanding the various learning disabilities (e.g. ADHD, dyslexia, mental health, memory retrieval, etc.), theories, models, universal design, and respectful language. Preventionists will gain hands-on experience and knowledge to be supportive of diverse learners.

LEVEL: Advanced  
TRAINER: Leonel A. Diaz Jr., M.Ed  
CONTINUING EDUCATION HOURS: 6.6  
FEE: \$130

Registration Page

**Successfully Managing Your OSAP Contract**

**June 4, 2020**  
Remote, Web-based, 1-Day

The Office of Substance Abuse Prevention (OSAP) receives money to fund communities from both federal and state governments. Both of these funding sources have requirements that OSAP must adhere to in order to stay in compliance and maintain funding for the entire state of New Mexico. These requirements trickle down to each OSAP provider into contracts and Scopes of Work (SOW). With decreases in funding availability, it is crucial to manage your OSAP contract and ensure your SOW is fully being met. This training will assist in successfully managing an OSAP contract using proven Project Management tools and techniques. Participants will review tips and practices for: the management plan; budgeting; final reports; how to work with OSAP when a strategy isn't working and suggesting a change in SOW; and developing an archiving process for the repository of project's institutional documents. (Note: This training is only open to OSAP providers.)

LEVEL: Intermediate  
TRAINER: Paula Feathers, MA  
CONTINUING EDUCATION HOURS: 6.6  
FEE: No fee (\$130 cancellation fee for no-shows or late cancellations)

Registration Page

The NM ATODA Prevention Workforce Training System is sponsored by the New Mexico Behavioral Health Services Division / Office of Substance Abuse Prevention (OSAP) in collaboration with Kamama Consulting.

Note

Sharing with the instructor my learning disabilities and need for clear, direct instructions, I recommended the use of universal design to avoid this problem occurring to others. This action was motivated by colleagues who had shared this being a problem with the training. Choosing to address it, the instructor chose to have a conversation with me about how to improve the training using universal design. This exchange resulted in

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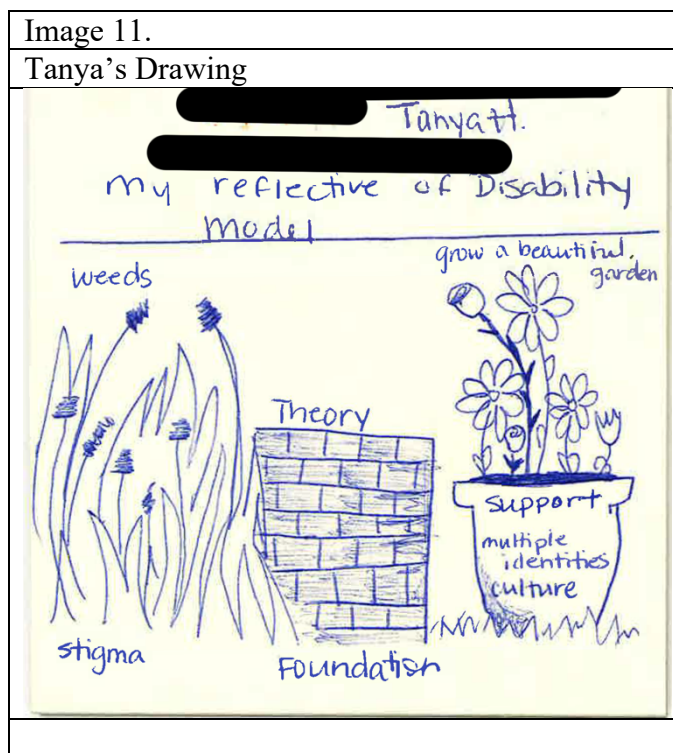
being invited to deliver a training on disabilities and substance use to prevention professionals in New Mexico.

In this training, attendees learned about the various disabilities associated to substance use, disabilities theories (those mentioned in chapter two of this research study), the history of disability rights, the challenges to the disability community, the Americans with Disabilities Act, disability laws and policies, and implementing universal design to remove barriers. It was an engaging training filled with reflection, paired and group discussions, short video clips, and practice activities. There were a variety of learners in the training. One person was highly experienced while one claimed to have minimal knowledge on disability. By the end of training everyone, including myself, had learned something new about disabilities. It was an amazing experience.

A friend, colleague, and attendee at the training, Tanya, chose to draw her reflection during an activity. She shared her drawing with the class. Upon viewing it, I thought it was great summary of what I taught in the training. Weeds represent the stigmas, with disability models serving as a way to stop the weeds from spreading in the form of a wall. The wall also represents a foundation for supporting and protecting those with disabilities. This allows us to grow gardens supportive of diverse learning and growing. After sharing with her how it would be great to include some artwork in my dissertation, she gave me permission to use her drawing (see image 11 below).

The reason I highlight this training opportunity is because it came about after I chose to advocate for myself. By being provided an opportunity to train prevention professionals in the state of New Mexico, it empowered and increased my self-esteem. It gave me confidence in my abilities to serve as an instructor, an advocate, an activist, and

ally. The feedback I received was highly encouraging, with the only area of improvement being converting the training from one day to two days. The attendees wanted more time with all the activities. This experience fueled my determination to write this research study. The attendees made it very clear that this topic is of high importance. It was a training they hope will be offered again. I must continue to follow my path in helping change the stigmas to disability. No doubt. No hesitation. Never surrender.



**A Tribe and Traveling Family.** Unable to fully conceal the visibility of my disabilities, I shared with close friends and colleagues the conditions brought forth. While initially daunting, their support and compassion was comforting. For those who did not understand, they asked if it was okay to ask me questions to understand while asking to forgive their ignorance. They did not judge my altered behavior. They sought to understand and identify methods to help. Some provided advice. Journaling, note taking,

making art, taking a meaningful pause, dissecting individual disabilities as enhanced abilities, predicting a better future, setting goals, identifying the systemic oppression towards people with disabilities, thinking about universal design, confronting toxic masculinity, growing plants, using counseling services, learning to advocate for myself, reading self-help books, and many more recommendations were provided in the hopes it would help in some way. Hundreds of hours of conversations took place with several people of all backgrounds. Some realized they had or were experiencing a disability as a result of our conversations. Without these people, I wonder how my experiences may have been different.

These people I refer to as my tribe and traveling family. My traveling family were among the first to learn of my disabilities. Given they are all educators across various areas of education, they provided me with tools and encouragement. My tribe are people who have gone out of their way to provide their best for my success. These people conducted regular follow-up phone calls and text messages. Some of them provided small little gifts like essential oils, candy, pastries, charms, hats, postcards, and meals. My traveling family is a part of my tribe. I distinguish my traveling family from my tribe because we would see each other frequently through our consulting contracts across the country. Their actions convinced me of the importance of having a group of people you can refer to as your tribe. A tribe is there to help, support, encourage, empower, motivate, heal, care, love, reinforce, inspire, and provide any assistance to ensure your success. They are honest, candid, brave, vulnerable, open minded, and compassionate. Everyone needs a tribe. There is too much evil in this world. We are stronger united, not divided.

Without a tribe, my story may have never been written. Sometimes I think, I would not be alive without all they did. They provided reminders about life obstacles to be conquered, much like a plight of champions. They knew I would be capable to rise above the challenges and become a better person in the process. They saw a future I could not see for myself. This reminds me of a quote by Fisher (1986). “Ethnic memory is thus, or out to be, future, not past, oriented” (p. 201). My tribe, a diverse representation of our world, always spoke of our experiences as the future. We think ahead. Our actions in the present improve our future. I imagine this is the idea Fisher held. Our past can be dark, treacherous, and painful. Our future can be better. Our present actions change our future. Our memories contain positive moments allowing us to propel forward. Positive and negative memories cannot be separated. Within negative memories exist the positive memories of a better future. Our ethnic memory shall always focus on the future to combat the injustice.

**Redefining Machismo as Positive, Not Negative.** A conversation with Dr. Frank G. Pérez, a professor at the University of Texas El Paso (UTEP), led to redefining machismo (manliness). After conducting fieldwork on a research study, I shared with Frank and his partner, Dr. Areli Chacon, the experiences discussed in chapter four. I felt comfortable speaking with them based on our shared identity of being first-generation from Mexican backgrounds in higher education. After sharing my stories, Frank stated, “You are a true definition of a macho.” “Frank! That’s mean,” said Areli. Frank proceeded to clarify his statement. His view is that men should be vulnerable and empowered to speak of their pains, traumas, hardships, health, and emotions. It is difficult for men to share their thoughts because society has defined masculinity as men

having to be aggressive, tough, rugged, emotionless, and strong (Barrett, 2001; Mirandé, 1997; Whitehead et al., 2013; Whitehead, 2009). Because of this, Frank believes I embody his views of what a “macho” should be, thus reclaiming machismo in a positive view. This requires for men to speak against toxic masculinity to redefine machismo.

Conversations about masculinity and vulnerability are required to help men confronting difficult life experiences impacting our wellbeing. Opening up to men allowed me to have rich and empowering conversations to redefine masculinity. Other men expressed confronting pressure and insecurities of what it means to be a good man. They did not know how to be open about their experiences. They feared being perceived as weak, emotional, and powerless based on the pressures of society reinforcing toxic masculinity. These experiences for men cannot continue. Sharing my stories has not been easy. Conversations experienced as I did with Frank and Areli are necessary. Help me redefine machismo in a positive view. Change starts with us.

**Educated Gangsta.** You might be wondering about the title for this section, “Becoming an Educated Gangsta.” On too many occasions, sharing the name of my hometown, Compton, California, raises eyebrows. Others ask questions of how a young man from “the ghetto” escaped or survived the rough conditions. Some people have assumed I may have gang connections or history. Other people have said a variation of, “You are lucky to have left that place!” Word? (Sure?) It upsets me to hear negative stereotypes and microaggressions about my hometown and identity. It began as a joke and turned into my serious response, “I’m a gangster of education.” This response helps challenge the responses I receive. It also helps me connect with students and people who



share my background. I will always be straight outta Compton. “The hood is where I’m from, but it is not, what I am” (Ice Cube, 2008).

### **Limitations**

Because this research study is a creative autoethnographic testimonio, there are some limitations. I cannot provide a view on why people in positions of power chose to make unjust decisions towards a Latino male with disabilities. They quickly demonstrated disinterest in providing any support. A productive conversation was not possible. There are details to my story that I did not include, such as names of people and departments, to avoid taking away focus from my experiences. It was a way to remove power from them. Some memories were not my own experiences; I chose to not share those details. It was my way of guaranteeing sharing only my perspectives. This experience is only my story. I encourage others to speak their truths and contribute through autoethnography, *testimonio*, or both.

### **Recommendations for the Next Generation**

Several thoughts come to mind on both research and practices one can use to remove the injustices on people with disabilities within the organizational culture of higher education. It includes developing a team of experts, changing policy, shifting organizational culture, changes to the medical systems, and counseling. This will require studying the problems further to establish new practice. For many of these recommendations to occur, you will have to follow the wise words of Master Yoda, “You must unlearn what you have learned” (Kurtz & Kershner, 1990). If you don’t believe it as Luke Skywalker did, it will be the reason you fail.

My first thought is the development of a team focused on changing the stigmas associated to disability in both the workplace and learning environment of higher education. This team should include people knowledgeable in disability law, accommodations, problem resolution, culture change, universal design, advocacy, counseling, and any other necessary skill set. Personally, I would enjoy naming this team the Justice League. This diverse team would be responsible for addressing and implementing changes to remove barriers to disability.

The second thought focuses on reviewing, improving, and changing laws and policy relating to disability, discrimination, oppression, hostility, bullying, and intimidation relating to the workplace and learning environments. Laws and policies should be updated every two years. This should include providing a faster investigation to allegations as well as accountability for those choosing to vacate their positions during an investigation. In addition, human resource departments must have a shift in culture by focusing on protecting students and employees not in positions of power, and not the college/university officials in positions of power and the college/university as a whole. This cannot continue.

Third, training and education on disability must be implemented immediately. A yearly online training will not be sufficient. It should include plans and goal setting for individuals and groups to establish universal design in classrooms, offices, and across every aspect of a college/university. People in positions of power should be required to be certified with fundamental knowledge of disabilities.

The medical system, specifically primary care, needs a shift on understanding health. This is my fourth thought. Medical systems need to view patient care holistically.

Sleep health must be prioritized. A person's health should be a collaboration among medical professionals. No medical professional should be allowed to speak about health as if they know everything there is to health. It is unrealistic for them to be subject matter experts on every subject of health. A patient should have a yearly visit with several health professionals such as dietitians, physical therapists, chiropractors, massage therapists, respiratory therapists (sleep), and counseling. A general care provider does not provide holistic care. Health care should not be a business. No person should have to worry about affording health insurance. This has to end. Let's make universal healthcare a priority!

Fifth, counseling. Counseling should not be a last resort option once a person has experienced a crisis or life altering experience. Everyone can benefit from attending counseling for any reason. Personally, I believe people resist seeking counseling because of the stigmas associated to counseling. People should be introduced to counseling at an earlier stage of life, beginning as children. There needs to be increase in counseling, especially diverse counselors. I was unable to find a male counselor, let alone a Black or Brown counselor or a counselor experienced with sleep deprivation or learning disabilities. This is a very important change required for a healthier society.

Sleep needs to be prioritized in our society. This is my sixth thought. It is the most core fundamental function required for a healthy life. People with a lack of sleep must be a priority of concern. Without sleep, our entire health diminishes. There needs to be a greater emphasis on the importance of sleeping.

Last, the COVID-19 pandemic. It was unexpected for the world to experience a pandemic of this magnitude. As I read the news, rarely is it mentioned how being infected with COVID-19 might create a short-term or long-term disability. The term

disability is rarely used. Even in the consideration of who should be vaccinated, the term disability was not used. “People with underlining health conditions” has been the term used. How will employers accommodate people with “lasting symptoms” of COVID-19 for employees unable to work remotely? What about the people who lost a loved person or came close to death? How about people with disabilities fearing returning to work, school, or a “normal” society and risking their “underlining health”? These are some of the many questions this pandemic has created. How will we, as a society, help those most impacted by the COVID-19 pandemic? How will the pandemic change organizational culture? With no doubt, the pandemic has increased the number of people with disabilities. Despite a year with a pandemic in the globe, there are people who will refuse to change and accept a world impacted by the COVID-19 pandemic. What does it take for people to seriously accept health warnings and severity? Will the world return to “normal”, or will it accept the changes and create a new norm? Will this be a cause for disabilities to be fully accepted and integrated into society? We will find out.

### **Conclusion: That’s it, man! Game Over, Man! Game Over!**

While writing this research study, I have come across news articles pertaining to my research topic. Issues range from workplace problems (Couch, 2021; Meyersohn, 2021; Morrow, 2021), a police officer resigning after misconduct (Brown, 2021), mental health concerns in society (Couch, 2021; Krawczynski, 2021; Melas, 2020; Miller, 2021; Narula, 2020;), disability discrimination (Andone & Alonso, 2020; Clark et al., 2020; Heasley, 2020; Shapiro, 2020; Virdi & Jackson, 2021), the importance of sleep (Badran et al, 2020; Blanchflower & Bryson, 2020; Beutel, 2020; Didion, 2021; UCLA, 2020; SEO, 2021), and people continuing to ignore safety during the pandemic (Alonso &

Waldrop, 2021). My creative autoethnographic testimony is a demonstration of issues within society reflective of the organizational culture of higher education. There are many problems in education and society requiring solutions. When we cannot resolve problems within society immediately, we can focus on improving ourselves and helping those around us. This is the most powerful approach any of us can take to combat injustice. This act alone can have a long-lasting impact. I was reminded of this during a museum visit.

On April 3<sup>rd</sup>, 2021, I visited the Frida Kahlo, Diego Rivera, and Mexican Modernism art exhibit at the Albuquerque Museum with friends. On two separate walls with Frida Kahlo's artwork, there was a quote on each by her:

Spanish: "Al final del dia, podemos soportar mucho más de lo que creemos que podemos."

Translation: "At the end of the day, we can endure much more than we think we can."

Spanish: "Nada es absolute. Todo cambia, todo se mueve, todo revoluciona, todo vuela y se va."

Translation: "Nothing is absolute. Everything changes, everything moves, everything revolves, everything flies and goes away."

Throughout the weekend, I reflected on Kahlo's words. Many years ago, I wondered how much I could endure in a life-threatening situation. If I time traveled to tell my former self how much was endured, he would not believe it. He would be in disbelief. It was exhausting to my core. Somehow, I endured more than I believed was possible. Kahlo's second quote supports much of the lessons my tribe provided. What is today is not

tomorrow. Change is always happening, whether we see it or not. On days I felt no progress occurred, I failed to notice very small movement forward. Each small movement led to my present self. Even when obstacles attempted to prevent moving, I endured. Kahlo's words resonate and summarize six of the most dreadful years in my life. In it, a new version of myself was forged. Kahlo's wisdom reminded me of my progress, endurance, resistance, and cadence. She left behind a long-lasting impact on society with her actions, artwork, and words. It encouraged me to continue paving a path forward and advocate against injustices of this world.

