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“Eye” Did Not Know Myself: Disability Identity Development in a Series of Vignettes

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EXECUTIVE SUMMARY

The purpose of this autoethnography is two fold: to synthesize literature about the concept of disability and Disability Identity Development; and to pair this literature with narratives of critical experiences in my life pertaining to my own diagnosis as someone who is legally blind. A comparison between different viewpoints of the key experiences discussed in this paper can also be seen through personal reflections and interviews with my mom, brother, and girlfriend about their perceptions of disability and their recollections. Participant responses were integrated into the research as references to discuss the medical model and social model of disability as socializing forces on individuals’ worldviews. Findings resulted in a clear and concise application of Gibson’s (2006) Disability Identity Development Model, a chronological narrative grounded in research about disability and its socialization, and recommendations for professionals in the field of education on raising disability awareness.

ABOUT THE AUTHOR

Originally from Hondo Texas, Hunter is a first-year graduate student studying student affairs in higher education at Texas State University. He attended Texas State University for his bachelor’s degree in English. His areas of interest are leadership, disability services, and research. At Texas State University, Hunter found his passion for student affairs after working as a resident assistant. From there he pursued any experience in student affairs that he could. He attended the ACUHO-I STARS College experience in 2019, held an internship with Texas State’s Department of Housing and Residence life developing presentations and trainings for resident assistants and attending residence director trainings, worked as a conference assistant, is an active member of National Residence Hall Honorary, and now works as the Outreach, Assessment, & Retention Graduate Assistant for the Office of Disability Services at Texas State.

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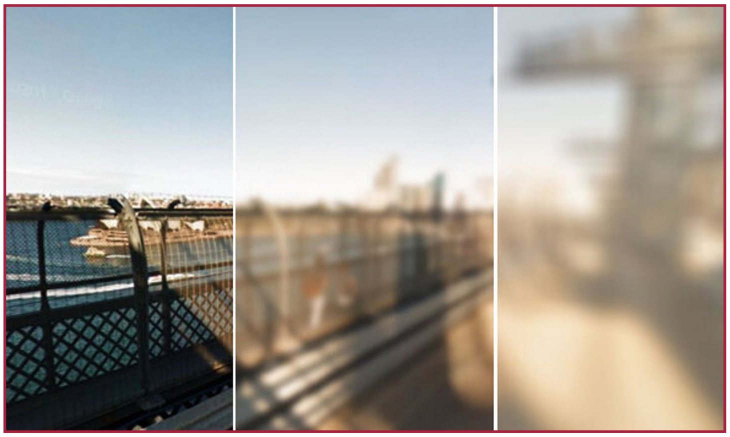
BACKGROUND

I have identified as someone with a disability for the past five years. When I was 19 years old and about two months away from graduating from high school, I found out that I am legally blind. The term "legally blind" means (1) central visual acuity does not exceed 20/200 in the better eye with correcting lens or (2) that the widest diameter of the visual field subtends an angle no greater than 20 degrees (American Optometric Association, 2020).

I fall into the second definition. Learning about my disability at such a late age meant that I had to understand myself again personally, socially, and legally during one of the most transitional periods in a person's life. My family at the time of my diagnosis viewed disability strictly through a medical model. This means they viewed disability as "an individual and/or a medical phenomenon that results in limited functioning that is seen as deficient" (Haegel & Hodge, 2016, p. 195). This viewpoint is common and damaging to the identity development of individuals with disabilities. Often this damaging rhetoric comes from separating disability from the influences of the political, environmental, and social spheres of society. This is because the medical model conflates individuals with disabilities with those who are inherently sick, in addition to discussing disability in a deficit model orientation (Haegel & Hodge, 2016).

The deficit model views an individual as inherently incomplete and in need of treatment. This language can influence how all individuals interact with and talk about individuals with disabilities and reinforces ableist views. For reference, a good definition of ableism is "practices, institutions and social relations that presume ablebodiedness, and by so doing, construct persons with disabilities as marginalized . . . and largely invisible 'others'" (Bogart & Dunn, 2019, p. 651).

Ableist views can manifest in many ways. For example, seeing disability as a punchline or something to joke about, assuming people with disabilities want or need to be fixed, framing disability as tragic in media portrayals, and questioning if someone is actually disabled because they don't appear to be. Other ways ableism can manifest include denying approved accommodations, creating inaccessible buildings and websites, or stereotyping disability as feeble or childlike. Given the problematic cultural discussions about disability, it is not hard to see why a family from small town Texas would share these same views. Luckily, as my family and I grew accustomed to my new label, we learned of a new viewpoint. This new viewpoint was the social model.



"The social model contests that it is society that imposes disability on individuals with impairments" (Haegel & Hodge, 2016, p. 197). In the social model, impairment and disability are separated. Impairment is the "abnormality of the body, such as a restriction or malfunction of a limb" (Haegel & Hodge, 2016, p. 197). Whereas, disability is the "disadvantage or restriction of activity caused by a social organization that does not take into account people who have impairments and excludes them from community life" (Haegel & Hodge 2016, p. 197).

This distinction is something I struggled with, even as someone with a disability. Often, I found myself viewing my inability to meet society's standards or ideals as something that separated me from others. I could not partake in certain social spheres because I could not keep up without an "even playing field." With this mindset, it became difficult for me to try new things because I would have to assess if I would need assistance first. The word disabled really had an impact on my confidence and I often wished there were another word for it. I felt so negative about the word that I would avoid it at all costs.

Since taking on this new identity, I have reconstructed my worldview to align with the social model and Person First Language to comfortably incorporate my disability into my identity. Person First Language can be defined as using language that puts the person before the disability (Centers for Disease Control and Prevention, 2020). An example would be saying someone is an individual with a disability instead of a disabled person.

As a result of this worldview change, I have seen a marked improvement in my self-image, mental health, quality of life, and successes in school. With these models in mind and my observations about the impact they had on me, I aim to add my personal experience to the existing literature surrounding Disability Identity Development to enrich the experiential element of disability.

METHODOLOGY

When choosing a method to conduct this research. I settled on autoethnography after consulting both Cheng and Tombro's books discussing autoethnography's merits. Cheng (2008) describes the benefits of autoethnography as threefold: "(1) it offers a research method friendly to researchers and readers; (2) it enhances cultural understanding of self and others; and (3) it has a potential to transform self and others to motivate them to work toward cross-cultural coalition building" (p. 52). In particular, benefit two is integral to the purpose of this piece. I think placing the lived experience into an easy-to-digest format like an autoethnography provides a gateway piece of literature for many readers into disability identity. When conceptualizing this piece, I worried about the subjectivity of the piece and if writing "personal research," as I call it, would be inherently flawed. According to Cheng (2008), "When the single tool is the researcher self, the unbridled subjectivity of autoethnographers can be more severely challenged. Although an obsession with objectivity is not necessary for qualitative research, autoethnographers need to support their arguments with broad-based data as in any good research practice" (p. 55). To address this concern, I collected 18 sources related to disability research and Disability Identity Development; I interviewed my mother, brother, and girlfriend to help me construct the narrative pieces; and, I regularly consulted my mentor, Marybeth Gasman, to make sure the focus and integrity of the paper could withstand academic scrutiny.

The interviews, in particular, were included to give participants a chance to be a part of the narrative. It felt essential not only to check my recollection of events, but to protect the voices of those connected to this story. Cheng (2008) warns that self-narratives like autoethnography still have the same responsibilities of confidentiality. Chang recommends that "since autoethnographers' personal stories are often linked to stories of others, no matter how explicit the linkage is, the principle of protecting confidentiality of people in the story is just as relevant to autoethnography" (pp. 55-56). After working to understand some of the pitfalls and benefits of autoethnography, I moved to learning about autoethnography and the writing process.

Tombro (2016) explains the autoethnography writing process as "an extended research project that allows you to investigate a subculture you have chosen to be part of or will choose to be part of and critically assess this subculture from both outsider and insider perspectives. To do this, you will be relying on your own experiences as well as assessing the experiences of other members of the subculture" (p. 53). Tombro (2016) supplements this with a handful of questions to consider. The questions are: "What have you learned about your subculture from this process? If you could share anything about your subculture to explain it to an outsider, what would it be? How would you like your final project to look and read? Based on your research, have you changed your mind about any aspects of your subculture? If so, which and why? What do you think the value of a project like this is or can be?" (p .53). The next step I had to consider was the integration of the research. Tombro's (2016) advice on quoting states,

> You quote for a number of different reasons. Most notably the reason you quote is that the speaker or author has articulated a concept in a specific way that helps you understand a point you otherwise could not understand. For this reason, the author or speaker's language is intrinsic to the point and thus you need to quote it directly. When you are reading the texts, you have gathered and reviewing your interviews, you will have to make choices about when you think the author's language is important to the point and when you can make a valid argument by summarizing and rearticulating this language yourself (p. 60).

When it came to the writing of the experiences, I needed examples. Tombro lists two examples of this experiential writing. Titled Sheila and Kelly, the two autoethnographies discuss the lived experience and subculture of a drag race and a neighborhood in Brooklyn. Each student successfully captures the embodiment of the environment they are trying to evoke. They are layering their writing with the subcultural nuances and the impacts their involvement with that subculture had on them. With these writings and their analysis as a foundation, I set out to write my piece.

Autoethnography, according to Maréchal (2010), "is a form or method of research that involves self-observation and reflexive investigation in the context of ethnographic field work and writing" (p. 43). Maréchal (2010) further explains that "the term has a double sense, referring either to the reflexive consideration of a group to which one belongs as a native, member, or participant (ethnography of one's own group) or to the reflexive accounting of the narrator's subjective experience and subjectivity (autobiographical writing that has ethnographic interest)" (p. 43). My approach to autoethnography is centered on a reflexive reflection on my lived experience. In particular, I placed myself and my experiences under a microscope underpinned by research. The research was integrated in such a way to analyze and validate my lived experience in academia. The interwoven nature of the autoethnography works to personalize disability. Once I made this human connection, I crafted recommendations for education professionals with the hope that readers will take a social model viewpoint and work to change their institutions. Autoethnography as a method of research in the context of this project is personal, socially bound, academically valid, and a microcosm of larger attitudes, beliefs, and constructs around disability.

To construct my autoethnography, I drew upon personal recollections, medical records, and interviews with my mother and significant other, who were both present for my major experiences. I integrated literature concerning disability and disability identity development. This methodology created an intimate narrative of experience and scholarship that will help humanize the literature surrounding disability identity development. Data sources for my study included personal recollections of critical moments in my identity development. These recollections are a reconstruction of these experiences. If they were long-term experiences or take place at intermittent times, they were reconstructed in chronological order connecting through a central theme. I also consulted my medical records to frame the discussion around my experiences and to inform the reader of my disability in a medical context. Finally, I conducted interviews with my mom, brother, and significant other discussing their perspectives on my experiences as they were present for and have perceptions of disability. These interviews were an hour in length and assisted in narrative construction.