Despite the struggles I endured, there has been one focus that was prioritized to improve my overall wellbeing: sleep. Without sleep, it is difficult to function and perform the most basic of tasks. Dr. Shana Díaz once said to me, "REM sleep is free therapy." The more I sleep, the more I heal, the better I am. The experience taught me to appreciate and prioritize sleep. It helped me understand what Charles Bukowski recognized about sleep when he said, "too often, the only escape is sleep" (p. 331). Once sleep therapy became highly effective, dreaming increased. Nightmares are appreciated the most. Dreaming, an escape from reality, heals a wounded soul. As one of my favorite basketball players, Klay Thompson (2020), said, "The psychological hurdles are probably the biggest things I need to overcome". Compared to my former self, I am better equipped to address the issues surrounding disability discrimination in higher education's organizational culture.

Some institutions of higher education are not what they appear to be on the outside. Although this research study is focused on one university, there have been similar experiences at other universities. My experiences are not an isolated case. They

reflect the experiences of others (Menchú & Burgos-Debray, 1984; Montejó, 1993; Warren, 1997). Sharing my personal experiences with a variety of people allowed me the opportunity to learn how frequently the problems discussed in this research study occur to many people of all backgrounds. These people were my inspiration, motivation, and encouragement to write about the injustices I encountered. It is a testament and reflection of what other people experience. In some ways, these unjust experiences make people like me better. In a conversation with a friend, Brandon, he remembered a quote from M. Night Shyamalan's film, *Split*, in which actor James McAvoy says, "The broken are evolved" (2016). I often shared with Brandon how I felt broken from the unjust experiences. He believed I was evolving into a better version of myself. I am an advocate, activist, ally, and champion towards unjust learning and working environments. I did evolve. When I experience another unjust action within higher education, the outcome will be different.

On the inside, some institutions of education are not accepting of diversity. It does not accept people with disabilities. It does not protect people from injustices. It does not hold people accountable for their injustices. This cannot continue. I am not the first to bring awareness to these issues, and I will not be the last. There are people in this country pointing to the issues of education. What will you do: ignore the problems, advocate for change, or implement change? We need to be social deviants. "Social deviants, as defined, flaunt their refusal to accept their place and are temporarily tolerated in this gestural rebellion" (Goffman, 1963, p. 145). This notion of being a social deviant continues within present society and we must continue to bring down oppressive norms, barriers, behaviors, and cultures to enable a fruitful, diverse, equitable society. Every

action towards change is a step forward. Educational institutions are only helping support the idea that they are not a place for learning, but a place for following instructions. If it was really there to help me learn and grow, I would not need accommodations as universal design would be widely implemented. I would have not experienced discrimination of any kind in any setting. An influential social deviant, Ice Cube, best expresses my frustration with his song, Hood Mentality (2008):

Fuck school nigga, they ain't trying to educate me.  
All they give a fuck is what I memorized lately.  
I'm gon' have to teach myself, clock that money, get that wealth.  
I wanna be like Santa Claus, I don't wanna be no fuckin' elf.  
No kid left behind, but he get the run-around.  
Can't you motherfuckers see that they tryin' to dumb us down? (timestamp 3:32)

### **One More Thing**

Before concluding this research study, there is one more thing. In chapter three, I considered the idea of writing a song. This is inspired by the absolute best gansta rap group in history, N.W.A. Their music and lyrics represent the oppressive and racist conditions upon Black and Brown communities, holding true over thirty years later. With the guidance of my new favorite music artist, On Brand, I wrote lyrics for a song titled, *To My Employers and Professors*.

### ***Introduction***

I have to endure this.

Deep breath,

*\*Exhale\**

Give me the strength...



*Verse 1*

My heart is rattling, each foot dragging.

It's baffling, how this place is lagging.

A basic respect, is there more to expect while awake?

Sometimes school had me thinking I was hallucinating,

but it turns out your teaching isn't illuminating!

In class, you say I'm digressing,

Shit, your teaching is regressing!

I wish I could stop ruminating,

But your actions are just discriminating.

Fuck this, I need to focus on recuperating.

This cycle is devastating.

*Verse 2*

These work conditions are despicable!

Your actions have become predictable.

I was vulnerable,

No longer intolerable.

Severely sleep deprived, doing my best to thrive.

It wasn't like I was inconsolable.

Tried to ask for help, without a single yelp.

Well, what you did was deplorable.

This cannot remain unspeakable.  
Being accommodating shouldn't be infeasible.  
My requests were not unreasonable.  
Unbelievable!

*Chorus (x 2)*

Your doctorate doesn't make you competent.  
It makes you intolerant and further incompetent.  
A student from the streets of Compton,  
My abilities are always unprompted.  
Actions cannot be forgotten;  
Your words are always rotten.  
The oppressive conditions of academia,  
Can you believe? have continued for over a millennia!

*Verse 3*

You told me to give it my best,  
How? I'm depressed.  
What are your reasons for keeping me oppressed?  
Are you a racist? Wait, is this a test?  
Like I got some kind of "S" on my chest.  
Tried to be super, man!  
But you were suppressing the lessons,

Teaching me nothing past a first impression.  
So much for soft focus when it's hard to pay attention,  
See I don't lack comprehension.  
Unlike your incomprehension, I'll have an ascension.  
And not to mention, this tension, doesn't help with retention.

*Verse 4*

You proclaimed I drank a quarter ounce of vinegar,  
Go choke on your quarter pounder, inhibitor.  
You want us to go complete a job, acting like you're a contributor.  
You snob! You're just an inquisitor,  
a descendent of a conquistador.  
Sit high and mighty in your ivory tower, coward!  
While you're hiding, I'll be a truth distributor.  
You think your whiteness is superior?  
Attempting to keep me prisoner?  
I'll be ready to hit you with a defibrillator  
And while you're shocked by this practitioner, I'll be free, yo!  
Your good boy club won't save you, discriminator!

*Chorus (x2)*

Your doctorate doesn't make you competent.  
It makes you intolerant and further incompetent.

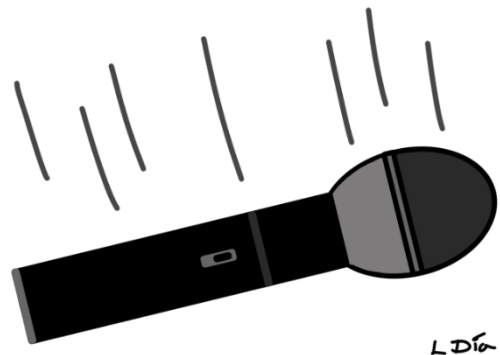
A student from the streets of Compton,  
My abilities are always unprompted.  
Actions cannot be forgotten;  
Your words are always rotten.  
The oppressive conditions of academia,  
Can you believe? have continued for over a millennia!

### **Verse 5**

Aiming to end years of oppressive structures,  
Aggressively ending your so-called infrastructures.  
It makes no sense for teaching conditions to be fractured.  
Even worse, how can work conditions be so ruptured?  
Stop acting like you have my attention captured.  
You make lesson plans and work schedules seem manufactured.  
This is all just so backward.  
Don't call yourself faculty, when you act so faulty.  
Often placing fault on me.  
Higher education doesn't need to be daunting, but it's shattered.  
Glad I'm pulling up my anchor before my boat gets battered  
By the waves of racism and oppression crashing down on me.  
I'm done being scattered and staggered, you hazard.

### ***Chorus (x2)***

Your doctorate doesn't make you competent.  
It makes you intolerant and further incompetent.  
A student from the streets of Compton,  
My abilities are always unprompted.  
Actions cannot be forgotten;  
Your words are always rotten.  
The oppressive conditions of academia,  
Can you believe? have continued for over a millennia!  
  
You can sit there quiet all you want.  
It's over now, go home and cry.



## CHAPTER 6

### AFTERMATH

There are many techniques and resources I gained from my experience. Some of these are ideas I wish I knew sooner. Some of them were referenced in previous chapters while others are new. Below are some recommendations if you find yourself in a situation similar to mine.

#### Online Resources

Ask Jan has several recommendations for accommodations for nearly every disability.

This helped create the list of accommodations I requested: <https://askjan.org>. If you want to know more about sleep disorders, this page from Ask Jan has a good explanation:

<https://askjan.org/disabilities/Sleep-Disorder.cfm>

The following have phone numbers and resources on their sites in the event you find yourself in or know of someone having a crisis:

- National Alliance on Mental Illness: <https://nami.org/help> | 1-800-950-6264 (NAMI)
- National Suicide Prevention Lifeline: 1-800-273-8255 (TALK) / 1-888-628-9454 (Spanish option)
- Substance Abuse and Mental Health Services Administration:  
<https://www.samhsa.gov/find-help/national-helpline> | 1-800-662-4357 (HELP)
- National Institute on Mental Health: <https://www.nimh.nih.gov/health/find-help/index.shtml>

This is resource specifically for Hispanic and Latinx/a/o communities with resources in Spanish. The National Hispanic Family Health Helpline:

<https://www.healthyamericas.org/help-line> |

1-866-783-2645 (Su Familia)

This resource is specifically for Black girls: <https://therapyforblackgirls.com/>

These two organizations gathered many Hispanic and Latinx/a/o counselors and listed them on their websites: <http://www.americansocietyhispanicpsychiatry.com/> and

<https://www.therapyforlatinx.com/>

If your organization does not have an ADA coordinator or you find yourself experiencing discrimination, contact the United States Equal Employment Opportunity Commission.

Their website for assistance is <https://eeoc.gov>.

The World Health Organization has this page focused on explaining mental health. It helped me better explain how mental health can impact our social environment to others:

<https://www.who.int/en/news-room/fact-sheets/detail/mental-health-strengthening-our-response>

## Books

This book has great information on campus training, inclusive climates, addressing internships and programs, and creating a supportive campus environment for people with disabilities.

- Evans, N.J., Broido, E.M., Brown, K.R., Wilke, A.K. (2017). *Disability in Higher Education: A social justice approach*. San Francisco, CA: Jossey-Bass

This book was recommended by a colleague. It was very helpful in helping me rethink my flaws and letting go of them. This is a book I believe everyone should read.

- Brown, B. (2010). *The Gifts of Imperfection: Let go of who you think you're supposed to be and embrace who you are*. Center City, MN: Hazelden Publishing

This book is a great read to understand neuropsychology and brain health. Many of the techniques I mention below are included in this book as a way to help improve the mind.

- Koltuska-Haskin, B. (2020). *How My Brain Works: a guide to understand it better and keep it healthy*. Santa Fe, NM: Golden Word Books

Recommended by a Yoga instructor, this book has been instrumental to my shift in thinking. If you are interested in mindfulness and meditation, this is a good starting point. I used it to guide my meditation and keep myself mindful on stressful days.

- Hanh, T.N. (1998). *The Heart of Buddha's Teaching: transforming suffering into peace, joy, and liberation*. New York, NY: Harmony Books



My sleep doctor recommended this book as a great starting point for understanding sleep deprivation and all it brings. It helped me normalize and understand many of my conditions with sleep deprivation.

- Walker, M. (2017). *Why We Sleep: Unlocking the Power of Sleep and Dreams*. New York, NY: Scribner

## **Films**

This is a free documentary, *Sleepless in America*, by National Geographic. It provides a good explanation of the issues lack of sleep creates for society:

<https://www.youtube.com/watch?v=1qlxKFEE7Ec>

On Netflix, there is a documentary about the lives of disability activists and their grassroots efforts to forge the path for the Americans with Disabilities Act. It is currently nominated for an Oscar Award. The documentary is titled, *Crip Camp*. There is a trailer available: <https://www.netflix.com/title/81001496>

## **Techniques**

**Gardening:** This taught me patience and perspectives on growing conditions. What I learned is applicable to people. Some plants require more water, less water, different soil, direct sun, indirect sun, and several other growing conditions. We, as people, also have different conditions for growing. For context, I have lost many plants, even as of recent. Each attempt helps improve my green thumb.

**Art:** One of my many backgrounds is in art. Crafts, photography, painting, drawing, sketching, mixed media, woodcraft, musical instruments, knitting, and cooking are some examples of the many possibilities. Find yourself an art hobby. Everyone has an artistic ability. I rotate my artistic interests to help expand my perspective. It helps with expression and heals the soul.

**Writing:** Sometimes we don't want to speak with someone about our life experiences. Writing in a journal, diary, word processor, or even on pieces of paper to throw away is a helpful way to unload your thoughts. Writing out life experiences can help you cope or celebrate. Writing some of my life experiences allowed me to notice my joy for creative writing.

**Exercise:** My favorite exercise activity is to jog or run. It helps me shake off stressful experiences. Find an exercise activity that does the same for you. Yoga is a great way to help you focus, meditate, and be patient. Walking is always a great option.

**Meditation and Mindfulness:** Learning how to calm and silence a busy mind was one of the most beneficial techniques I learned. Learning to be mindful and meditate helped me address ADHD, difficulties falling asleep, and managing stressful situations. It is best to start with guided meditation until you feel comfortable meditating alone.

**Tribe:** Surround yourself with a group of supportive and honest people. Let go of people who you feel cause harm and stress. The people you surround yourself with makes a

significant change in life. The people in my tribe are willing to disagree and point out their observations in a respectful manner. A tribe should be a group of people you find yourself able to be vulnerable with. It is something we all need to allow fruition of our best self.

***Counseling:*** Like many people, I was hesitant about seeking counseling. In my process, I have learned finding the right counselor can make the greatest of difference. If you don't like the first counselor after a few sessions, find another one. In fact, ask that person for recommendations. They are aware they are not always the right fit for every person.

### **Final Words**

This is not a complete list of every resource available. There is help available if you need it and this chapter should provide you a starting point. Addressing disability is no easy task. There are moments in life when we all need help. It does not make us weak. It makes us stronger. Keep in mind, no one truly teaches us how to cope with difficult situations in life. Disability, specifically negative mental health, is not spoken about in society. To remove the stigmas to disability, we all need to accept and normalize it. We all experience disability at some point in our lives; it is how we deal with it that makes all of the difference. Please feel free to contact me with any questions at [leoneldiazjr@gmail.com](mailto:leoneldiazjr@gmail.com).

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## Appendix A – Timeline of Events

July 2014	Arrived in Albuquerque, NM
June 2016	Travel to Switzerland
June 2016 – March 2017	Problems in Job #1
August 26, 2016	First Dental Visit: sleep apnea identified
Fall Semester 2016	Faculty #1 Problems
October 17, 2016	First Sleep Center Visit
December 4, 2016	First Sleep Study
January 2017	Sleep Therapy Equipment Received
Spring Semester 2017	Faculty #2 Problems
March 2017 – March 2019	Problems in Job #2
Fall Semester 2017	Faculty #3 Problems
October 2017	Nasal Surgery
March 2, 2018	Second Sleep Study
Summer 2018	Neurological Assessment: Learning Disabilities Identified
August 2018	ADHD medication prescribed
Fall Semester 2018	Faculty # 4 Problems
September 12, 2018	Accommodations Approved
October 2018	Concussion
March 2019	Amazing Job #3
April 2019	Concussion Heals; ADHD Returns
April 5, 2019	NASPA Latinx/a/o Knowledge Community Webinar
Fall Semester 2019	Faculty # 4 and 5 Problems
May 27, 2020	Disability Training Delivered
August 2020	Sleep Therapy Issues Resolved
September 2020	Unemployed

## Appendix B – Clinic Note

Document info

Result type: Result date: Result status: Performed by: Verified by: Modified by:

Clinic Note

Letter - Sleep Center Oct 17, 2016, 05:00 p.m.  
authenticated

Chief Complaint:

Consult OSA

History of Present Illness:

Referring Provider: Self-referral

RE: Leonel Diaz

Problem List:

Anxiety Depression

Hx of gastroesophageal reflux (GERD) Hypertension

I had the pleasure of seeing you at your request, for an initial consult for Obesity evaluation for sleep apnea at the Sandoval Regional Medical Center Sleep Past Medical History: Disorders Clinic . Patient has a past medical history of GERD, No qualifying data available. allergies, anxiety, depression, hypertension, obesity, and sinus problems who presents with symptoms suggestive of obstructive sleep apnea. These include loud snoring, waking up gasping for breath, witnessed apneas during Past Surgical History: sleep, inability to sleep on his is back for unknown reasons, shortness of No Surgical Procedures for all visits. breath supine, waking up with heartburn, waking up with a sore throat, No qualifying data available. waking up with a headache, often having a dry mouth when waking up. The snoring has been present for many years, the rest have developed within a year or so.

SLEEP SCHEDULE:

The patient reports usually going to bed at approximately 11:30 PM and waking at approximately 6:30 AM on weekdays . It takes the patient approximately 1:40 hours to fall asleep. The patient goes to bed at 11:30 PM and wakes up at 8 to 9:00 AM on weekends. The patient reports feeling not rested anytime upon awakening. Patient does not take naps. Patient usually wakes up 3-4 times during the night one time to urinate and returns to sleep within 5-30 minutes.

Total average sleep time per night: 7-9 hours. SLEEP-WAKE COMPLAINTS:

Employment School

Employed, Student, Activity level: Desk/Office. Highest education

Patient reports restless sleep, difficulty falling asleep due to racing thoughts, dream enactment, hallucinations while

awake, frequent somniloquy, problems with relationships, work or education, concentration, and memory because of sleepiness.

Epworth Sleepiness Score: 11/24. SLEEP ENVIRONMENT:

Patient describes the bedroom as quiet, dark, secure, and at a comfortable temperature. The patient reports the mattress is comfortable.