OBSERVATIONS

I created four questions for interviews with my mom, brother, and significant other, and allowed for expansion on each talking point. The questions were: (1) How would you define disability? (2) What is your perception of disability? (3) Do you perceive disability as an identity, similar to race and gender? If not, why? (4) Did learning of my disability change your perception of me in any way?

Then there were questions for each individual person. For my mom and brother there were five: (1) In detail, describe what it was like when the Department of Assistive and Rehabilitative Services (DARS), counselor showed you what my visual field looked like and if and how it changed the way you understood my disability; (2) Discuss if there was any difficulty accepting my disability as truth and does anyone in the family still has trouble seeing me “as disabled?” (3) In detail, describe the doctor appointment at Kerrville and at Lion’s Low Vision Center. What were you thinking? (4) 5 years have passed since the diagnosis of my disability, in what way do you think knowing someone who identifies as disabled changed your perspective on disability? (5) Have you noticed a positive or negative response when I discuss my disability? Please explain.

For my significant other there were four questions: (1) Have you seen or experienced a shift in thinking about disability since knowing me? (2) Describe in detail the time a professor denied an accommodation for my disability and how you perceived the situation. (3) Can you recall times I was frustrated or fearful because of my disability making me dependent on others for transportation? (4) Have you noticed a positive or negative response when I discuss my disability? What are some common themes?

DATA ANALYSIS

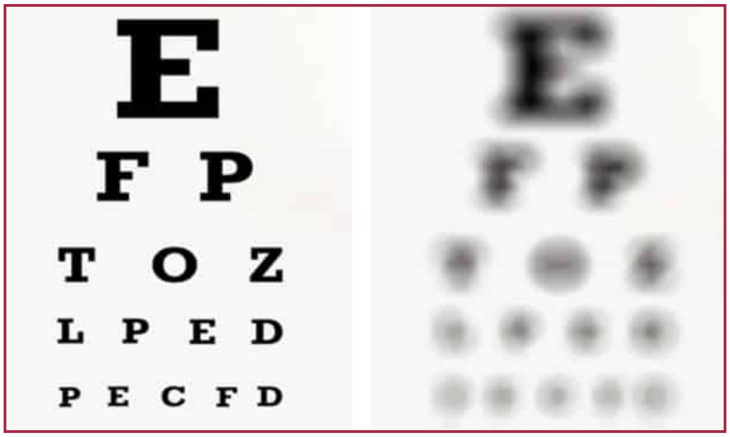
I conducted data analysis by weaving interview perspectives together with my recollections to build a narrative. Then, I found research concerning disability identity, disability models, ableism, and other facets of disability, which I interspersed throughout the narrative in order to relate my experience to the larger body of literature.

Limitations

There are some limitations to my research approach. First, disability is a complex and varied identity with no universal experience, which will limit the generalizability of this research as it only explores my experience. Second, disability is one facet of self-identity and is shaped by the intersections of other identities such as race and gender. This means that not all intersections can be understood and applied to this piece, only ones related to me. Finally, I discovered my disability at 19 which, gives me an experience of two “lived identities.” This is different from someone aware of their disability at a younger age.

The Doctor Visits

I was 19 years old; it was the middle of March; I had recently been accepted to Texas State University; and, I was waiting in the waiting room of an optometrist’s office in Kerrville that I had never been to. This was not an exceedingly unique office by any means; it had a drab brown carpet and beige wallpaper. A grey sofa was the only bit of furniture aside from the examination chair. The table was filled with various lenses, frames, a tonometer, and an ophthalmoscope. My mom and I discussed that I needed to take my driver’s test and get a car before going to college as we waited for my brother’s exam to end. My brother finished up a pretty routine eye exam, nothing more than the eye chart projected on a screen and choosing between “number 1 and number 2.”



As I got into the eye exam chair I began to feel a familiar sense of anxiety and dread. It was always a struggle to get through an eye exam in less than two hours. To try and calm down, I made myself think of things we were going to do after the appointment. In particular, answering the question of where we were going to eat was at the forefront of my mind. As I sat in the chair waiting to begin, I prepared myself for eye dilation, thinking that was going to be the hardest part of the day.

The appointment began as every appointment did, reading the letters that were always too far away and having a light shone so directly in my eye I swore I was seeing the sun. But then something different happened, the doctor asked me to follow a little toy dog with my eyes. She showed it to me and then moved it to the right outside of my visual field by stretching her arm. I asked her “How am I supposed to follow something no one can see?” She said, “Ok I will move it closer.” I still could not see it. She did it again “How about now?”, she asked. “No,” I repeated back. I began to sense something was wrong. She abruptly ended the appointment and handed my mom a prescription and a referral to Lion’s Low Vision Center in San Antonio, Texas. At that point, my anxiety spiked so hard I heard my heartbeat in my ears, my hands shook, and I began to wonder what was wrong with me. There was a fear of losing all my vision. “Had my vision been getting worse? I hadn’t noticed…” I also was afraid of losing my independence and autonomy before I even got it. What the fuck just happened?

Two weeks later, I was sitting in the office of Lion’s Low Vision Center waiting for the tests to begin. It is also important to note that I am someone who had dealt with bullying because I have a limp from a birth defect that impacted my tibia and fibula bones. Growing up with a limp, I got called a “cripple” a lot and as I sat there about to take these tests I began to think about those experiences. With those experiences and feelings rushing back to me after so many years, I began to have negative thoughts about myself and my body. In particular, I remember thinking “Am I made with spare parts? I hope that this is just a mistake.”

The tests consisted of tracking my eyes as they followed a flashing light that progressively got farther away from the center of a circle. Then, I organized colored blocks in the order of the rainbow. When I got the tests back, I found out that I had a visual field of 7 degrees, struggled with night vision, and I am color blind to reds. I broke down and a choked sob escaped my throat. I was told I would lose my learner’s permit; I would need to identify as disabled at school; I would have a cane; and, all I could think was “I am made of spare parts. I was right.” I was angry; “Why me? Why can’t I be normal?” I fully rejected this information. I am able, I am normal, and I WILL NOT tell anyone. I can walk, I can see even if it is not the best. I don’t even LOOK disabled!” This experience is the foundation of this paper.

Looking back, I can see that I felt as if my skills and intellect were challenged by this diagnosis, which can explain why I felt a strong need to reject my identity. In my mind, I was rejecting negative views of myself. This desire to prove oneself and to blend into the “norm” of society is a common experience for people with disabilities. So much so, that when Meyers et al. (2011) surveyed 139 visually impaired students in regard to their feelings about their disability and its impact on their life, more than 80% of respondents were in the final stage of identity development. But 69% of those in the final stage admitted they still do more than others in an effort to prove their ability. With that knowledge, I definitely should not have been so hard on myself.

Looking Through a Pinhole

After three weeks of wrestling with my new identity, my Department of Assistive and Rehabilitative Services (DARS) counselor brought a device that replicated what my visual field looked like to my house. To best understand this experience, it is important to know that the device is called a Low Vision Simulation Kit, and that a DARS counselor has skills and resources to get people with disabilities ready for college and assist them in finding a job that is right for them (Virginia Department for Aging and Rehabilitative Services, 2020).

I pulled this definition from the Virginia Department for Aging and Rehabilitative Services, but it is an accurate description of the Texas Department as well. Along the way, the counselor offers guidance and checks on progress. The purpose of the Low Vision Simulation Kits is, as my counselor said, "It helps families understand the disability better by walking in their shoes for a moment." My mother went first. We were in the living room, which was a shared space with the kitchen and dining room. As my mom attempted to walk, she mentioned how anxiety-inducing it was to "only be able to see the top of tables and chairs but have no idea where you are placing your feet." My mom also walked extremely slowly with her hand outstretched as she said, "I am so amazed you made it this far like this." More comments like this were shared and even though they were meant to be positive and endearing I felt … weird. Why was my existence so "impressive?" I go to school, walk to the store, run, hike, and do other things that everyone else does? So why is it amazing when I do it? She described looking through my perspective as seeing the world through a pinhole. I still felt relatively positive about the experience because she began to understand why I interacted with the environment the way that I do. She mentioned how it made sense that I "had a hard time finding things, tripped over curbs, [and] ran into things like fire hydrants and A-frame sandwich signs."

Next, my brother Holden was walking arms outstretched toward the kitchen as he used the device. I moved into the living room and told him to look at me. He pointed out how he had to turn his head and search to find me. He then continued walking and stubbed his foot on a dining room chair. He commented, "Now it makes sense why you bump into walls or things hanging on the wall. You don't even know it's there." He then asked "Why didn't you say anything?! We could have seen someone?"

My mom said "We did! Ever since he was a baby, he saw Dr. Mumma and Dr. Zwaan, and he had surgeries for his strabismus." Strabismus is a condition in which both eyes do not look at the same place at the same time and is corrected by surgery (American Optometric Association, n.d.). I had roughly five surgeries for this condition. It usually occurs in people who have poor eye muscle control or are very farsighted. Even though I always mentioned that I struggled to see, I did not know that what I had for vision was not within the realm of "normal." I complained to doctors. I saw specialists since birth. I was given new prescriptions. However, every time I said I could not see well, I was told that was the best it would get, and I should make peace with that. I will never know why I slipped through the cracks when I did everything right.

As part of the interview process for this paper, I asked my mom to define disability in her own words. She because I never really see anybody as having any limitations. Everybody has their own strengths and weaknesses, so I have never really put a label on just one person. And even this being my first-year teaching in a public high school, I really saw that everybody has their own exceptional qualities. I don't really see a label as an exact definition of what somebody is capable of." Looking at her answer, I can see that through her education and exposure to disability in her new position as a teacher she has started shifting away from her viewpoint of disability as purely medical. She is beginning to discuss labels and is not viewing disability as a limitation. While this viewpoint may be a bit flawed by wanting to avoid the label of disability because it is still viewed as taboo, viewing disabilities as non-limiting and appreciating the individual's other qualities shows her progression toward the social model of disability.

I also talked to my brother, who is a senior in high school now, and asked him to define disability in his own words. He said, "Well, I'll probably take apart the word ability, like your means of doing things and then 'dis' lack thereof. So, something that impedes your ability." This definition is actually pretty close to the Americans with Disabilities Act (ADA) of 1990. The ADA states "a disability is (1) a physical or mental impairment that substantially limits one or more major life activities of such individuals, (2) a record of such an impairment, or (3) being regarded as having such an impairment" (U.S. Department of Justice, n.d.). The next question was, "Do you believe disability is an identity similar to race and gender? If not, why?" He responded, "It can be a part of your identity. I do not think it has to be if you do not want it to be. But I think there is a way that maybe people facing similar struggles might be more relatable." He explained that he was comfortable with disability because of another relationship. He elaborated on this relationship, "Well you're not the only person I've ever known with a disability too. But it definitely gave insight to maybe being legally blind. We both used to have a stepbrother that had a severe disability. And so, I had been very aware of the challenges people can face and how we are all different. Knowing how to be mindful of different people [is key]." This experience with my disability and our stepbrother influenced his perception of disability as well. This comfort level may also be due to age. Friedman (2019) found that "family members' implicit negative attitudes increased with age. This also could be due to the fact that younger people grew up with the Americans with Disabilities Act and were more likely to have more people with disabilities integrated into their classrooms, communities, and workplace" (p. 208). My brother mentioned,

> [The Low Vision Simulation Kit] gave me a lot of insights to understand that the challenges you face are very real. Because growing up, I always thought 'he is just clumsy.' Excessively clumsy. I knew it had to do with your bad vision. But legally blind kind of makes you step back and say, okay... there is something here that makes us very different, and you got to step back and think about it. If I had that level of vision, would I have missed that step? Yes. So maybe I should not be like, "oh my God, pull it together." We should not be so quick to any sort of judgment because we do not know what someone else is experiencing.