EXPOSURE HISTORY: Caffeine Consumption: NONE Alcohol Consumption: 1-3 drinks every other week Tobacco Use: One to 2 cigarettes a month Recreational/Illicit Drug Use: NONE

Medications (herbal, OTC) to help with sleep: Marijuana 3-4 nights a week

Review of Systems:

(within past 2 weeks):

CONSTITUTIONAL: Denies fevers, chills, or excessive sweating during sleep. \_

NEUROLOGICAL: Denies fainting. Reports morning headaches, dizziness. EYES:

Denies double vision. Denies eye irritation or discomfort. Reports blurred vision

ENT: Denies epistaxis, dysphagia, or sore throat. Reports nasal congestion, otalgia.

NECK: Reports neck stiffness or pain. \_

PULMONARY: Denies wheezing, shortness of breath with activity. Denies hemoptysis.

Denies nighttime cough. Reports shortness of breath at rest. CARDIOVASCULAR:

Denies tightness or pressure, palpitations or discomfort in neck or left arm. Reports discomfort in jaw and occasional chest pain.

GASTROINTESTINAL: Denies vomiting, change in bowel habits, or hematochezia.

Reports acid reflux or heartburn, nausea, melena. \_ MUSCULOSKELETAL: Denies loss of coordination. Reports back pain, joint pain.

GENITOURINARY: Denies incontinence. Denies frequent nocturia. \_

HEMATOLOGY/IMMUNOLOGY: Denies abnormal bleeding, easy bruising, or recent infections. \_

INTEGUMENTARY: Denies skin sores or lesions, Denies edema. Reports rash.

PSYCHOLOGICAL: Reports anxiety, panic attacks, or depressed mood. \_

Physical Exam:

Vitals & Measurements

Systolic BP Sitting: 161 Diastolic BP Sitting: 99

PHYSICAL EXAM:

GENERAL APPEARANCE: Pleasant, well-nourished patient, in no acute

level: Post graduate degree(s). Operates hazardous equipment: No.



Substance Abuse

Current, Marijuana, Previous treatment: None. IV drug use: No.

Tobacco

Cigarettes, 1 per day. Ready to change: No. Second hand smoke exposure: No.

Family History:

distress. Patient alert.

EYES: Pupils equal round and reactive to light, anicteric sclera, no conjunctival injection, EOMs intact.

ENT: Ears: bilateral light reflex to tympanic membranes. Nose: Nares patent, mucosa pink. Throat: Mucous membranes moist. Tonsils +1. Mallampati

4. mild retrognathia and micrognathia. NECK: Supple without adenopathy.

CARDIOVASCULAR: Regular rate and rhythm.

PULMONARY: Clear to auscultation bilaterally. Breathing is non-labored.

GASTROINTESTINAL: Positive bowel sounds, soft, non-tender.

SKIN: Warm, dry, without edema.

NEUROLOGIC: No focal neurologic deficits noted. Patient ambulates with steady gait.

PSYCHIATRIC: Mood and affect appropriate.

Assessment/Plan:

ASSESSMENT:

1. Sleep disordered breathing (obstructive and/or central sleep apnea (OSA/CSA). Due to the following significant symptoms that are known to be associated with sleep apnea ,loud snoring, waking up gasping for breath, witnessed apneas during sleep, inability to sleep on his is back for unknown reasons, shortness of breath supine, waking up with heartburn, waking up with a sore throat, waking up with a headache, often having a dry mouth when waking up, the patient will be scheduled for a split night polysomnogram. If sleep disordered breathing is present, the patient will be titrated with PAP therapy to minimize respiratory events and improve overall sleep quality. Once the results of the polysomnogram are available, these and ongoing recommendations will be reviewed with the patient by telephone.

2. The importance of PAP therapy to reduce respiratory events of sleep apnea and to improve sleep quality was reviewed as follows: Treating sleep apnea is known to reduce the risk of cardiovascular, neurologic, and behavioral co-morbidities that are associated with untreated sleep apnea, including hypertension, impaired glucose control (diabetes melitis), cardiovascular disease, cerebrovascular disease, exacerbation of neurodegenerative diseases, as well as depression, hyperactivity, difficulty with memory and concentration, and exacerbation of psychiatric co-morbidities.

3. Records/charts/labs/polysomnogram(s): Available medical records, charts, laboratory results, and polysomnograms were reviewed and discussed with the patient.

4. Other significant problems: insomnia

1. Sleep-disordered breathing ICD10 G47.30

2. Excessive daytime sleepiness ICD10 G47.19

3. Insomnia ICD10 G47.00

Orders:

SRMC Sleep Lab Study Referral  
PLAN:

1. The patient will be scheduled for a split night polysomnogram (aka sleep study). During a split night study, if clinically significant sleep apnea is present within the first 2 hours of the study, treatment with PAP therapy will be initiated to eliminate sleep disordered breathing and improve sleep

Immunizations:

—

quality. During a diagnostic or a home study, if clinically significant sleep apnea is found, patient will be scheduled for a PAP titration study at another visit.

2. The patient is encouraged to maintain ideal body weight.

3. Healthy Sleep Practices

a. The patient is encouraged to sleep an adequate amount of time each evening. A typical adult sleep time is 7.5 - 9 hours, preschoolers age 3-5 years of age, 11-13 hours per night, 5-12 years of age 10-11 hours, and 13-19 years of age 8-9.5 hours.

b. Sleep hygiene: Insufficient sleep time frequently causes significant daytime sleepiness, depression, hyperactivity, difficulty with learning and concentration, and headaches. Consistent bed times and wake times are recommended as is morning bright light.

c. Avoid watching television (TV) to fall asleep as the blue light from TV, and all electronics suppresses the normal release of melatonin, inhibiting and/or delaying sleep onset.

4. Follow-up with your referring provider for ongoing medical care and follow-up with the Sleep Center for ongoing management of sleep problems (sleep apnea, insomnia, restless leg syndrome, etc.).

5. Patients placed on PAP therapy will be instructed to return monthly until usage is greater than 70%, which is defined as 4 hours per night at least 5 nights per week. Insurance companies require 70% minimum usage, known as compliance, in order to approve and pay for supplies and refills. Compliance must be met for a period of 31 consecutive days within the first 90 days for CPAP and 61 consecutive days within the first 90 days for Bi-PAP (Bi-PAP ST and ASV).

Patient agrees to plan and demonstrates understanding by repeating it to provider.

Thank you for the opportunity to participate in the care of your patient. In the event of any questions or concerns, please do not hesitate to contact the Sleep Center by telephone. A sleep specialist will return your call at the earliest convenience, typically within 24 hours.

## Appendix C – Sleep Polysomnogram Report

Document info

Result type: Result date: Result status:

Sleep - Polysomnogram Report Dec

04, 2016, 04:46 p.m.

authenticated

Performed by:

Verified by:

Modified by:

Patient: Leonel Diaz

University of New Mexico and Sandoval Regional Medical Sleep Disorders Centers

Members of the American Academy of Sleep Medicine

NOCTURNAL SPLIT NIGHT POLYSOMNOGRAM REPORT SUMMARY

Date Of Study:

Patient Name: Patient MR#: 12/4/2016

Leonel, Diaz

Type of Study:

Age: Gender:

Full Night Titration

male

DOB: Height:

Study #: Weight:

Primary MD: Unknown BMI:

Referring MD:Self Location: SRMC

Ordering MD: Study Technologist:

Reading Sleep MD:

Scoring Technologist:

CLINICAL HISTORY (Indication for study):

Patient has a past medical history of GERD, allergies, anxiety, depression, hypertension, obesity, and sinus problems who presents with symptoms suggestive of obstructive sleep apnea. These include loud snoring, waking up gasping for breath, witnessed apneas during sleep, inability to sleep on his is back for unknown reasons, shortness of breath supine, waking up with heartburn, waking up with a sore throat, waking up with a headache, often having a dry mouth when waking up. The snoring has been present for many years, the rest have developed within a year or so.

#### SLEEP SCHEDULE:

The patient reports usually going to bed at approximately 11:30 PM and waking at approximately 6:30 AM on weekdays. It takes the patient approximately 1:40 hours to fall asleep. The patient goes to bed at 11:30 PM and wakes up at 8 to 9:00 AM on weekends. The patient reports feeling not rested anytime upon awakening. Patient does not take naps. Patient usually wakes up 3-4 times during the night one time to urinate and returns to sleep within 5-30 minutes.

Total average sleep time per night: 7-9 hours.

#### SLEEP-WAKE COMPLAINTS:

Patient reports restless sleep, difficulty falling asleep due to racing thoughts, dream enactment, hallucinations while awake, frequent somniloquy, problems with relationships, work or education, concentration, and memory because of sleepiness.

Epworth Sleepiness Score: 11/24.

#### SUMMARY OF SLEEP DATA:

Baseline Data Awake: Respiratory rate 14, oxygen saturation 99%, and heart rate 66.

Sleep Architecture: Total recording time 383 minutes, total sleep time 326 minutes, sleep efficiency 85%, wake after sleep onset 41 minutes. The initial sleep latency was 16 minutes, REM latency 85 minutes. Distribution of sleep stages: 19% NREM 1, 64% NREM 2, 0% NREM 3, and 17% REM sleep.

Arousal and Awakening Data: A total of 4 awakenings and 93 arousals were seen over the course of the night resulting in a mean of 0.7 awakenings and 17 arousals per hour of sleep. There were 13 arousals per hour of sleep related to respiratory events, 2 to periodic limb movements, and the remainder to no particular cause.

Sleep-Related Respiratory Patterns: A total of 25 apneas (10 obstructive, 7 mixed, 8 central), 95 hypopneas (95 obstructive, 0 central) and 29 respiratory effort-related arousals (RERAs) were observed in 326 minutes of total sleep time.

The patient underwent a baseline diagnostic period of 121 minutes during which time the Medicare apnea/hypopnea index (AHI) was 17 events per hour of sleep. According to guidelines established by the American Academy of Sleep Medicine (AASM) in which the defining feature of a hypopnea is an electroencephalographic arousal and/or 3% (rather than 4%) oxygen desaturation, the AHI was 29 events per hour of sleep. The respiratory disturbance index (RDI, which includes apneas, hypopneas, and RERAs) was 29 events per hour of sleep.

Oxygen Saturation Data: The 4% oxygen desaturation index was 14.

Heart Rate Data: The mean heart rate during wakefulness was 66 beats per minute, during sleep 69, during NREM sleep 70, and during REM sleep 67. The patient

demonstrated a normal sinus rhythm throughout the study. No abnormalities of cardiac rate or rhythm identified.

Periodic Limb Movements: The number of PLM series was 0 with a mean of 0.0 periodic limb movements per hour of sleep noted.

Electroencephalogram/Parasomnia: There were no abnormalities or evidence of seizure activity in the limited electroencephalographic record. No parasomnia was recorded.

Therapeutic Intervention: Positive airway pressure (CPAP/bi-level) titration.

Other Observations: None

Clinical Diagnosis and Interpretation:

- Moderate Obstructive sleep apnea (ICD-10 G47.33)

- Excessive daytime sleepiness (ICD-10 G47.10)

Sleep Study Summary:

1. Following the diagnostic portion of this study the patient was titrated with PAP therapy. The patient failed CPAP due to continuous respiratory events and was titrated with bi-level pressure. PAP therapy improved sleep consolidation, oxygen saturations such that at optimal settings the oxygen saturations were above 88%, and the patient had REM sleep in the supine position.

2. Summary of apneic events during the diagnostic period is as follows: CMS-AHI 17, AASM-AHI 29 and the oxygen saturation nadir was 78%. An AHI <5 is considered normal, 5-14.9 is mild sleep apnea, 15-29.9 is moderate, and >30 is severe.

3. The patient spent a total of 2.5 minutes with an oxygen saturation less than or equal to 88%.

4. No clinically significant leg movements, cardiac abnormalities, or parasomnias observed.

Recommendations and Plan:

1. S-10 Auto-Bi-level with an EPAP of 10, PS of 8, maximum IPAP 24, with heated tubing and heated humidification.

2. Equipment utilized: Quattro Air in Large.

3. Maintenance of ideal body weight is recommended.

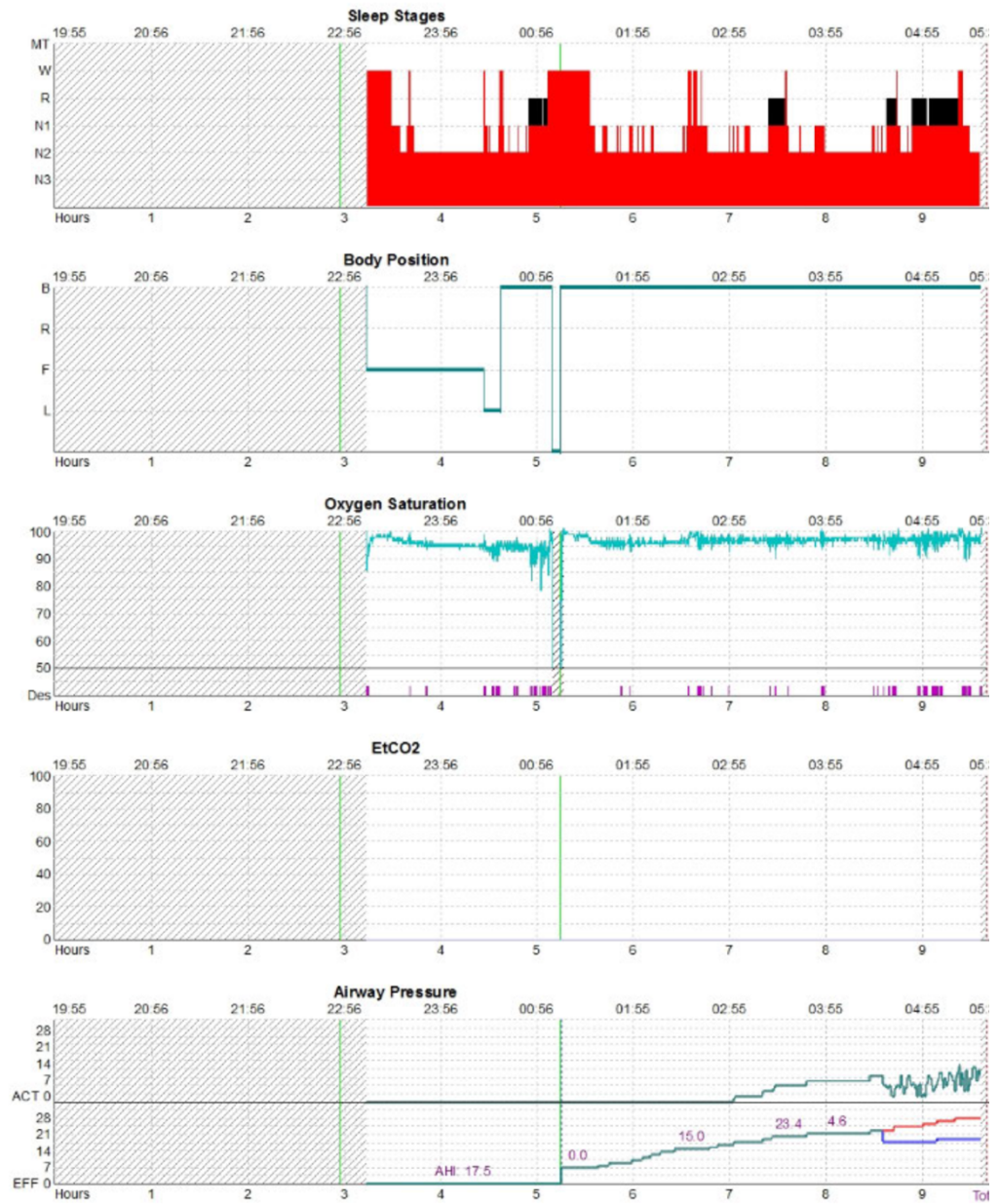
4. The patient should be careful to avoid any situation where daytime sleepiness would present a hazard.

5. Patients new to PAP therapy will be instructed to attend a PAP class in order to familiarize themselves with the equipment. Subsequently, follow up in the clinic with a sleep technician, and then follow up with a sleep specialist within 3 months.