These viewpoints reflect someone who is more inclined to view disability from the social model, actively attempting to be aware of and avoid ableism.

I interviewed my mom about the device that showed what my visual field looked like to get her perspective on the experience as well. I asked her the following question:, "Describe what it was like when the DARS counselor showed you what my visual field looked like and how it changed the way you understood my disability." My mom responded, "[once the DARS counselor left] Holden and I talked afterward, and we actually cried together because we had no idea what it was like until you have walked in someone's shoes. And that is so true. And that [device] actually put us walking in your shoes." She continued, "When she brought that to our house and we put them on, I could not believe just looking out and seeing what you could see when I knew there was so much more there in that picture. Like when I looked into the kitchen and you could not even see the trash can was there. And when I looked out into the dining room, I could see the table, but like not the legs of that and the chairs. And I just could not imagine how frightening a world like that would be, that I was going to trip and fall." When I asked her to elaborate on that fear she said:

> It was all kinds of fear. It was fear of life. How have you made it this far in life? Fear that that is your day-to-day normal. I think the fear came from knowing that was your last year at home with me and you were going to be going off [to college] and it is probably easier to make it in a house where you know where everything is, but you were going on to a whole other life on a big campus and dorm rooms and everything else. And I just thought, oh my goodness, what if you get hurt? What if you do not see a car coming or fall off a curb or just all kinds of stuff. So, I think it really was that we lived in such a small town and you were so familiar with it because you had been there your whole life and I felt like you were safer. But then there was the bigger fear of knowing that was all about to change.

These same fears were on my mind as well. And statistically, they are not unfounded; my success at college would, in fact, be directly shaped by my disability. The Disability Compendium hosted by the University of New Hampshire (2020) found that young adults with disabilities are less likely to have attained a bachelor's degree or more when compared to young adults without disabilities. In 2018, 10.9% of people without disabilities had attained a bachelor's degree compared to 22% of their peers without disabilities by the age of 25.

I often feared I would not be able to find my way around a town I had never been to. I had never lived somewhere that I needed a bus to get around. My fears were unfounded of course. Nothing had fundamentally changed about my abilities. However, the language around my disability had changed so I felt that I had changed. Language is important though. In fact, language influences the way individuals with disabilities are perceived and engage with everyday interactions (Haegel & Hodge, 2016). I would say this experience with the DARS counselor and the visual field device is the first time my family and I saw "eye to eye" about my disability and could finally communicate about my difficulties effectively.

Downplaying my Disability

The conversations that are in this section highlight some attitudes that my family held about my disability when it was first identified. My family has gotten better about discussing and accepting my disability now because they realize how important my identity is to me. However, these experiences were a major reason I had such trouble accepting that part of myself. The first conversation is with my brother. We had just gotten into an argument about me getting "everything handed to me" and "having it easy" because my college tuition was covered for being exemption from the payment of tuition fees at any institution of higher education using public funds if the person presents:

(1) certification that the person is a “blind person”, or a “deaf person” as defined in Subsection (a) by the Department of Assistive and Rehabilitative Services in a written statement, which certification is considered conclusive;

(2) a written statement of purpose from the person that indicates the certificate or degree program to be pursued or the professional enhancement from the course of study for that certificate or degree program;

(3) a high school diploma or its equivalent;

(4) a letter of recommendation from the principal of the high school attended by the deaf or blind individual, a public official, or some other responsible person who knows the deaf or blind individual and is willing to serve as a reference; and

(5) proof that the person meets all other entrance requirements of the institution” (2019).

I had mentioned that I would trade full eyesight for my tuition because it is not easy. He said, “You aren’t that disabled you are just making that up for attention;” “You just want everyone to pity you and feel bad for you.” I told him to fuck off and noted that he knows about my disability. I stormed off saying that was below the belt and he needed to leave me the fuck alone. After this, I sat in my room and all I thought was “How can I expect people who haven’t known my experience to accept me if my family can’t. They were there for everything and still don’t get it.”

Reflecting on this conversation, I noticed an impact that attitudes, like the one mentioned above, have had on the way I approach disclosure. This conversation is not the only time the merits of my accomplishments and struggles have been downplayed. However, it effectively highlights common attitudes I have faced concerning the aforementioned downplaying very well. I still have to get a read on a person before sharing my disability status. If they are someone who I feel is not going to respect the accommodations and challenges I face, I will hide my disability status. I think a major factor in this is the initial reaction from family and not wanting to expend the emotional labor on teaching someone about my disability. These reactions are a form of stigma.

“Stigma can be defined broadly as social devaluation based on a discrediting identity or difference” (Bogart & Dunn, 2019, p. 654). Stigma can be unintentional or intentional, but regardless of intent “if someone is being the target of stereotyping, prejudice, or discrimination, it can become internalized and privately endorsed overtime” (Bogart & Dunn, 2019, p. 654). This internalization may be a root cause of why I can be hesitant to share or discuss my disability openly.