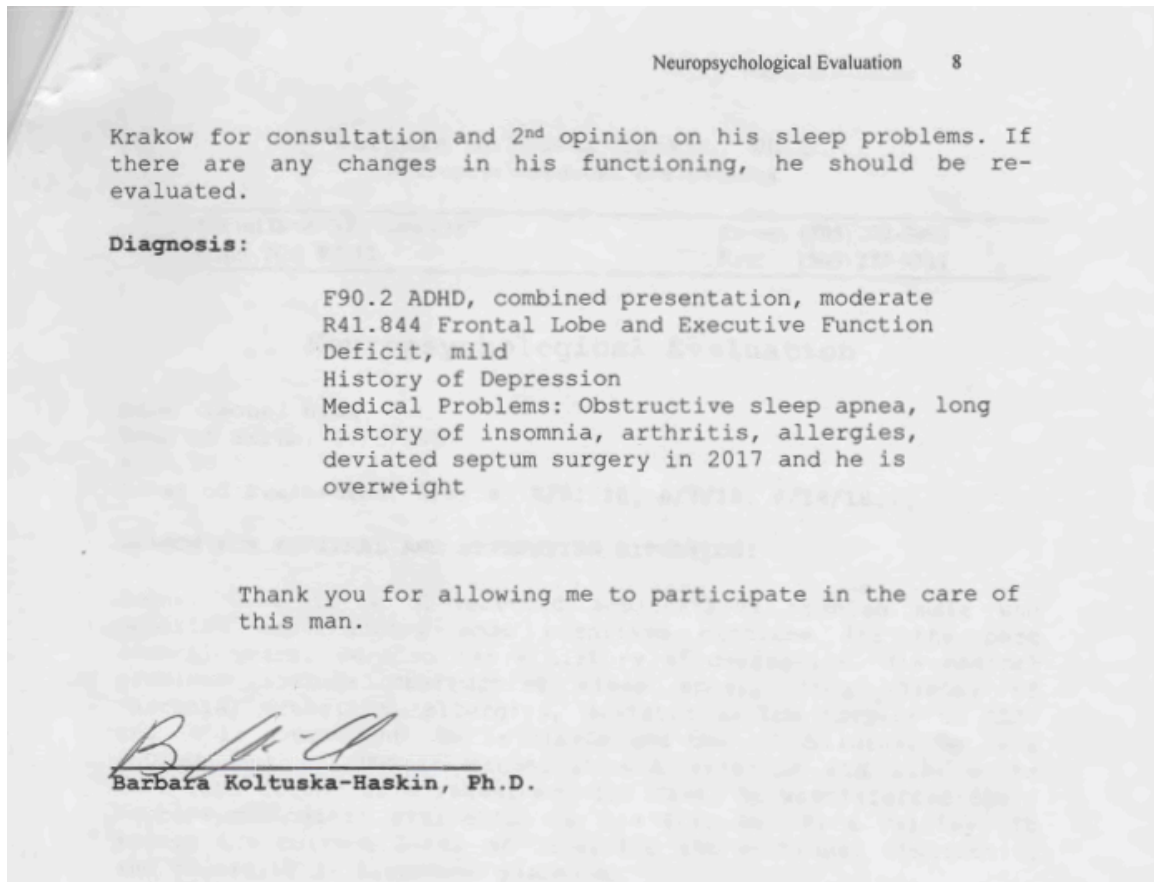
6. Patients placed on PAP therapy will be instructed to return monthly until usage meets or exceeds the 70% usage required by insurance companies in order to approve and pay for supplies and refills. Compliance is defined as usage of 4 hours per night, at least 22 nights per 31 days. Compliance must be met for a period of 31 consecutive days within the first 90 days for CPAP and Bi-PAP, and 61 consecutive days within the first 90 days for any timed device such as:

Bi-PAP S/T and ASV. Once a patient meets "compliance" then the patient may be seen on a yearly basis.

7. In the event of any questions, please do not hesitate to contact me via the UNM PALS line.



## Appendix D – Neuropsychological Assessment Findings



## Appendix E – Documentation of Work Problems

**Week of February 13, 2017:** After receiving job offer call from Senior researcher, Administrator calls to discuss next steps in hiring. She said, “I want to let you know the only reason you got hired is because of [friend name].” [friend name] is a former [department] employee that referred me to the job but did not serve as a reference.

**[August 17, 2018 insert] Sometime during February 2017 - March 2017:** I recalled that during my interview for this position, I had asked if there would be opportunities to attend conferences of my choosing. I was told there was not much money in the budget to send me to conferences but would look into it. Once I was hired, Administrator stated that she and Senior researcher decided that although there wasn’t enough money in the budget to send me to conferences, they would support me by allowing me to use worktime to attend conferences. They also said they were allowing me to continue my involvement on campus as long as it did not interfere with my work responsibilities and there weren’t urgent matters to address that day or week. This meant it was okay for me to continue doing workshops on campus, continuing advising student groups, continue my role as a leader in NASPA, allowing me to use my annual leave for consulting work outside of UNM, and time to visit faculty related to my PhD program. I made sure I clarified this word for word during my first week as a THE RESEARCH DEPARTMENT employee.

**March 9, 2017:** During my THE RESEARCH DEPARTMENT orientation, Administrator states that, “Researcher and I will be your co-supervisors.” “Researcher asked me to co-supervise with him.” Being a new employee to the center, I decide to trust her because I found [Aug 17,2018 insert: it] disrespectful to question it.

**March 25, 2018:** During breakfast at hotel in El Paso, New employee asked if Researcher was joining us. I state he isn’t a breakfast person. Administrator shares story of how Researcher was very different years ago and how much he has changed. Shares how he has grown distant and doesn’t know why. [August 17,2018 insert: I found this to be unprofessional of Administrator to discuss a colleague’s behavior. There was no reason to talk about Researcher. It made for an uncomfortable breakfast.]

**April 23, 2018:** After Monday meeting, Administrator calls me over to her office to discuss my behavior, or facial expression showing unhappiness. I explain how Senior researcher does not listen to me regarding problems with projects and began following ideas I had provided that Senior researcher first deemed as “would not work”. Defends Senior researcher by saying COLORADO RESEARCH TEAM is special to him. She states her job responsibilities were moved around to focus on ALCOHOL RESEARCH PROJECT due to Researcher inability to move projects forward. Explained that Researcher is Senior researcher’s mentee. Asked if I knew what was up with Researcher recently since he looked distant. Said she would be more vocal in meetings and that I should share my ideas with her so that she could deliver to Senior researcher as he would listen to her. Says I shouldn’t act like Researcher. Tells me to take the high road. \* Researcher is out on AL the week of April 23-27. \*

**April 24, 2018:** Senior researcher asks me to meet with him. Discussion is focused on my behavior, or facial expression during Monday’s meeting. Focus is on why I am unhappy at work. His questions are follow-ups from my meeting with Administrator. I reiterate my point of how he has not listened to my concerns with HPV GIRLS PROJECT project.



Asked if I had shared concerns with Researcher. I say yes, and that I decided to bring up directly with Researcher in meetings. Senior researcher doesn't listen to either of us. Senior researcher follows up by asking about my work relationship with Researcher on how things are going working with him. Wants to know if Researcher is doing his job and begins to get upset. I say Researcher and I cannot move forward because COLORADO RESEARCH TEAM is behind schedule. Says COLORADO RESEARCH TEAM is not issue and that he is working on it. I state there is lack of communication of what is happening in the background with HPV GIRLS PROJECT project. I state project is failing due to lack of communication. He defends COLORADO RESEARCH TEAM.

**April 30, 2018:** During staff meeting, Administrator shares with Senior researcher the complaints I had regarding HPV GIRLS PROJECT project and COLORADO RESEARCH TEAM not moving forward. Senior researcher listens to her immediately and decides he will be more vocal with COLORADO RESEARCH TEAM regarding issues with project. I had been bringing up the same problems since October 2017 and Senior researcher would ignore me each time. Administrator says it once and Senior researcher takes immediate action.

**May 15, 2018:** Administrator comes to me asking why I stayed late on May 10. I share that I stayed till 7:20pm doing my final exam for a course. I had previously asked Tom (security) how late he was staying and said Former director and John stay late and his timesheet was set for 8pm. Said I was okay to stay until they left. Administrator leaves and returns after speaking to Department manager. Said she said that she trusts I'm telling the truth and Department manager did not. Relayed that Department manager said no one should be in building if not working and that I could not stay to do homework. I don't like the decision; I say that is fine and would follow orders. Administrator says she doesn't care if I stay and is okay with me staying. Says not to say she said that or else she would deny it.

**May 16, 2018:** While working on ALCOHOL RESEARCH PROJECT material preparation, Administrator asked if Researcher looked checked-out. Says Researcher hasn't looked happy lately. I state it is probably because of Senior researcher not sharing the co-PI responsibility. She defends Senior researcher and says it is Researcher's fault for not stepping up to the plate. Says Senior researcher has given Researcher several opportunities that he fails to take. I say that is a problem both need to resolve.

**May 17, 2018:** While finalizing money packets for actors on ALCOHOL RESEARCH PROJECT, says if I come across any money issues, that it is okay to get rid of receipts and fix the numbers in case I am short on money returned. Tells me not to share that with anyone. Tells me if there is money missing, it will come out of my pocket. Tells me not to hesitate to contact her if I come across any money issues and that she will come in on her day off to help count money.

**May 18, 2018:** I asked Researcher if Administrator and he were co-supervisors to me. He says no, that only he is my supervisor. I share with him that Administrator had said several times over the year how she was my co-supervisor along with Administrator saying that I was only hired because of Tiffany. Researcher says I had a good interview and that Administrator's statement is not true.

**May 29, 2018:** During HPV GIRLS PROJECT meeting, Administrator says she is very busy this week due to grant proposals needing to be submitted. Says she might be busy till next week and won't have time to get to other things.

**May 30, 2018:** [Inserted August 17, 2018: Administrator] [s]hows up late with food to ALCOHOL RESEARCH PROJECT meeting. Briefly after [the] call ends, [she] asks us how the last trip to Las Cruces went. Everyone (Researcher, New employee, and I) briefly share our experiences. Administrator asks if money was submitted. I reply I had every penny accounted for with no problems. No further questions are asked by Administrator.

**June 4, 2018:** During Monday meeting, Researcher gets up briefly to grab item from his office. Administrator says, "This is a good time now that Researcher has left." She follows at asking me why she had a charge on her P card and accuses me of causing the charge. I state the amount sounds incorrect and that I don't recall that being on my statement from hotel. Researcher returns and she continues by asking Researcher about charge. Administrator screams at Researcher and I for looking at our phones while she is talking. I look at her and show my phone that I had just pulled up the hotel invoice. I say that charge isn't from me. I explained how hotel charged my credit card and not the P-card. Senior researcher and Administrator talk for 15 minutes about importance of receipts and returning invoices to her and not Administrative assistant. Senior researcher says all work items should be paid by P-card and references the first and second El Paso ALCOHOL RESEARCH PROJECT trip where I had to pay using my credit card. I state how hotel didn't charge P-card the first time due to their business policy. I state that the second time was Administrator's choice to not pay using P-card because she didn't like that the hotel prints out form with credit card info and places it into a binder.

Administrator says, "Let's not start pointing fingers at each other." Meeting continues with changes with SUB-CENTER. Administrator looks down and doesn't say a word.

**June 6, 2018:**

Morning: During ALCOHOL RESEARCH PROJECT meeting, El Paso PI asks about actor payment to Administrator. Administrator says I waited two weeks to give her the timesheets and had just handed it over yesterday. I had provided timesheets on Monday, June 4 after the meeting. Administrator does not state that she was on AL the first week and had grants due after returning from AL the previous two weeks. Makes it sound like I am not doing my job to a group of 8 on a conference call.

Evening: Senior researcher asked me to meet with him as I was getting ready to leave work. Asked me why I looked unhappy again at Monday's meeting. I state I'm fasting and the sleep apnea doesn't make that easier. Says he is tired of hearing about my sleep apnea and that wasn't the issue. I ask, "Is that all?" He says, "What is really going on? I want to know." I focus on how his recent projections on recruitment for HPV GIRLS PROJECT is unrealistic and I want to know what will happen to my salary and job if we lose grants. He says not to worry. I ask for concrete proof that I will have job if we lose grants. Again, asks what else is going on and I say nothing, I already told you. Follows up by saying that Administrator said Researcher and I have something against her ever since ALCOHOL RESEARCH PROJECT Las Cruces trip. Says I didn't communicate with Administrator, didn't return box to her office, and did not track receipts with money log. I said Administrator never made such requests, and if she did, I forgot. I say it's not my job as Researcher was on trip and should have communicated that with Administrator. Senior researcher agrees that Researcher should have communicated to Administrator. Asks why Researcher and I have something against Administrator. I say I had nothing against her, and if Researcher and Administrator have problems, I don't

know why I am getting dragged into it. I share how I made sure money was accounted for and have been working on data entry. Senior researcher says I don't understand at all the importance of tracking receipts. I share with him I didn't appreciate Administrator yelling at me during Monday's meeting and accusing me first about extra P-Card charge when there were 3 UNM people at ALCOHOL RESEARCH PROJECT trip. I also state how Administrator made me look bad regarding actor timesheets in the morning during ALCOHOL RESEARCH PROJECT meeting. Senior researcher defends Administrator saying none of that was true. I follow by saying Senior researcher has provided empty promises. I mention how I was told I would get to go to professional conferences and my attempt to contribute by volunteering to create poster for ALCOHOL RESEARCH PROJECT have been shut down by him. He denies it all. Says COLORADO RESEARCH TEAM is prime and does conference posters. I follow by saying that COLORADO RESEARCH TEAM is behind schedule and my idea was to alleviate workload for COLORADO RESEARCH TEAM by taking on poster. Senior researcher says COLORADO RESEARCH TEAM is another story and not part of conversation and returns to problems Administrator has brought up. I again bring up how Administrator had previously said that my job was primarily based on HPV GIRLS PROJECT and it would have a significant impact if we lost grant. Senior researcher says that is inaccurate and Administrator didn't not say such things to me. I again press on wanting concrete evidence on how much time I would have left on my contract if we lost HPV GIRLS PROJECT grant. I ask for it in writing by email. Says he would ask Administrator to run numbers. I noticed Senior researcher was treating me like I was stupid. His tone is condescending.

**June 7, 2018:** Administrator replies to my email [Aug 17, 2018 insert: (notifying everyone I'd be at an on campus meeting and on sick leave for a doctor appointment)] saying to make sure I submit my timesheet with annual leave and sick leave request. I notify Researcher about her response and says he would take care of things as he had granted me to attend a free conference [Aug 17, 2018 insert: (UNM Tech Days)] at UNM campus.

**June 11, 2018:** During Monday meeting, Administrator explains budgets for all if we lost HPV GIRLS PROJECT grant. It was verbally shared but not emailed as I requested. Meeting focus was on following procedures for ALCOHOL RESEARCH PROJECT. Administrator says she wants me to always copy her on my AL requests to Researcher. Senior researcher says no more phone/tablet use during meeting to prevent further issues. Senior researcher asks if I knew what "carry forward" meant, as if I was stupid. Again, his tone is condescending. [August 17, 2018 insert: The carry forward conversation was regarding budget projections.]

After meeting, Administrative assistant informs me that UNM policy states that I only request AL requests from direct supervisor. All requests are between employee and supervisor and no one else. Says I don't have to copy Administrator and that is my choice.

Researcher and I meet in the afternoon. Explains he shared with Department manager about Administrator's AL copy request. Researcher says I am not required to copy Administrator. I say Administrative assistant had said the same to me earlier and that I agreed and was well aware that was the UNM policy but wasn't sure if it might be a THE RESEARCH DEPARTMENT policy. Researcher says it is not a THE RESEARCH

DEPARTMENT policy and that I have the choice to not follow Administrator's request as it is against my union and UNM policy. I ask Researcher about my timesheet for previous pay period. Says Administrator attempted to force me to use AL but he blocked it. Said there is a UNM policy that allows employees to attend university events based on supervisor approval. [August 17, 2018 insert: Researcher also shared that Administrator took money out of his PI account to cover the time I was at the Tech Days conference because the conference was not part of my job responsibilities through the grant.] He approved it and there was no need for me to use AL. Researcher recommended I speak with Department manager.

**June 13, 2018:** Senior researcher sent me an email with subject line, "Reporting." The email body said, "Leonel, While Researcher is on leave and in my absence, please report to Administrator for administrative matters and work tasks. Best, Senior researcher Sent from my iPad" [August 17, 2018 insert: I have never once received an email notifying me of what to do when Senior researcher or Researcher is out of office. I see this as Senior researcher reinforcing Administrator's authority as a superior in the office. Upon my hiring, Senior researcher had said everyone in the office was on the same level (regarding job titles) regardless of pay and that there was no hierarchy. His email reflects a change of who I am seen as an employee.]

**June 19, 2018:** I was out sick the previous day and missed the Monday meeting. Researcher comes into my office to update on the projects. After briefing me on things, he tells me he was going to share something that he found inappropriate during the meeting. Researcher explained that Senior researcher said that I had a tendency for trailing away from the protocol for WTSE. The example Senior researcher provided was the recent Las Cruces trip that I had added an establishment that was not on the original list and that he recalls that I did something similar in El Paso. Researcher said he stepped in to make Senior researcher aware that I called him to request permission before proceeding and that I was following protocol. Senior researcher followed by saying that I might need to be monitored more closely when on the field. I explained to Researcher that I called Senior researcher while on the field in El Paso to request permission to visit a site not on the list and that he approved it. Researcher agrees that he recalled that conversation and didn't mention then. Researcher also added that Senior researcher suggested I had not vetted locations well. Researcher, again, defended me by saying that no one in the team lives in Las Cruces to visit all the places and that a phone call simply isn't a fair way to verify alcohol serving establishments. Senior researcher said that some of the establishments did not sell alcohol and attempted to place fault on me. Both Researcher and I are fully aware that Administrator made the choices of which establishments to visit. She did not say anything about it during the meeting according to Researcher. I thanked Researcher for defending me during the meeting. I notified Researcher that I would be adding this scenario to my list and if it was okay to document it on my end. He said yes and to proceed with my tracking and documentation.