Issues that families may have when trying to understand a family member who is disabled may be connected to the fact that “people with disabilities often have solo status, meaning they are often the only member of their family or community who have a disability, challenging the formation of ingroup identity” (Bogart & Dunn, 2019, p. 652). Bogart & Dunn (2019) also state that “people with disabilities, like older adults and children, are perceived to be warm but incompetent, leading people to disregard and neglect individuals with disabilities” (p. 656). This attitude comes from a lack of interaction with people with disabilities, and being socialized in a culture that lacks meaningful representation of individuals with disabilities. In the case of my brother, for example, he was only 13 and was basing his perception of disability from movies and tv shows that portrayed disability as something apparent, feeble, and primarily affecting old people. So, of course, he would not see his 19-year-old brother as disabled.

The second conversation related to downplaying my disability was with my stepdad. We were in the living room, tense and angry. My stepdad was telling me about how I could never survive on my own. I yelled back, “I’m 3 years into college so I think I’ve done pretty well.” He shot back, “We have had to take you to doctor appointments and your school is covered by the government, so you don’t take care of yourself.” I said, “I’m blind, I’m sorry that I’m using what the law allows and you know I cannot legally drive a car!” He responded, “Oh give me a break you are just a drama queen.” I told him to leave me alone. As I left, I shouted, “I can take care of myself!” After this, I felt minuscule, insignificant, but worst of all a piece of me feared he was probably right. Maybe I would always need them to drive me; maybe college was a short bubble of freedom that would disappear, and I would revert to being confined to my house. Or that whatever life partner I had would need to fill that role, creating an uneven power dynamic.

Reflecting on the preceding conversation, I see that attitudes espoused in conversations like this one led me to be hypersensitive about my ability to live on my own. I overstress about being perceived as independent to the point of rejecting any and all help from others. I feel like I am one mistake from being ripped out of autonomy and sent back home. This attitude is represented by Tast's (2017) research, which says, "Overgeneralization about what persons with disabilities can do, what they are like, how they communicate, and how they can be helped, create widespread attitudinal barriers for people with disabilities" (p. 10). Tast (2017) expanded saying, "Human beings, in an attempt to make sense out of a world they cannot control, often blame the individual living with impairment(s) rather than recognizing the handicapping nature of the society in which they live" (p. 11). Tast (2017) further elaborates on this idea saying, "Perceptions that pity, mourn, or shame persons with disabilities construct rigid attitudinal barriers that are difficult for people to knock down" (p. 11). When referencing this research, I can see my stepdad shamed me and blamed me because it was easier to blame me than have to reevaluate the systems and attitudes that led to my struggles and his privileges.

The last conversation I want to highlight is between my family and myself. I had lost something and asked my brother to help me. I said, "Hey, I lost something, and I need to find it. Can you please help me?" My brother said, "No, I didn't lose it so it's not my problem." I said, "Please it's twice as hard for me to find something." My girlfriend, Quieraney, chimed in, "It's true he does often need my help because it's tough for him to scan." My mom shoots back "Quieraney, I don't know how you put up with him he's such a drama queen." I tried to explain how in my job as a Resident Assistant I was not allowed to work in the mailroom because my eyes were not good enough to see and write in the log. My brother and mom said, "REALLY HUNTER REALLY?!" And shook their head in disgust and disbelief and asked my girlfriend to help me because they were annoyed. In frustration and needing space to calm down I locked myself in my room. I began to feel a sickness in my stomach. After this conversation, I decided to never ask for assistance because people view it as a burden, an annoyance, and a bother. I should just take longer to do things instead of burdening someone else with my incapability.

Reflecting on the conversation discussed above, I see why I am someone who has to fail at something before seeking accommodations. I was in an environment that believed I was in a mentality of helplessness. My family's belief in everyone being "able" was a good intention that turned into ableism and often minimized negativity. I believe they viewed an acknowledgment of my disability's effect on me as if they were removing my agency in life or were engaging in infantilization. This sentiment aligns with Friedman's (2019) findings, which note that parents may face ableism and enforce ableist views onto their relative with a disability. Families can also enforce ableist views by downplaying their relative's disability. However, even if this was done unintentionally and with good intentions, in the moment it was difficult to disengage from these conversations because they made me feel so invalidated. I found myself angry with myself for needing the help, for burdening my girlfriend with advocacy, and feeling that I was weak for asking for assistance. Mentally, I had built a family hierarchy that put me on the bottom because I began to believe I was reliant on others so much that I was expendable or lesser than.

When viewing this interaction from the lens of the medical model, a few things surface. First of all, in the medical model, "people are considered disabled on the basis that they are unable to function as a so-called normal person does" (Haegele & Hodge, 2016, p. 195). They do not fully believe I am disabled because they could not come to terms with the fact that I would struggle with functioning as a normal person does. As mentioned by Bogart & Dunn (2019), disability is an identity that someone can either be born into or attain later in life. This distinction is another unique factor in why I believe my family and I struggled to communicate about my disability. My family and I had lived separate lives. There was a life without disability and its associated experiences, and a new messier and more complex life.