**June 25, 2018:** During a ALCOHOL RESEARCH PROJECT assessing establishment list meeting, we discussed a Garcia's Kitchen as a possible site for the study. Senior researcher said to remove it from the list because it was in the Northeast Heights. I followed by saying that I had visited the restaurant several times and have spoken Spanish with the staff. Senior researcher proceeded by saying to remove it. I, again, pointed out that I, a Spanish speaker, live in the Northeast Heights and have spoken in

Spanish to the staff and they have responded in Spanish. Senior researcher, again, said “you also speak English,” we were not going to include it, and to move onto the next establishment on the list. Senior researcher was clearly bothered by my statement and personal experience. I took this portion of the conversation as a micro aggression towards Spanish speakers in Albuquerque. I also see it as racism. To me, his actions imply that Spanish speakers do not live in the Northeast Heights and did not believe my experience to be valid by ignoring my experience and interactions with staff at Garcia’s Kitchen. My supervisor, Researcher, was in the meeting and noted the interaction. I spoke with Researcher after the meeting and he confirmed and validated my view of the interaction. Senior researcher did not provide a valid reason for dismissing the site other than “it’s the Northeast Heights.”

**June 26, 2018:** Researcher asked me to call him when I get free while I was in class and out of work. Researcher called me to share that Senior researcher met with him to discuss my behavior during the meetings today. Researcher said that Senior researcher explained that my I was displaying a “sour” look and wanted to know what the problem was now. Researcher said he didn’t know and does not ask me personal questions. Researcher pointed out that I was upset over Senior researcher’s comments regarding Garcia’s Kitchen the previous day and how I saw it as discrimination from a white man. Senior researcher did not respond to this with words. Researcher stated that his expression showed discomfort. Researcher mentioned that I have been going to many doctor appointments and it could be related to my health. Senior researcher dismissed the idea of my health and said I didn’t have sleep apnea when I first started working here. Researcher corrected Senior researcher and said I did have sleep apnea when I did start and that it was an ongoing health problem. Researcher pointed out that I was straightforward about the effects it has on me. Researcher said that Senior researcher wants me to look “happier” during the meetings. Researcher personally does not see my facial reactions as a problem. I shared with Researcher that I had my sleep therapy settings changed on Monday (June 25) and that the first few days are always difficult as my mind and body readjust to settings. I explained that Senior researcher is discriminating me regarding my health as this is not the first time he dismissed my health. I am offended that a researcher that works on health research projects is dismissing my personal health by stating that my health does not affect me in the work environment. I asked Researcher if it was okay for me to document this conversation and he said yes.

**June 27, 2018:** On Friday June 22, I found an error with the IDs for data entry. I contacted our IT person that created the database to look into. On Monday June 25 the IT person tells me it’s a human error in the IDs and not the database. Works gets busy and I return to the issue with Researcher on Wednesday June 27. Researcher decides to bring this up to Senior researcher to help resolve the problem. I had found two sets of IDs for that corresponded to the data entry. I wasn’t sure which was the correct set. Researcher, Senior researcher and I met to resolve the ID issue. As Senior researcher looks at the spreadsheets with the IDs and the documents that I was doing the data entry from, he asks who created the IDs. I state, “Administrator.” From this point forward, Senior researcher kept referring to Administrator as, “whoever created these,” and “the person that worked on this.” Senior researcher never once mentioned Administrator’s name in discussing who created the mistake in choosing the IDs. I never added or said anything beyond her name. All I wanted was to fix the IDs so that I could continue the data entry. I never once

said anything about Administrator other than saying her name when Senior researcher asked who created the IDs. After resolving the problem, Senior researcher says he will talk with Administrator about this.

**July 2, 2018:** During Monday's meeting, Senior researcher informed the group that HPV GIRLS PROJECT decided to remove the grant from us for not meeting milestones. In preparation for his afternoon meeting with HPV GIRLS PROJECT, he asked me to compile some data regarding participants in the study that were control and intervention along with how many have begun the surveys. About 20 minutes before noon, Senior researcher walks into my office to ask if I was done with the data. I said I'm writing him an email with the details. Without asking, he decides to walk around my desk and stand behind me to see if I was doing what he requested. In was in this moment that I realized he had done this the previous week and that it made me feel uncomfortable. Senior researcher never used to walk around my desk to view my work prior to the incidents beginning. He just stands behind me as I work, observing what I am doing.

Later in the day, I replied to an email sent from Administrative assistant with a reply from Administrator regarding a new invoice I had submitted to pay a clinic in a research study. I noticed the email never sent and was stuck in my draft folder. I reply to email from Administrative assistant and Administrator that showed confusion over the invoice. I clarify and mention it got stuck in the draft folder and had attached it to the current email. I explain it's the last invoice for the clinic. Administrator replies asking for the list where I double check the participants before adding them to the invoice.

**July 3, 2018:** I reply to Administrator's email with the information she requested. She replies again asking for the passwords to the spreadsheet on a shared drive that also contained the clinic's patient list. I was in meetings most of the day and don't reply. In the evening, Senior researcher replies to email asking that I respond "as soon as possible" because Administrator is working remotely and it would be "important and helpful."  
[Aug 17, 2018 insert: At this point in time I begin noticing a pattern of having Senior researcher reinforce Administrator's requests of me.]

**July 5, 2018:** I went to visit CARS this morning to discuss the work problems I am experiencing and how much anxiety and stress it is causing me. With the psychologist's guidance, I revisited coping strategies as well as mindfulness.

I returned to work only to realize Administrator did not take time-off as she had said she would the previous week. I responded to the email with the password included. I forwarded the email to Department manager to make her aware of the current situation. Administrator has replied again asking for the passwords to all the spreadsheets. I replied saying I did not create one and was copying the person that did create it as she might have the password. I have to point out that this is not the usual procedure when I submit an invoice for the clinics in the research study. This is the first time Administrator has decided to double check my work. There was no reason given to me as to why my work was being double checked. I believe she is retaliating because I found a mistake in her work and now she wants to do the same to me. The usual procedure is for me to verify the patient list for eligibility regarding the study requirements, create an invoice, ask the clinic to verify the amount, once approved, I forward it to Administrator to initiate payment. Administrative assistant continues the process by completing the payment. Administrative assistant then sends it or a notice to Purchasing for them to create the check and mail. This has been the routine since November 2017. She decided to

scrutinize my work without providing a reason. I do not understand why she felt the need to double check my work on the invoice when there have been 17 other invoices for a variety of clinics before this current one (18<sup>th</sup> invoice). If it was a matter of checks and balances or reliability, she would have done this for all the previous 17 invoices. For this reason, this is retaliation towards me. Senior researcher replied to the email thread saying there is no need to password protect the files since it is behind THE RESEARCH DEPARTMENT's firewall. I decided not to reply to his email as that would make me look defensive. The truth in this scenario is that two files were password protected because they were sent to a clinic for verification of their patient list. Since the file was sent through email, we password protect them and send the password in a different email or phone call. The other file that has a password that I don't know was created by New employee, a part-time hire. Because New employee works from home, Administrator had asked that we password protect files that I send to New employee for security reasons since New employee does not frequently work in the office and does not have a firewall to protect the files we send. At this point, I have learned that if I attempt to bring clarity or remind Administrator and Senior researcher of what exactly happen, they will change the narrative. It does not matter how I bring it up, they see it as an attack from me. I met with EEOC in the afternoon to discuss my experiences in the work environment. I shared my experiences and answered their clarification questions. EEOC employees explained to me their procedures, identifying jurisdiction, retaliation protection, and timelines of an investigation.

**July 6, 2018:** At 10:36 AM, Administrator came to my office and said, "If Researcher is not here in the next 30 minutes, you need to submit your timesheet." I replied, Researcher will be here soon. Administrator replied, "I need you to submit your timesheet to me in the next 30 minutes." Her tone of voice was that of a bully as she was not giving me another option. She never explained why she was imposing a time limit. I spoke with Department manager about this incident and she explained that I do not have to submit it to Administrator if I do not have my direct supervisor's signature. Department manager said I can always submit a timesheet early Monday if something ever prevents my timesheet from being submitted by Thursday or Friday. Department manager also provided a solution of having me email Researcher my timesheet and having him approve by email as long as he signs the timesheet when he returns to office.

**July 9, 2018:** I visited Mike Brown at Human Resources this morning to discuss the problems I have experienced at work. Mike recommended I speak to Mei-Lee and HR Rep to discuss the policy violations that have occurred. He believes my case falls best under HR than EEOC due to the policy violations that are occurring such as the Respectful Campus policy. Mike also asked me to continue my documentation and add as much details as I can in my writing along with continuing the timeline.

There was a regular Monday morning meeting with Senior researcher, Researcher, Administrative assistant, Administrator, and myself. Senior researcher started the meeting with saying he has never believed in the chain of command. Senior researcher stated that anything regarding the projects needs to be referred to Senior researcher. We are to refrain from doing anything else. Senior researcher was visibly upset. Senior researcher continues by saying that actor hiring for ALCOHOL RESEARCH PROJECT is still unresolved. The conversation continues regarding the HPV GIRLS PROJECT grant and HPV Boys project. During the conversation for ALCOHOL RESEARCH

PROJECT, there is conversation of hiring a second actor for Albuquerque sites. Senior researcher and Administrator decide to hire a second actor as a professional service. During this conversation, Administrator decides she wants to see the ALCOHOL RESEARCH PROJECT data forms. She says she feels she is being “blocked,” “walled off,” and “left out” from the project because she doesn’t know what is going on with the project. Researcher asked her to specify. Administrator says they can talk about it on the side after the meeting. Researcher says they can talk about it now. Administrator states that she isn’t being copied on the emails, that “Leonel walked out the door” without giving her the ALCOHOL RESEARCH PROJECT forms when she requested them, and was not informed about the IDs. Researcher answers all her points by saying that he, Daniel (from COLORADO RESEARCH TEAM), and myself were working on testing the data entry programs and had instructed me to give him the forms before delivering to Administrator. Researcher also clarifies that she isn’t copied on recent emails as they all related to the database. Last, Researcher explains that she wasn’t here the day we identified that the IDs were incorrect and that the urgency to get it resolved quickly was so that I could continue doing my work. Once Researcher explained these three points, Administrator had no further comments. Administrator returns to her initial statement about wanting to see the data forms for the project.

**July 20, 2018:** I received an email from Administrator on July 19 stating, “Can you please give me the order of the establishments for Albuquerque and El Paso.” I asked Researcher if he knew what Administrator meant. Both Researcher and I were confused and decided I should reply asking her to specify what she meant by, “the order of the establishments.” Administrator replied today saying, “I was under the impression that you have mapped it like we did before. If you don’t have this please map the establishments so that I can finish the paperwork. I would like to have my end of the work done by this afternoon.” An hour and six minutes later, Senior researcher replied saying, “Leonel, Let’s get the mapping and route of premises in Albuquerque done. We need to schedule these starting next week.” I noticed this has become a pattern with Administrator and Senior researcher where Administrator will email first followed by Senior researcher reinforcing Administrator’s requests. This was never the case prior to the events unfolding after June 4. There has also never been an instance where I have refused to do my work for them to even decided to implement their recent tactic. Both Senior researcher and Administrator keep claiming that we need to all communicate with each other yet this is an instance of both Senior researcher and Administrator not communicating with Researcher and I that 1) scheduling for the project is beginning, 2) I have not been asked if I have availability for the weeks they plan on conducting the field work, 3) I had not been instructed to create maps by anyone until today, 4) the dates selected did not involve feedback from Researcher and I, and 5) there are no timelines established for this part of the project and inconsiderate of everyone having to partake in it.

**July 24, 2018:** I received an email from one of the clinics participating in our HPV research project. Medical manager, the clinic contact person, was asking about an invoice that has not been paid. She said, “Good afternoon, I was wondering if you can follow up as to when we will be getting pmt on the last list of names. I thought you had already gone through the names because you said there were 5 duplicates, can you get back with me? . thank you Medical manager.” On June 28, Medical manager had asked about the



invoice being paid. She then followed up about the second invoice for the month. My role with the clinic invoices is to verify that there are no duplicate patients/participants so that we don't pay double for them. This particular clinic has recruited a significant amount of patients/participants, thus sometimes a duplicate patient/participant is included in the lists provided to our office. On July 2, I clarified to Administrator and Administrative assistant that there were two invoices for payment and the last invoice (2<sup>nd</sup> for June) was the last of the patients/participants. Administrator then decided to double-check my work, which she has never once decided to do. The July 2 and 3 entries above contain the remainder of this story. Medical manager's current email demonstrates that Administrator has not yet resolved paying this clinic nor double-checking my work as she said she was going to do. This email demonstrates how the work conflict is affecting our partner clinic. This in turns makes our office look bad for not doing things in a timely manner and becomes a reflection of UNM. I replied to Medical manager and said, "Good morning Medical manager, I don't have an answer as to why the list of names is being checked again. I also don't have an answer as to when you'll receive the payment. Administrator's mother passed away recently and we don't know when she will return. I'm sorry I don't have a better response for you. My supervisor, Researcher, is copied on this email so that he is aware of the pending payment. leonel." Delay in paying clinics has been an ongoing issue with Administrator. This is not the first clinic to experience such difficulties. Along with this, there has also been a delay in paying research participants.

**July 26, 2018:** While meeting with our Operations Specialist for Infrastructure, Helen, she was extending my job contract since Administrator has been out for two weeks. While waiting for Helen to finish before helping me with a research project, she asked who my supervisor was. I replied, "Researcher. He's the only supervisor I have." Helen replied, "Administrator is listed as your supervisor." It reminded me that I had noticed that in my UNM portal while looking at the banner/MyUNM update. I wasn't sure why Administrator's name was listed next to my job position on MyUNM, but I didn't think much of it. Helen decided to update the entry and put the correct supervisor in her system. Helen was confused as to why Administrator was listed as my supervisor. I relayed this to Researcher. Department manager, our Admin Operations and HR representative, is currently out on annual leave. Researcher and I will be bringing this to her attention upon her return.

**July 27, 2018:** I met with HR Rep at UNM Human Resources to discuss the problems I have been experiencing. She listened to my experience and said she would review my documentation.

**August 6, 2018:** I received an email from Administrator stating that Researcher would no longer be my supervisor and that herself and Senior researcher would now be my supervisors. The decision was made because Researcher has to spend 50% time at SUB-CENTER.

**August 8, 2018:** I have my first meeting with Administrator as my supervisor. She behaved as if there have been no problems between us and did not bother to address any of the ongoing problems. She started by saying she was going to do things differently from Researcher. She said she wants us to meet weekly so that she knows what I am always working on. She continues by adding that she might add New employee to the meetings so that we can all be on the same page. She followed by assigning to me to work on the Medical doctor's Pediatric clinic patient/participant invoice list to double

check for duplicate paid entries and unpaid entries. This is a task she created without reason and has now assigned onto me. I am now responsible for double-checking my own work. As Administrator explains what she has been doing to double-check participants/patients (never once saying why), it becomes clear to me that she never once read my instructions as to how I was keep tracking of participants. She used an old spreadsheet that had inaccurate information. I said to her that the spreadsheet was old and that a newer one existed because she had asked me to keep all clinic payments in one file. She asked me to clean the most recent spreadsheet and update it with her notes from the spreadsheet she was using. Administrator says she will email Medical manager letting her know what we are doing. I asked Administrator what I can do to help with the upcoming ALCOHOL RESEARCH PROJECT site visits tomorrow (Thursday). She says she would take care of it and let me know if I am needed. Last, we settled on meeting every Monday morning at 9am.

**August 9, 2018:** 10:30 am, Medical manager (employee at Medical doctor's pediatric clinic) calls asking why Administrator is double checking all the invoices I created relating to the HPV GIRLS PROJECT project patient/participant recruitment. I was honest with Medical manager I said I had no idea. I tell her I just got assigned the task and all I can do is follow the orders the boss gives me. Medical manager asks for a timeline of when I'll be done and give her an estimate of a week plus whatever time Administrator takes in verifying my work. I apologize to Medical manager for not being able to give her better responses.

Later in the day, Researcher shares with me a conversation he had with Senior researcher on Monday, August 6 regarding meetings on my calendar and if I have been going to job interviews. Researcher emailed me the audio recording of this interaction. Both Researcher and I find it odd that Senior researcher has been looking at my calendar. Researcher and I both see this as retaliation towards me as Senior researcher didn't want to be blind sighted by my possible departure. (Audio file provided: Conversation-Aug 6.mp3)

**August 10, 2018:** I learn ALCOHOL RESEARCH PROJECT Project did not happen from New employee. There was no communication from Administrator to either Researcher (Project PI) and I about this decision. Administrator had emphasized on

**August 13, 2018:** This is the first Monday meeting with Administrator. There are no significant updates from either one of us. She spent ten minutes talking about her sick dog and vet visits. After she finished talking about her dog, I emphasized my ongoing sleep apnea issues along with stating that I was diagnosed with ADHD and that it is impacting my sleep. She asked as to how they were related and I specify that the lack of attention tends to occur within my sleep, thus disrupting my sleep.

After our weekly Monday staff meetings, I shared with Senior researcher my ongoing sleep apnea issues. I tell him that my sleep therapy was updated and that the new settings were not working well for me but that I had to suck it up so that the doctor could gather enough data to make informed decisions. He rambled on about his diseased wife having to be on air support and recommended I look into using CBD for my sleep.

**August 16, 2018:** At 3:25 PM, Administrator questioned my timesheet entry again (first time being on June 7) regarding two meetings I had on Tuesday, August 14. She said she looked at my calendar and wanted to know what SGAO and SAC meetings were about. I said they were Student Activities meetings regarding the Student Veteran group I advise.

She followed by asking if this is something Researcher had approved and if these meetings were related to my job. I said that it was allowed for me to continue my advisement of the group upon my hire. She followed by asking that she has noticed I have had a lot of meetings outside the office during the last several weeks, especially an all-day veteran meeting on a Monday. I followed by saying that it was a veteran training sponsored by the UNM President. She replied, "I know. We might need to limit your hours you spend working on this." She continued by saying that I have let her know when I am going to these types of meetings. I said okay and the interaction ended. This interaction coincides with a conversation Researcher had with Senior researcher on Monday, August 6. It is clear that both Administrator and Senior researcher had a conversation regarding meetings on my calendar. Neither Senior researcher or Administrator were my supervisors prior to August 6. I feel uncomfortable knowing that they are closely monitoring my meetings. In addition, I have never once been told that I might have to limit my campus involvement. I already do limit my involvement because of the continuing problems I experience. I'm also rarely too busy in my current position. The HPV boys project hasn't started due to COLORADO RESEARCH TEAM, the ALCOHOL RESEARCH PROJECT project isn't progressing due to COLORADO RESEARCH TEAM, and the HPV GIRLS PROJECT project is on the verge of being discontinued. My work is minimal.

About 10 minutes later, she returns to ask me which long distance code I use for the HPV GIRLS PROJECT project. I provide it to her. I am not sure why she wanted to know which code I used as she is the one that assigned one long distance code for everyone to use for the HPV GIRLS PROJECT project. If something different has occurred regarding the long distance code, I was not informed.

**August 17, 2018:** An emergency staff meeting occurred this morning. Senior researcher and Administrator informed Administrative assistant and I that HPV GIRLS PROJECT had ended funding for the project as of August 16. In the discussion, Administrative assistant asked what would happen to Senior researcher as the HPV GIRLS PROJECT projected funded Senior researcher as a UNM employee. Senior researcher said that he would still keep his office because of his status as Professor Emeritus, the money he has brought into the university and THE RESEARCH DEPARTMENT, and because there are two others in THE RESEARCH DEPARTMENT that have offices but are no longer UNM employees. I added this entry because it seems unethical that someone no longer employed by the University be allowed to keep an office space.

**August 20, 2018:** I met with Administrator at 9am for our second Monday meeting. I provided updates regarding the HPV GIRLS PROJECT project and asked questions to get answers I need to close out the project. We moved on to talk about the ALCOHOL RESEARCH PROJECT project and discussed issues with data entry. For no reason, Administrator decided to share that IT guy (our THE RESEARCH DEPARTMENT I.T. colleague) may not be able to help us with our request to update our Access database because his father has been in the hospital and hasn't been in the office much. To me, it appeared that Administrator was attempting to make a research decision without asking the PIs of the project. There was no point in her sharing a colleague's personal life situation. This concerns me because that means anything I may have to share to her as my supervisor she may share with others. I have no trust in her. She said it would make sense to keep two of the cities labeled as the city they are closer to. In my professional

experience, this creates data issues. She followed by asking if Researcher or Senior researcher had responded to me. I said that Senior researcher briefly mentioned it on Friday but said we would discuss it later because of the notice from HPV GIRLS PROJECT that we had been terminated. She follows by saying she would bring it up during our staff meeting today. There was nothing left to discuss and our meeting should have ended at this point. Instead, Administrator opens up the Google staff calendar to ask me what my meeting on Thursday is about. I decided not to share that it is a meeting at CARS and said that it was a confidential meeting that I am not allowed to disclose. Her expression changed from a smile to serious. She then asked if I had anything else on HPV GIRLS PROJECT. I said nothing else I could think of. She follows up with saying that there is a UNM policy that allows for employees to attend job interviews on campus. She said she expects for me to be open about sharing if I decide to apply for jobs because it is allowed by the policy for me to attend interviews. She continues by saying that is the reason she was asking if I had any further stuff on the HPV GIRLS PROJECT project and wants to be able to justify my time regarding meetings I attend. I was able to change the focus of the conversation by asking what time remains on my contract now that HPV GIRLS PROJECT is no longer funding us. She gave me time estimates by saying they are keeping me till November 2019 and that once the other grants are approved that it would push me till the end of 2020 and possibly longer. She said I would receive a 30-day notice if there would be no more money to fund my position. It makes me feel uncomfortable to be asked to justify meetings. This was never an issue with anyone (Researcher, Senior researcher, Administrator) prior to May 2018. Administrator asking me to share if I am applying for other jobs also comes with intimidation and bullying towards me. Senior researcher has brought this up to Researcher (see August 9 entry) and Administrator has made it very clear she is monitoring my calendar today and on August 16. I see no reason why I should have to disclose to her every single one of meetings and my interest in searching for a new job. I fear that disclosing any information will only increase the work hostility, bullying, and intimidation.

**August 21, 2018:** I spoke with EEOC's Compliance specialist over the phone regarding completing my ADA form. I followed up with asking for an update regarding my case. Compliance specialist said that the respondent had not replied to their email.

**August 27, 2018:** I approached Administrator's office at 9am to ask her if we were going to continue meeting. I said I had not been instructed to do otherwise. She says she had no idea what was going on either. "Screw em," was her response. I have it in audio recording.

**August 28, 2018:** There was a one-hour meeting to go over the HPV Boys project website. Senior researcher assigned me the task of creating a master list of the issues with the website. This occurred before Researcher arrived to the meeting (he was running late from another meeting). This meeting is not related to HPV GIRLS PROJECT.

**August 30, 2018:** Researcher asked me to only put work-related events on my calendar for my protection and remove Senior researcher from my calendar as he is no longer a UNM employee.

**September 4, 2018:** I received an email from Administrator on Friday, August 31. It read, "Just a reminder to please provide the approved leave backup when submitting timesheets." Researcher responded, "Hi Administrator, I believe you approved Leonel's AL for today." Administrator replied, "I did approve the leave but it is the employee's

responsibility to please provide the backup documentation along with the timesheet at the time of submission. Department manager will request it when she approves it.” This is concerning because this was never the procedure at any point until this week. Before this email exchange, Administrator used to request I copy her on emails I sent to Researcher asking for annual leave. That changed the moment I realized I had been lied to about having Administrator as supervisor. In addition, Administrator had documentation I requested AL as she is the one that approved it. I printed my leave request and delivered it to Department manager. Department manager said it was already included with my timesheet. Neither Researcher or Administrator followed up that it had been resolved prior to delivering my approved leave request to Department manager. Later in the day, I heard Researcher politely greet Senior researcher as both crossed paths outside my office door. Senior researcher ignored Researcher. The same occurred between Researcher and Administrator where Administrator also chose not to greet Researcher. These interactions only reinforced the hostile work environment that is taking place.

**September 10, 2018:** Senior researcher sent out an email the previous day to project members at THE RESEARCH DEPARTMENT: Researcher, Administrator, New employee, Administrative assistant, and myself. Senior researcher sent out a list of tasks, two of which are assigned to me. This concerns me as Senior researcher is no longer a UNM employee and continues to provide me tasks. This seems unethical given that a non-UNM employee can provide tasks to UNM employees.

**September 14, 2018:** Researcher sent me an email stating that Interim director had added one determination to my ADA accommodations to inform THE RESEARCH DEPARTMENT staff and faculty when I am recording because they have the right. Researcher also asked me to follow the THE RESEARCH DEPARTMENT policy. I asked for the policy. There is none. I asked Department manager for it; she said it was Interim director’s verbal policy. This only seems to apply to me and I feel I am singled out by this as there has been no notice sent to everyone in THE RESEARCH DEPARTMENT about such policy. I forwarded the email to EEOC and set a meeting with the director.

**September 17, 2018:** The first thing Senior researcher says at the beginning of the Monday staff meeting is for everyone not to have mobile devices (phones and tablets) during the meeting. He asked us to leave them in our offices and return. Administrator was the only one who had a previous notice as she was the only one not to leave the room to return her phone. I just got ADA accommodations from Researcher and this now prohibits me from using my accommodation request to record meetings for note taking. I find it odd that the decision for Senior researcher to enforce no devices during staff meetings came after Researcher’s email from Interim director. This makes me think that I cannot trust Interim director as there was no explanation from Senior researcher as to why we couldn’t hold devices. This all looks suspicious to me. In addition, there was a lot of tension between Researcher and Senior researcher/Administrator. It is clear there are problems between them that I am unaware of. Senior researcher was extremely aggressive to Researcher. Later in the day, Administrative assistant and I acknowledged to each other that there were problems brewing that we were likely to get dragged into.

**September 26, 2018:** We (Department manager, Researcher, and I) met with EEOC director at EEOC to discuss Interim director’s request and Senior researcher’s request.

EEOC director helped us find ways to avoid having me disclose my accommodations to anyone other than Researcher and Department manager. She helped answer questions we all had about our current situation in regards to my ADA rights.

**October 1, 2018:** During staff meeting, Administrator was the only person with a mobile device/smartphone. Senior researcher said nothing to her when she took it out. Administrative assistant, Researcher, and I had no device. Rules seem to apply only to some of us. This is wrong of them to do. I still find it strange and unethical that Senior researcher, a non-university employee, continues to act as our boss and continues sending weekly tasks for us to do.

**October 25, 2018:** Researcher shares with me that there was an anonymous complaint about my cologne. I shared with him that I don't wear cologne. Both being confused as he is aware I don't wear cologne; he says that the anonymous complaint was that the person has allergies to it. My only suspicion is that it might be my air freshener, but it isn't a cologne and I have used it several times before.

**October 30, 2018:** Researcher, again, shares that there is a second anonymous complaint from the same person. It is strange as I don't wear cologne. Perhaps it is my air freshener, but I have used it before and no one had expressed having an allergy to it. Everyone in this suite said they liked the lavender scent.

**November 9, 2018:** Administrative assistant walked into my office reminding me to submit my timesheet. I reminded him that I placed it on his desk the day before while he was talking to Carly. He remembered and walked away. Minutes later, Administrator walked out her office and stood in the hall and shouted, "LEONEL! TIMESHEETS COME TO MY OFFICE." I responded firmly without yelling, "I was following Researcher's instruction." This was a very unprofessional and disrespectful interaction from her. It was clear that she was shouting at me without approaching my office.

**November 13, 2018:** While we gathered in Senior researcher's office for the weekly Boys HPV meeting, Administrator walked in and slapped Researcher's shoe as he sat on the couch corner closest to the door. Administrator's behavior was extremely friendly, but it was clear that the slap on the shoe was made with strong force. Researcher was very uncomfortable from the interaction. It was an extremely uncomfortable situation given that Administrator and Researcher's interactions have been very minimal and they have not been talking to each other unless it is work-related. I asked Researcher about it afterwards and shared that he wondered why Administrator had suddenly decided to act like they were close friends.

**November 14, 2018:** During the alcohol research project meeting, I noticed that Senior researcher always tends to exaggerate accents on Spanish words during these meetings. I find it really offensive in that when he cannot pronounce a Spanish word correctly, he defaults to using an Italian, French, or any other European language that resembles Spanish as a copout. He does this at most of these meetings and no one questions him on his actions given that he is the primary PI to the grant. This is a microaggression.

**November 26, 2018:** Department manager met with Administrator and I to discuss new supervision lines. I will report to Administrator and Administrator will report to Department manager by direction of Interim director. Administrator will be the PI on the projects. This is effective today. Researcher will no longer supervise as of today. I spoke individually with Department manager later in the day. She said that my accommodations would be discussed with Administrator so that there would be a smooth

transition. Department manager explains that the meeting would take place with EEOC later in the day.

**November 27, 2018:** Administrator approached my office after the HPV Boys meeting at around 2:25pm. She said she would be asking Administrative assistant to be a note taker on all meetings and that the notes will be uploaded and shared on the P drive so that it doesn't single me out. At this point, it is clear to me that a meeting with EEOC had taken place over my accommodations as Department manager said would happen.

**November 28, 2018:** In the afternoon, Administrator approached my office and asked if I had access to a folder on our server-drive. I said no after checking. She asked I could come over to her office to talk about a work task related to the folder and to move away from "these two" which she hinted towards Researcher and Senior researcher. I walked over to her office. She explains what she wanted me to work on once I gain folder access. She wants me to find all IRB documents that need a name change from Researcher to Administrator and begin making those changes. She also says she hopes we can work on this peacefully next week. She says she feels that THE RESEARCH DEPARTMENT has a big cloud looming over it and that it will hopefully go away with Researcher and Senior researcher being out of the office next week. She states there is a lot going on at the moment at THE RESEARCH DEPARTMENT because of Researcher's transition. I find this interaction about a "big cloud" being a form of bullying and the toxic environment that I am in. I didn't bring up anything to discuss what THE RESEARCH DEPARTMENT is experiencing or about Senior researcher and Researcher. This conversation was bringing me into whatever problems exist between Administrator, Senior researcher, and Researcher. All Administrator needed to do was assign a work task. I also realized that I did not have my ADA request met as written instructions were not provided and she verbalized the instructions.

**November 29, 2018:** Department manager emails HR Rep and myself to notify us that Interim director placed a moratorium on Department manager becoming Administrator's supervisor. I emailed Department manager since she was not in her office today.

**November 30, 2018:** Interim director approached me this morning on a way to a meeting. He asked if he could meet with me and I said I was on a way to a meeting but could meet after. He said the conversation would be brief. He explained that he decided to try a different approach to further help protect me and to give him some time with it. He said he was working on making things better. I thanked him for sharing that and said that it doesn't make me feel any better. I remain concerned followed by that what I am experiencing is very different from what he is experiencing.

I emailed Administrator to update her on the work task assigned. I included in the email the following: "Last, this is a friendly reminder to please send me written instructions on work tasks per my ADA accommodation. It helps me make sure I am completing tasks as requested and don't leave out anything I was supposed to do."

Administrator replied four minutes later: "I also appreciate knowing that you need written instructions I was not aware of this." Administrator clearly violated my ADA rights. She had met with EEOC, Department manager, and Interim director just three days ago (November 26) and it is my understanding that all my accommodations were explained one by one to her.

**December 3, 2018:** During the Monday meeting, Administrator discusses changes that are going to take place since Researcher will no longer be the PI. She describes that

Administrative assistant will be taking notes at all meetings and placing them in each project folder. Administrator then continues to explain what she wants to see on a timesheet should match our Google Calendars. She then says, "If your door is closed, I assume you are not working." This is a second direct violation of my ADA

accommodation rights. I contacted HR (HR Rep) and EEOC (EEOC director) about this.

**December 5, 2018:** Interim director emailed me asking to meet. I met with him in the afternoon. Interim director chose to share that he was doing his best to protect me in the work environment. I explained to him that he could never understand my experience of being a Latino male that is constantly being discriminated against in society just based on the color of my skin, accent, and ethnicity. He explained he could never understand me but would do his best to prevent it at work. He acknowledged that he was in the meeting with EEOC director (EEOC), Department manager, and Administrator when my accommodations were explained and that there was no excuse for Administrator. He provided his cell phone in case anything comes up in the work place. He also shared that Former director would be serving as my supervisor due to the fact that she would be PI for an upcoming grant that I would be eventually placed on. He says that he would share meeting notes with Former director to transition me over to her.

**December 12, 2018:** I met with Former director and explain work circumstances. She goes over how transition will work with supervision. We discuss my ADA accommodations and FMLA leave. Administrator and I are to copy Former director in all work email exchanges. Administrator will request work tasks and always include Former director. We set the expectations for each other. I make it clear to Former director that Senior researcher is not to know about my ADA and FMLA.

**December 19, 2018:** During meeting with Former director, she says she spoke with EEOC director regarding accommodations while on work travel. She says that EEOC director suggested using recording if needed.

**January 3, 2019:** I replied to an email from Administrator providing me with an assignment. I replied to her asking her to be specific as in her email she states that she will be checking the assignment "several times a week." *Note: As of 1/22/19, Administrator has not replied to the email. Update: On 1/30/19, Administrator replied in a new email with tasks to complete. There were still some vague instructions.*

**January 7, 2019:** During Monday meeting, Administrator asked me about how much time I spend on the ALCOHOL RESEARCH PROJECT manuscript. I said it varied depending on the task. Her approach was evident that she was fishing for information rather than wanting to understand. This was aggressive. She wasn't interested in knowing what I do. She was very specific on asking for time. Surprisingly, Senior researcher reinforced my words that conducting lit reviews and analyzing data is time consuming. Administrator backed off immediately.

**January 8, 2019:** Administrator approached my office in a confrontational tone after the HPV boys meeting asking why my printer was offline. I replied that it does that and I had no idea why. I tell her to ask IT guy (THE RESEARCH DEPARTMENT IT) about it since that is his job. She stood at my doorway staring at me for a few seconds before walking away without a reply. I chose to ignore her as she did this and went back to working on my tasks. This is hostility, bullying, and aggression towards me.

**January 14, 2019:** During the Monday meeting, Administrator asked me to print materials. I explain to her that the printer is not responding to me and that IT guy (THE



RESEARCH DEPARTMENT IT) needed to service the printer. Administrator provided some tasks in preparation for a ALCOHOL RESEARCH PROJECT trip to El Paso for usability testing. Administrator does not provide written instructions as required by my ADA accommodations. This is now the second time she does not provide written instructions.