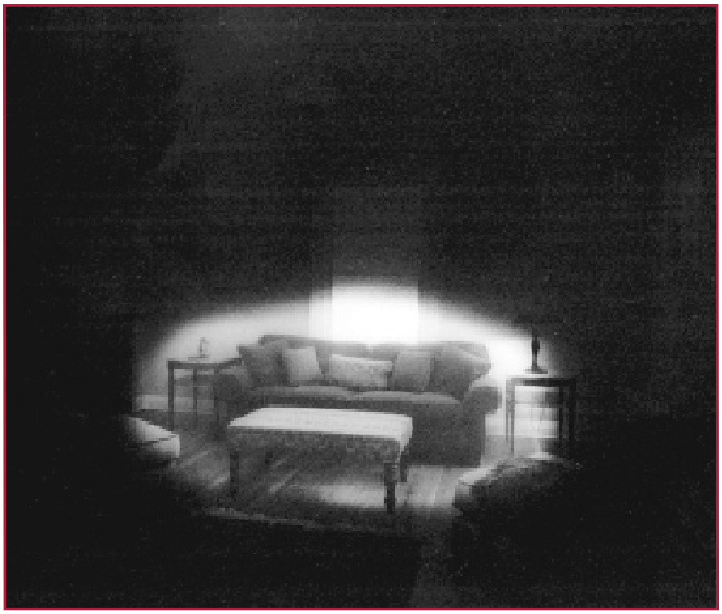
Denied Accommodations in Class

I was in a speech communication class in my junior year of college. I had to memorize a speech and it could not be longer than 5 minutes or less than 3 minutes. There were timecards that would count down from 5 to show how much time was left in minutes as I gave the speech. However, we had to stand at a podium in the center of the class and the timecards were in the farthest right corner of the front of the classroom and about half the size of a sheet of paper. I noticed that the cards would not be visible to me because I needed to face forward to look professional while speaking; when I faced forward the cards were out of my visual field. Only when turning my head to a 45-degree angle was I able to see the cards. I did not request accommodations for this ahead of time because the details of the assignment were not released till one week before the assignment was due. After learning the details of the assignment, I mentioned to the professors that I had an issue and offered two solutions: (1) "Can I move the cards, so they are held by someone in the center of the classroom?" Or (2) "If the first option doesn't work, can I set a silent vibration alarm on my phone for the one-minute mark?" My professor responded to both options saying "These options would provide you an unfair advantage because the experience would be changed for you and no one else."

I was afraid to say anything because I did not want him to judge me as incompetent. I attempted the speech the following week. As I was speaking, I felt as though I had reached the five-minute mark and I frantically looked for the cards. As I did this, I lost my place in the speech and failed for going overtime. I began to cry in front of the class. I was angry and embarrassed because I knew I could have passed the assignment if I had been able to use timecards to pace myself like everyone else. After class, I called my girlfriend and began crying again telling her “I'm so embarrassed. I looked like an idiot and could not do anything about it. I was screwed from the beginning all because of my freaking eyes.” She told me I needed to report them, but I was too afraid that the professor would fail me or hold it over me in some way. I was frustrated, angry, and shocked.

This experience set me back in the class by a lot. I had to attend extra-credit events and office hours to earn additional points to bounce back to my desired grade of a B. In total, I think I attended 11 extra-credit events and was the only person in the class who went to more than two. Looking back, this experience should never have happened. I had to put in a ton of extra work just to keep up with other students even after advocating for accommodations. I learned that the laws and guidelines for requesting accommodations need to be followed not because you will always need them, but to protect yourself in case you do. It never crossed my mind that someone would not accommodate me if I asked but, now I have firsthand experience where power dynamics and ignorance led to a barrier that specifically affected me. As a white, cis-gender man, I had never faced something like this quite so bluntly. If I could redo it, I would have reported the professor to the department head, but I was fearful of the power I thought he had over my grade in the class.

Looking back, this experience aligns with research from Peña, et al. (2016) that higher education literature focuses on disability without contemplating the structural inequalities that are in place. Peña, et al. (2016) goes on to say, “Such an approach perpetuates an ableist worldview, suggesting that people with disabilities should strive toward an able-bodied norm, reflecting society's perceptions that certain abilities are essential to fully function in the world” (p. 86). In this instance, my professor was not willing to acknowledge the inequities that would arise from this situation. In fact, he was enforcing an “able bodied norm” under the guise of equal treatment. However, using the social model's definitions of impairment and disability, my impairment only transformed into a disability once my professor refused to accommodate the environment (Peña, et al., 2016). I specify the environment because a disability only occurs when there are disabling factors in the environment such as accessible ramps, hearing aids, and other reasonable accommodations. This experience not only showed a lack of disability awareness, but also a misconception that equality and equity are interchangeable. This experience was and is the first-time ableism had a direct and tangible impact on my success.



When I interviewed my girlfriend for this paper, we discussed this classroom experience in depth. I asked her “Could you describe in detail the time a professor denied an accommodation for my disability and how you perceived the situation?” To which she responded, “I believe it was for a presentation, and with your disability, you need certain things placed in a certain place so that it's easier for you to see it. And I think he had it placed where it was out of your visual field. And you asked for accommodation for the timecards because you could not see them and needed them moved to a different spot. And he said that it put you at an unfair advantage, I believe. Correct?” She then went on to describe her reaction and the thoughts and feelings of confusion she had. When I asked her to elaborate, she shared:

> I think my reaction was just anger, of course, but I think I was just confused because you learn about the disabilities act and how back then there were not any ramps, but when you are not born then, you kind of just grew up in this world where it is like, oh, a person with a disability obviously, they would be accommodated. You know what I mean? Especially when you do not think like that. When you have always been raised to accommodate. You know?” She continued, “So, you don't really think they would not be accommodated, but for a person with a disability,

> you could probably ask them, and they will probably tell you it is not all the time that people are willing to accommodate. Or like now I am starting to see on social media videos where a deaf individual will go and try to get a donut or something at a drive-thru and people working will get frustrated and say, 'ugh, you are confusing me. I am not going to serve you.' It is wild. It's unfathomable that you wouldn't just take five minutes to make sure that this person was able to just live.