**January 16-17, 2019:** We head out to work in El Paso for ALCOHOL RESEARCH PROJECT. Administrator was strangely acting as if we were friends and nothing had occurred. She did this once before and I trusted her, hoping things would get better at work. I trusted her then only to get betrayed shortly after. I decided not to trust this act again and just remain as neutral as possible. I have no reason to trust her act of kindness. It's extremely awkward to have someone you don't talk to at the office to suddenly try to be chatty with you and ask for your opinions on non-work-related matters.

**January 18, 2019:** During the return drive to Albuquerque, Administrator discloses information from an email by Interim director. She shares with New employee (new employee pulled from SUB-CENTER) and I that THE RESEARCH DEPARTMENT is experiencing budget problems and that they were considering removal of having a security guard on the premise and wanted our thoughts about it. I texted messaged Department manager (due to lack of Internet while on the road) and asked how that would impact me if I stayed after hours and shared what Administrator said. I don't feel comfortable engaging in conversations of any sorts with Administrator so I rather ask Department manager. Thirty minutes later, Administrator reads out loud an email from Interim director asking her to never disclose confidential information and disappointment in Administrator's action. Once she finishes reading the email, she turns around and screams at me with an angry tone, "Did you say something?!" I look up and say no. She yells again, "Did you say something to someone about the security?" Again, I say no. She asked a third time, still yelling, and I reply no. She then turns to New employee (whom she asked to drive her vehicle) and asked him politely, with a calm and soft tone. He says no. She does not ask him three times as she asked me. She then says, "Then who said something? I only shared it with you two." She resumes doing whatever she was doing on her laptop...which was surfing the internet and reading emails. It was very clear how aggressive she was towards me in comparison to New employee. She didn't challenge or question New employee as she did me. I did not appreciate having her scream and yell at me. I also did not appreciate that she disclosed confidential information from the THE RESEARCH DEPARTMENT director as this is a disrespect and demonstrates she cannot be trusted with any confidential information. If she is disclosing confidential information the director sent out, there is no reason for me to ever trust someone like her when it comes to my privacy and confidential information such as my ADA accommodations and FMLA. Her actions only reinforce the fact that she cannot be trusted. This whole instance is retaliation, bullying, aggression, and hostility towards me specifically. Once we returned to the office, I ran into Interim director. He normally is friendly to me. He ignored me. It made me uncomfortable.

**January 23, 2019:** During the beginning of ALCOHOL RESEARCH PROJECT conference call, people always announce themselves and any absences for those in groups. New employee speaks on behalf of Administrative assistant and myself noting that UNM is present. Administrator called in from home and says, "I didn't hear Leonel." I rarely speak up during these phone calls as Senior researcher proved to me a while ago

that my thoughts and ideas are not important. I find this instance to be a form of retaliation and microaggression. I didn't see why there was a need to verify my voice on the call. It always feels and appears to be that Administrator is always trying to find something against me. I also find it odd that she didn't tell anyone that she would be working from home in the afternoons. She has complained about not keeping my calendar up-to-date and not knowing where I am (even when I am talking to THE RESEARCH DEPARTMENT colleagues in the other suites) to both Researcher (when he was my supervisor) and Department manager (on the day of the transition of supervision for the second time), which both defended me. Administrator does not update me on where she goes but others always seem to know such as Administrative assistant and New employee.

**January 28, 2019:** During this Monday morning group meeting, Administrator shares that as of last week she would be working half days from home and does not provide a reason. Senior researcher then makes a reference about her new dog by asking how it was doing. She says that she needs to take care of it since it's a puppy and she can't leave it alone for long since it's a few months old and that it helps to be at home. Based on the context of this conversation, Administrator works half days to take care of her new puppy. Is this ethical?

**February 4, 2019:** It's another Monday morning group meeting. The usual stuff is discussed. Administrator begins reminding everyone of their tasks. As she reminds me about completing the SOP (standard operating procedures) for the HPV grant, she later says that once I complete the SOPs, that New employee can begin working on the HPV project. From this I have gathered that I am taking the research protocol and simplifying it for New employee. If the goal is to have me write what I do so that New employee learns, it would have been much faster, efficient, and easier to just go over things with New employee as they come up in the process. After all, she said she would send me an email with what she wanted me to teach New employee when he started working on these grants. That never did happen. The interesting part to this all is that everyone has worked on the project and there is no need for SOPs. The research protocol also contains what Administrator is asking me to write for SOPs such as recruitment procedures. It's a clear difference in treatment between New employee and I. When I started this job, I was just handed the protocols and other research documents to study. I learned as we moved forward. She didn't make it easy for me as my "co-supervisor," which she lied about being co-supervisor with Researcher when I started working here.

**February 6, 2019:** I met with Former director for our bi-weekly meetings. I shared with her the meeting of Monday's outcomes regarding SOPs. Former director replies that SOPs are useful for future reference for projects and she was sure they would have another purpose later down the road when revisiting the project. I explain that what I am doing is exactly what is on the protocol and saw the SOPs as unnecessary, especially given that these two grants are different from the previous one that was terminated by the grant holders. Former director mentions that Administrator is working from home to be better able to concentrate with all the work she has. [I find it strange she said that since it appears Administrator is working half days from home to be with her puppy.] Former director shared that Administrator requested that I stop using my phone during meetings because it is a distraction. I think this is retaliation and aggression by Administrator. I reply to Former director that everyone, including Administrator, has been on their phones

during meetings which is why I started using my phone, which I mainly use to look at emails. I said I would comply but would also begin documenting when someone begins using their phone during meetings to prove a point. Former director wasn't happy to hear that but also did not say anything about it. Former director was defending Administrator's actions. During these meetings, she has a tendency to defend Administrator's actions and will in some way ask that I do my best to give her the benefit of the doubt and be patient. How come I'm not given the benefit of the doubt? I've done my best to follow the chain of command to address the work problems. This is white privilege and hierarchy against me. My problems and concerns are not being resolved nor addressed. I also requested Former director to have my office moved. She said she would speak to Interim director.

**February 11, 2019:** As I said I would, I kept track of everyone that used their phone during the Monday meeting. Both New employee and Administrator had their phones out on the table but did not use them. Administrative assistant picked up a phone call as the meeting started and was texting during the meeting. Administrator didn't say anything to him.

**February 12, 2019:** Halfway through the HPV Boys conference call, Senior researcher distracts the everyone by saying he got an image of a pangolin that a colleague sent him. He grabbed his iPad (which he claims to use to view the meeting agenda but normally spends time navigating it) and showed everyone in his office followed by emailing it to his staff member in Colorado for her to email to everyone in the group. This distraction took about 2 – 3 minutes as the colleague that sent it to him was on the phone call.

Clearly, this was distracting and irrelevant to the meeting. Senior researcher tends to do this every so often and Administrator has not once said anything to him. Senior researcher was the one to request no more phone/tablet use during meetings in June of 2018 and then again on September 2018. So far, this seems to be a rule that only applies whenever Administrator wants to enforce it and who she wants to enforce it on.

**February 13, 2019:** Both Administrator and Administrative assistant used their phones during the ALCOHOL RESEARCH PROJECT meeting. Again, Administrator said nothing to Administrative assistant.

**February 18, 2019:** I decided to look for the meeting notes on the shared network drive that are to be taken due to my ADA accommodations. The following dates have no notes available: 12/10/18, 1/14/19 – 2/11/19.

I ran into Interim director today. We greeted each other. He seemed to have avoided small talk with me. I wonder if this is because of the issues in this department that I have brought to his attention.

**February 20, 2019:** I had my bi-weekly with Former director today. During the meeting, she questioned why I was charging hours to the ALCOHOL RESEARCH PROJECT grant when I was told not to do so by Administrator Brooks. Former director read the email to me and said in a very accusatory tone, "It's very clear to me that you were instructed not to work on WTSE." I followed by saying that I have been working on the manuscript and I was not specifically told not to work on it. I followed by saying this is a task I've been working on since Researcher was the supervisor and at no point have I been explicitly told to discontinue work on the manuscript. I pointed out that Administrator's email does not mention the manuscript and suggests to not work on any new aspect of the grant. I continued by saying that Administrator mentioned on Monday not to work on the WTSE grant to conserve the funding. At that point, I realized that I

was being indirectly asked to discontinue the manuscript, which I alerted the writing group of my resignation. They were disappointed. Former director didn't reply and continued on with the meeting. This instance made me feel that this supervision isn't working out to be a neutral party. Former director leans on supporting Administrator rather than making things fair and equal. I am still at a disadvantage. Instructions are not clear and direct. Per my ADA accommodations, I have requested things to be clear and concise. This isn't being supported and I am being accused for not following orders when the orders are not specific, clear, and concise. I feel I am being set to fail and this work environment does not support my needs. Last, I requested an update regarding having my office be relocated to another area in the building. Former director did not speak with Interim director. She said she preferred to have me wait and see how the possibility of being moved to SUB-CENTER goes. I specifically said that I would rather have peace of mind for one month which would also decrease incidents with Administrator. Former director, again, said it seemed like a lot of background work for others and would rather have me wait another 2 to 3 weeks to see how things play out. Former director had suggested having me move offices in the beginning of this work relationship and now she has chosen not to act on it.

After the meeting, Administrator replied to an email where New employee was the note taker and sent the meeting notes for Monday's meeting. In her email, she states, "Again I want to reiterate that no one should be charging hours to ALCOHOL RESEARCH PROJECT without my knowledge regardless of previous assignments. I met with Former director at 9am and ended before 9:30 am. Administrator sent the email at 10:11 am. This specification was not provided on Monday by Administrator nor in her email regarding my assignments for the month. This email happened after my conversation with Former director. This made me realize that when I ask for clear instructions, it takes weeks to respond such as the SOP assignment. Former director is quick to enforce and support Administrator's actions but my accommodations are not met or enforced by Former director to Administrator. In addition, New employee made a comment about website changes having been updated since last week regarding the HPV website for the project. It made me realize that I wasn't included last week on this task. I'm extremely frustrated by all this.

During a meeting to review the HPV website, I caught both Administrative assistant and New employee using their phones during the meeting. Again, I was told not be using my phone two weeks ago by Former director. Administrator has not said anything to anyone as the activity of phone use continues.

**February 25, 2019:** During a late Monday staff meeting, both Senior researcher and Administrative assistant used their phones during the meetings for non-work related stuff.

**February 26, 2019:** During the HPV meeting, Administrator and Administrative assistant both used their phones.

**February 27, 2019:** During a recruitment meeting for ALCOHOL RESEARCH PROJECT, Administrator assigned us all parts of the flyer to work on. Administrator did not provide a complete date and an estimated number of hours we should spend working on this assignment. There was phone use by Administrator during this meeting with her phone constantly making disruptive sounds from notifications she was receiving. She never did turn off her phone or switch it to silent. During the second ALCOHOL

RESEARCH PROJECT meeting, Administrative assistant was using his phone. Administrator did not say anything.

**February 28, 2019:** I submitted my timesheet to Former director. She replied saying that I had claimed hours to ALCOHOL RESEARCH PROJECT that were not approved by Administrator. Her choice of words was placing blame on me for not following instructions. I replied to her that Administrator had stated during a meeting last week that we are to only mark 1 hour on our timesheets for ALCOHOL RESEARCH PROJECT due to our weekly standing meeting. Former director's email demonstrates that Administrator did not communicate this to Former director, yet Former director decided to accuse me of not following instructions. I am disappointed that Former director is quick to judge me but will not confront Administrator regarding my accommodations not being met. Additionally, I have not yet received an email from Administrator regarding the assignment for ALCOHOL RESEARCH PROJECT on when the expected deadline is for us and the number of hours we should claim on our timesheets.

## Appendix F – Accommodations



THE UNIVERSITY OF  
NEW MEXICO  
OFFICE OF EQUAL OPPORTUNITY

September 12, 2018

The Office of Equal Opportunity (OEO) received confirmation that Leonel Diaz (Diaz) [REDACTED] Research Coordinator, and his supervisor, [REDACTED] Research Scientist, have agreed on reasonable accommodation(s) for Diaz' disability or serious medical condition as defined by UAP 3110. This agreement serves to memorialize the workplace accommodations agreed upon by Diaz and [REDACTED].

Accommodations include:

1. Provide written instructions via email.
  1. The supervisor and project team members are to provide written instructions by email on tasks assigned to Leonel. Instructions should be specific and detailed.
2. Provide reminders of tasks.
  1. The supervisor and project team members are to provide friendly reminders of all tasks assigned, especially tasks that do not have deadlines when initially assigned.
3. Allow for a flexible schedule.
  1. The supervisor will allow Leonel to have a flexible work schedule as needed as long as his 40 hours are met within a week.
4. Allow recording device for note-taking.
  1. Leonel can use a recording device for note-taking purposes during all meetings as needed.
5. Allow working with office door closed.
  1. To help with concentration and focus, Leonel can work with his office door closed as needed each day.
6. This accommodation will be periodically reviewed for effectiveness.

  
Leonel Diaz



## Appendix G – Investigation Report



June 13, 2019

Leonel Diaz

Sent via e-mail to: [ldiaz@unm.edu](mailto:ldiaz@unm.edu)

**Re: Final Letter of Determination – [REDACTED]**

Dear Mr. Diaz:

The purpose of this correspondence is to relate to you the proposed findings with regard to the above-referenced civil rights claim. The record shows that Leonel Diaz (herein Complainant), submitted a written response to the Preliminary Letter of Determination on Wednesday, June 12, 2019, consisting of corrections of minor details that have no bearing on the final decision. In addition, neither Complainant nor [REDACTED] (herein Respondent) provided additional factual information in response to the Preliminary Letter of Determination issued from this office on June 7, 2019.

**Complainant has provided the attached statement:**

Email from Complainant to OEO dated June 12, 2019, in response to Preliminary Letter of Determination.

Please be advised that the Preliminary Letter of Determination is unchanged.

**FINDINGS:**

**POLICY VIOLATION** with regard to Complainant's assertions of Respondent failing to accommodate Complainant's disability.

**NO POLICY VIOLATION** with regard to Complainant's assertions of Respondent retaliating against him after initiating a complaint regarding the failure to accommodate with the Office of Equal Opportunity.

**POLICY VIOLATION** with regard to additional assertions of Respondent retaliating against Complainant after initiating a complaint regarding the failure to accommodate with the Office of Equal Opportunity.

**CONCLUSION:**

The facts revealed in the course of the investigation did substantiate, more likely than not, Respondent failed to accommodate Complainant's disability by failing to provide written

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*Equal Access and Treatment for All*

OEO# I-2018-12-75  
June 13, 2019

instructions; therefore, there is a **POLICY VIOLATION** determination that Respondent violated University Policy #3110: Reasonable Accommodation for Employees, Job Applicants, and Participants with Disabilities.

The facts revealed in the course of the investigation did substantiate, more likely than not, Respondent did not retaliate against Complainant on the car ride back to Albuquerque; therefore, there is a **NO POLICY VIOLATION** determination that Respondent violated University Policy #2200: Reporting Suspected Misconduct and Whistleblower Protection from Retaliation.

The facts revealed in the course of the investigation did substantiate, more likely than not, Respondent did retaliate against Complainant when Respondent challenged Complainant's leave; therefore, there is a **POLICY VIOLATION** determination that Respondent violated University Policy #2200: Reporting Suspected Misconduct and Whistleblower Protection from Retaliation.

#### **RECOMMENDATIONS:**

OEO will refer this matter to Human Resources, to take appropriate action. With respect to the finding of policy violations, OEO requests to be provided with a detailed account of actions taken to address this matter.


The investigative file should be closed.

#### **RIGHT TO APPEAL:**

The finding in this matter is subject to discretionary review by the President and Board of Regents. Notice of an appeal must reach the President's office with five (5) business days of the date of this letter of determination. The President and the Regents will normally accept review only in extraordinary cases, such as those where proper procedures have apparently not been followed, where the decision appears to be unsupported by the facts, or where the decision appears to violate University policy.

#### **NOTICE:**

Please be advised it is contrary to University of New Mexico policy and federal and state civil rights law to retaliate against any person and/or employee for having filed or participated in a discrimination investigation. This provision includes any witnesses who provided information during the investigation.

  
EEO Compliance Specialist

  
Director



## Appendix H – Annual Review Letter



### *Organization, Information & Learning Sciences*

Dear Leonel,

It is the intent of the University of New Mexico and the Program of Organization, Information, and Learning Sciences (OILS) to provide frequent feedback to our doctoral students. The purpose of this letter is to let you know if your progress toward your degree meets expectations or not. If your progress does not meet expectations, you may need to meet conditions outlined by your advisor prior to enrolling in coursework.

Based on the collective input from the OILS faculty and your transcript, your progress in the doctoral program **is of concern to the faculty**

The following issues are of particular concern:

- Your effort in classes: your quality of your assignments have not been at the high level. It seems like it was an effort issue that you might not put enough effort in your reading, reflection, and response to feedback. Your contributions to in-class discussion were also confusing in time.
- Professionalism: In times, you were disengaged in some activities [including group activities with your peers]. For examples, I received the annual review package weeks after the deadline.

You must schedule a meeting with your advisor as soon as possible to discuss these concerns about your progress and develop and plan to address those issues.

As a reminder, you should meet with your advisor every semester to continue to make progress on your degree. If you have any questions about this letter or about your program of studies, please contact your advisor at [REDACTED]. We look forward to working with you in the coming year.

Sincerely,

A black rectangular box redacting the signature of the advisor.

Advisor

A black rectangular box redacting the signature of the program director.

Program Director

Appendix I – Medical Letter



3001 Broadmoor Blvd. NE. Rio Rancho, NM 87144

505-994-7397

Medical Specialty Clinics

Date: 4/21/2017

Please Excuse Leonel Diaz from work/school. He/she was seen in our clinic for an appointment today. He/she may return on 4/25/2017.

\* This is to inform you that the above patient is being followed for care with the Sleep Disorders Center for Sleep related issues.

Staff signature

A handwritten signature in black ink, appearing to be "JB", is written over the "Staff signature" label.

## Appendix J – Annual Review Submission

March 22, 2019

OILS Faculty:

“This again...ugh.” That was my first thought upon seeing the email regarding the annual review process. I wasn’t the only individual to feel this way but I am also the only one willing to address the problem directly. I don’t fear any of you as my peers do. They are afraid of having any sort of conflict affect their career paths and degree attainment. As a consultant and Student Affairs professional, this signifies there are problems within the program. I could have chosen to comply like my peers but that would be too easy. We have too many problems in the world because people remain silent. A mentor once said to me, “We write to avoid the humiliation of silence in the face of cruelty and injustice.” I’ve chosen to write as my protest to the annual review process because doing otherwise is to continue to support a process that is not inclusive, just, supportive, or beneficial to me. This letter is my voice. My truth. My reality. The goal is to help you see my perspective and provide feedback to you all with recommendations on how to move forward.

I’m extremely disappointed in the annual review process for doctoral students. In the previous two years, I have gained nothing important or useful from the process. In the first year, I received negative feedback regarding my performance without any follow up or plan for improvement. This was also the same year in which my health declined significantly, bringing me close to death. I shared my health problems and my struggles, placing myself in a very vulnerable position, to which I received no guidance or support. I was told, “Just do your best.” I would expect organizational development researchers and learning scientists to fully understand how a person’s well-being impacts their performance. In the second year of the annual review process, I received a statement that I was doing well. Nothing more or less. In each instance, no one followed up with me regarding my goals, no feedback on my CV was provided, no one was concerned about my health, and no one met with me to see if I was taking courses relevant to my career path. I wish I could say this is a unique isolated case, but it is not. There are other students that share this sentiment. It is sad that the graduate students are not willing to speak up due to possible retaliation and how it may impact their career or degree status. Not even the Graduate Student Coalition for OILS (GSCOILS) was willing to take a stand on this for the same reasons as our peers. No graduate student wants to risk having their career destroyed. This alone should be a huge red flag of concern.

What are the learning outcomes from this process for the student, the faculty advisor, and the program? How does this process help a full-time professional with personal and professional development? How does it help a student who has already completed all course work and has limited interactions with the OILS faculty with the exception of their faculty advisor? How does it help a student who has taken no courses within OILS due to taking courses not offered or needed in other programs? How does providing you with my goals help us when advisors don’t ever follow up with goal attainment or even ensure that the goals are specific, measurable, achievable, relevant, and time-bound (SMART)?

Why is there no use of SMART goals in the review process? My understanding is that the information we provide is used for the Academic Program Review (APR) process, so why not also use it as an opportunity to gather information on how to best improve the doctoral program? From an organizational development standpoint, this process should not be one sided and should seek ways to improve the doctoral program and the faculty approaches (course offerings, teaching improvement, research opportunities, advisement improvement, etc.). An effective and successful organizational should be focused on taking a holistic evaluation. This entire process is top down and not multi-way as it should be.

Professionally, I am a member of a national organization and have held a leadership role within a sub-group for five years, have a solid CV that has yielded 9 job interviews and 2 job offers within 10 months, recently presented at a national conference with sponsorship on the session, have a research manuscript in progress to be submitted for publishing, began a new job, have an upcoming webinar presentation to deliver, and have on-going consulting contracts. How does this annual review process help someone like me that has a significant amount of professional experience? This process has never provided me with anything attainable that would allow me to continue my development personally or professionally.

Your priorities should always be centered on student success. This annual review process appears to be a one-time a year solution to faculty advising that should always be taking place as needed by the graduate students. Simply saying that other doctoral programs also conduct an annual review, or “common practice,” is not sufficient or an appropriate response. It’s a cop-out response. It makes the response seem like it was not well-researched. Is there any research supporting the annual review process as an effective tool? This process has no return on investment depending on who the faculty advisor is to the graduate student. These inconsistencies are a problem that need to be solved. If you are all really invested on student success, demonstrate that you are willing to take time to address the problems I highlight and improve this process so that it is more encompassing of students at different stages academically, personally, and professionally. Demonstrate to me and to the entire OILS graduate students that you do care about your roles to support student success and take action in improving this process and other areas of the programs. If you’re thinking about just sending me a letter acknowledging receipt of this and telling me your working on things, don’t bother replying. Words are meaningless unless they are supported with positive action. You are all researchers. Study the problem. Find a third party to interview graduate students and collect data for you.

Chances are that no action will be taken by any of you because I appear to pose no risk to any of you. The narrative would probably change if I released this to the journalism community. Don’t worry. I don’t need media attention either.

Consider this letter my annual review packet.

A handwritten signature in black ink, reading "Leonel A. Diaz Jr." in a cursive style.

Leonel A. Diaz Jr.

## Appendix K – Annual Review Response

### Regarding the annual review process

[REDACTED]

Sat 6/15/2019 9:53 PM

To: Leonel Diaz Jr <ldiaz@unm.edu>

Cc: [REDACTED]

Hi Leonel,

First, thank you for your feedback regarding the annual review process. I am sorry for the delayed reply.

To respond to your feedback, I first have to apologize that I did not follow up with you after your first annual review. At that time, you told me regarding your health issue. So, my only concern was your well-being. Therefore, I thought my best support was providing time and space for you to recover. I worried that followed up with you would have given you unnecessary pressure.

Because of your feedback, the OILS faculty discussed and reviewed the doctoral annual review process. The purpose of the annual review process was to provide more structure in the advising process to support our doctoral students. Obviously, there are rooms for improvement as some students could not see the benefits of goal setting and reflection (and other administrative processes such as updating CV and bio). The faculty had some serious discussion regarding how to better advise/support our doctoral students. Unfortunately, we have not been able to finalize a better process, yet. My hope is that the discussion will continue in Fall and a significant change will happen in 2020.

Once again, thank you for your feedback. Our goal is to provide the best learning experience to our students. If you have any other concerns, please feel free to let [REDACTED] and I know.

Thanks and hope you a great summer.

[REDACTED]

## Appendix L – Medical Note

**The University of New Mexico  
Health Sciences Center**

### Work/School Excuse

To Whom It May Concern:

The above named patient was seen in our clinic on \_Thursday, September 19, 2019

Check one:

	May return to work today.
xxx	May return to work on ___.Monday, September 23, 2019

Restrictions (check one):

xxx	No restrictions.
	Restrictions (list)

Sincerely,

### Signature Line

Fritch, Robert C DO  
Attending Physician  
Department of Internal Medicine

Signed Date: 09/20/19

Signed Date: 09/20/19

RCF/

## Appendix M – Dismissal Letter



April 12, 2021

Leonel Diaz Jr.

Via email: [ladiaz@unm.edu](mailto:ladiaz@unm.edu)

RE: Dismissal Letter [REDACTED]

Dear Leonel Diaz:

This letter serves as notice that the Office of Ethics, Compliance and Equal Opportunity (CEEO) is issuing a discretionary dismissal of the allegations brought forth in the above-referenced civil rights claim. Leonel Diaz Jr. (herein Complainant), UNM graduate student, asserted that he was subjected to hostile environment discrimination and differential treatment, based on disability, by [REDACTED] (herein Respondent), Interim Dean of the College of University Libraries & Learning Sciences (CULLS).

### **I. APPLICABLE UNIVERSITY GUIDELINES OR POLICIES**

- [UNM Administrative Policy 2720](#): Prohibited Discrimination and Equal Opportunity

UNM Administrative Policies can be found on the UNM Policy Office website at <http://policy.unm.edu/university-policies/index.html>.

### **II. CEEO AUTHORITY AND SCOPE OF INVESTIGATION**

The University of New Mexico is committed to creating and maintaining a community in which students, faculty, and staff can learn and work together in an atmosphere that enhances productivity, draws on the diversity of its members, and is free from all forms of disrespectful conduct, intimidation, exploitation, and harassment. CEEO, acting under the authority of UNM Administrative Policies [2720](#), [2740](#), [2750](#), [2310](#), [2215](#), [3110](#), [3210](#), [3790](#), Board of Regents Policy [2.3](#), and various Memoranda of Understanding, may take necessary action to investigate behavior that allegedly violates UNM policies or impacts the academic or work environment.

CEEO is an independent, impartial, and neutral campus entity designated to ensure compliance with all UNM policies that apply to civil rights, including investigations of any allegations of civil rights violations. UNM prohibits harassment on the basis of sex, gender, race, color, religion, disability, age, national origin, ancestry, and any other characteristic protected under applicable law. When UNM faculty, administrators, and supervisors witness or receive a report or complaint of discrimination or harassment,



they are required to engage in appropriate measures to prevent violations of this policy and to promptly notify CEEO, including notification of any actions taken to achieve informal resolution of the complaint.<sup>1</sup>

CEEO has sole discretion to determine which specific allegations it will investigate and the manner in which it will conduct the investigation.<sup>2</sup> When investigating an allegation of civil rights violations, CEEO acts as the finder of fact and, unless a matter is dismissed, prepares an investigative report at the conclusion of the investigation that is then forwarded to a Hearing Coordinator in preparation for a live hearing before a Hearing Officer. CEEO has no sanctioning or disciplinary authority and makes no determinations about policy violations.

### **III. JURISDICTION**

Pursuant to Section III of the CEEO Discrimination Grievance Procedure, individuals who believe their civil rights have been violated at UNM or in a UNM program should file a complaint within 180 calendar days from the most recent alleged discriminatory incident. This time frame may be extended due to the severity and/or pervasiveness of the allegations (such as sexual violence), allegations of a continuing pattern of conduct, or as determined by CEEO.

Complainant raised allegations of hostile environment discrimination based on disability, which occurred in October 2019. Complainant did not provide evidence of misconduct by Respondent that occurred within 180 days from the date that the complaint was filed. CEEO determined that the allegations are not sufficiently severe or pervasive to justify an extension of time frame designated by the Discrimination Grievance Procedure. As such, CEEO is issuing a discretionary dismissal of this complaint.

CEEO will refer the matter to the Provost Office for further review.

### **IV. OBJECTIVES AND PROCEDURAL BACKGROUND**

This investigation was conducted in accordance with the CEEO Discrimination Grievance Procedure. This investigation focused on a fair and impartial collection of all available evidence, including but not limited to, witness accounts and documents. The parties were given opportunities to offer evidence for inspection and review. This Dismissal Letter provides an opportunity for the parties to review all evidence obtained as part of the investigation. This Dismissal Letter provides a summary of all relevant evidence collected and reviewed as part of the investigation as well as the reason for the dismissal.

#### **Initial Report**

[REDACTED], UNM Chief Compliance Officer, received an email from Complainant alleging disability-based misconduct by Respondent on March 10, 2021.

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<sup>1</sup> UNM Administrative Policy 2720, Section 11.

<sup>2</sup> [CEEO Discrimination Grievance Procedure](#), Section VI(C)(3)(c).

Following an interview with Complainant, which is explained in greater detail below, [REDACTED], EEO Compliance Specialist, met with [REDACTED], CEEO Interim Director, to conduct a jurisdictional review.

#### **Complainant Outreach and Interviews**

[REDACTED] confirmed receipt of the initial report with Complainant via email on March 16, 2021. Complainant met with CEEO on March 25, 2021, at which time [REDACTED] reviewed CEEO's Discrimination Grievance Procedure, Complainant's rights and responsibilities, confidentiality, and the University's anti-retaliation policy. Complainant was advised of their ability to bring a support person to any meeting with CEEO; Complainant did not bring a support person to the meeting. Complainant did provide a verbal statement during this meeting. [REDACTED] explained the availability of supportive measures to Complainant; Complainant stated that no supportive measures were needed.

The Confirmation of Allegations (COA) was sent to Complainant on April 2, 2021. Complainant returned the signed COA on April 6, 2021, with edits. Complainant did not provide any witnesses.

#### **Respondent Outreach and Interviews**

[REDACTED] did not contact Respondent.

#### **Witness Outreach and Interviews**

[REDACTED] did not contact any witnesses.

### **V. SUMMARY OF RELEVANT EVIDENCE**

According to Complainant's COA, including Complainant's edits, Respondent participated in Complainant's comprehensive exam committee. During a comprehensive exam meeting on October 15, 2019, Respondent asked Complainant numerous questions outside the scope of Complainant's study, which caused Complainant to express frustration in his voice and facial expressions. Respondent would also laugh at Complainant's responses. At the conclusion of the meeting, Respondent told Complainant, "You can go home and cry now."

Following the comprehensive exam meeting, Respondent made Complainant complete revisions to his dissertation, which Complainant believed was unnecessary because it was outside of Complainant's research. Complainant also believe that Respondent was being intentionally rude to Complainant and was pushing him into a research area that Complainant didn't wish to explore.

### **VI. SUPPORTING DOCUMENTATION AND EVIDENCE**

#### **Appendix I**

Appendix I contains all relevant evidence collected during the course of the investigation, and includes the following:

- Complainant Statement
- Exhibit 1: Email containing Complainant's Statement revisions
- Exhibit 2: Audio recording of October 15, 2019 meeting

#### Appendix II

Appendix II contains any evidence submitted by the parties or obtained by CEEQ that was ultimately determined to be irrelevant for the purposes of this investigation, and includes the following:

- No applicable evidence

#### Appendix III

Appendix III is a document detailing the procedural steps taken in this matter from the receipt of the formal complaint to the submission of this Investigative Report, and includes the following:

- Complainant Certification Form
- Jurisdiction Form
- Investigation Checklist

#### Complainant's Statement

1. Complainant is a PhD student in the Organization Information Learning Sciences (OILS) program.
2. On October 15, 2019, Complainant participated in a meeting with his Dissertation Committee which was comprised of [REDACTED], faculty member, [REDACTED], faculty member, and Respondent.
  - a. Complainant had been working on an autoethnography on disability-based discrimination in employment and academic environments.
  - b. The purpose of the meeting was for Complainant to answer three questions posed by [REDACTED], and Respondent.
3. As part of Complainant's research, Complainant shared his disabilities and its manifestations with the committee members.
4. As the meeting progressed, Respondent began asking Complainant questions about work culture, which was outside of Complainant's dissertation research.
  - a. Because of Respondent's questions, Complainant began exhibiting facets of his disabilities, to include issues with memory recall. Numerous times, Complainant asked Respondent and others in the committee to repeat their questions.
  - b. Respondent continued their questioning and Complainant began to express his frustration through his speech and facial expressions.
  - c. Respondent would occasionally laugh at Complainant's responses.

5. Following the meeting, Respondent told Complainant, "You can go home and cry now."
6. Complainant was very frustrated and disappointed by Respondent's comments and questions during the meeting, especially since Respondent knew that Complainant had disabilities<sup>3</sup> and Respondent stated that he had a family member with a disability.
7. Complainant also believed Respondent was intentionally being rude towards Complainant.
8. At the conclusion of the meeting, Respondent informed Complainant that he passed with revisions two times. [REDACTED] informed Complainant that he passed with revisions. [REDACTED] also passed Complainant with a revision.
9. [REDACTED] also passed Complainant with a revision.
  - a. Complainant felt like Respondent's revisions were pushing Complainant outside of his scope of work as Respondent wanted Complainant to discuss foundational theories of work culture that Complainant did not want to address.
10. Following the October 15, 2019 meeting, Complainant provided the revisions as requested, replaced Respondent's committee role with another faculty member, and never talked to Respondent again.
11. Complainant has since progressed in his dissertation and had another dissertation committee meeting. He passed the subsequent meeting with revisions, though Complainant believed the revisions were justified.

#### **VII. PROCEDURAL NOTICE**

The determination in this matter is subject to discretionary review by the President and Board of Regents. Notice of an appeal must reach the President's office within **seven (7) business days** of the date of this letter of determination. The President and the Regents will normally accept review only in extraordinary cases, such as those where proper procedures have apparently not been followed, where the decision appears to be unsupported by the facts, or where the decision appears to violate University policy. For instructions to file an appeal, see Section X of CEEO's [Discrimination Grievance Procedure and the accompanying appeal form at CEEO's website](#).

Please be advised it is contrary to University of New Mexico policy and federal and state civil rights law to retaliate against any person and/or employee for having filed or participated in a discrimination investigation. This provision includes any witnesses who provided information during the investigation.

The matter will be forwarded to the Provost office.

[REDACTED]  
\_\_\_\_\_  
EEO Compliance Specialist

cc: File

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<sup>3</sup> Complainant believes that Respondent was aware of Complainant's disabilities because of the basis for Complainant's research and disclosures therein.