As my girlfriend said, "It's unfathomable that you wouldn't just take five minutes to make sure that this person was able to just live." Accommodations in all aspects of life are a way to create equal access to an environment and are necessary for an accessible and equitable world. This equal access must also extend into the classroom.

Academic accommodations, contrary to what my professor believed, "provide students with disabilities equal access to learning; accommodations do not afford students an academic advantage or ensure their collegiate success, rather, they remove environmental barriers in an attempt to make learning possible" (Tast, 2017, p.11). These attitudes that lead to this emotional toil are not only shared and espoused by professors but can often be shared by other students and even the individual with the disability.

Tast (2017) recounts an interview with a student who overheard criticism of another who used academic accommodations in college: "Well, I don't know what her problem is, I've got a disability too… but you don't see me running for [accommodations]. I work hard to get where I'm at" (p. 28). Experiences like Tast's interviewed student can lead to a phenomenon called "great achievement syndrome'' which is "inferring that students who use accommodations are less than other students with disabilities who do not" (p. 29).

This phenomenon had such a profound impact on me that for nearly a year I began to stop mentioning my disability because I did not want my disability to impede people's opinions of my accomplishments. I began to stop mentioning it in interviews, scholarship essays, assignments, and any other medium that might ask to "tell a little about myself." This is because, unsurprisingly, students want to be viewed by their peers as "normal" as opposed to odd or strange (Tast, 2017).

Placing My Experiences into Gibson's Disability Identity Development Model

Identities are labels that help people categorize parts of their self-concept. Under this application, disability should be viewed as an identity in tandem with other identities such as race or gender, and the intersectionality of the identity must be acknowledged (Peña, et al., 2016; Dunn & Burcaw, 2013). Some barriers to understanding the intersectionality of disability are the heterogeneous nature of disability, the impact of disability diagnosis, and the changing ways in which disability is conceptualized (Peña, et al., 2016). Luckily, there are many frameworks to explain the formation of disability identity. For example, Gibson, (2006) created a model to help practitioners understand the challenges and perceptions that individuals with disabilities face.

In Gibson's (2006) model there are three stages and various constructs within each stage: Stage 1 is passive awareness and constructs are: no disability role model, shy away from attention, and medical needs are met. Stage 2 is realization and constructs are: self-hate, anger, concern with how others perceive self, concern with appearance, developing a "Superman/woman" complex, much ponderance is given to the question "why me," and the beginning of seeing the self with a disability. Stage 3 is the final stage and is called acceptance. Acceptance is the stage where the disability is integrated into the individual's identity. Some constructs of the acceptance stage are an individual shifting focus from "being different" in a negative light to embracing themselves, beginning to view themselves as relevant; no more no less than others, beginning to incorporate others with disabilities into life, involving themselves in disability advocacy and activism, and integrating themselves into a majority (able-bodied) world.

Stage one is interesting because it is called the passive awareness stage or the stage where the individual is aware. The individual is different but cannot quite articulate or identify why or chooses not to. In my case, this stage is where medical needs were not met and I was taught to deny my conditions as less severe than a disability (Meyers, et al., 2011). Since this information came from doctors, which in my family are trusted as experts, we denied the possibility of a disability being present. Without the diagnosis, I went through the first 19 years of my life without being able to articulate why I needed a specific seat in a classroom to see the board or why I refused to go up and down staircases without railings. While in my case, this stage lasted from birth to 19, it can last into late adulthood.

My experiences share a lot of the constructs present in each stage as well. For example, looking at my doctor visits, I responded to the information by deciding not to tell anyone and to deny my identity very intensely. In particular, I remember thinking "I am normal, and I WILL NOT tell anyone. I can walk, I can see even if it is not the best. I don't even LOOK disabled!" This line of thinking fits into the constructs of self-hate and anger. I even used the "why me" statement very often, which is common in Stage 2, known as the realization stage. Stage 2 lasts from adolescence to early adulthood and is where the majority of my experiences are situated (Meyers, et al., 2011).

In my experience with the professor who denied my accommodation, an interesting phenomenon occured. I would have classified myself as beginning to enter Stage 3, the acceptance stage. The acceptance stage sees the individual "involve [themselves] in disability advocacy and activism" (Meyers, et al., 2011, p. 4) and "integrate [themselves] into [a] majority (able-bodied) world" (Meyers, et al., 2011, p. 4). In this experience, I involved myself in my own personal advocacy by voicing my complaint to a professor for the first time. By doing so and attempting to create an accessible space for myself in the classroom, I was integrating myself into the able-bodied world on a micro-scale. For the first time, I attempted to actively make a space that was accessible according to my disability. This is a distinct difference from prior times where I had tried to work around or in spite of the environment. After the initial rejection, however, I reverted back to Stage 2 the "realization stage," which, according to Gibson (2006), is common if someone faces discrimination in their work or personal relationships, even if they believed they were past those feelings.

To further explain this reversion, I would like to look at an excerpt discussing the experience from earlier in this paper from the Denied Accommodations in Class section. After being denied accommodations, I recount my feelings and thoughts as follows, "I am so embarrassed! I looked like an idiot and could not do anything about it. I was screwed from the beginning all because of my freaking eyes." "My girlfriend tells me I need to complain, but I am too afraid he will fail me worse or hold it over me in some way. I am frustrated, angry and shocked." I mention looking like an idiot because of my eyes, which looks like the constructs of self-hate and concern with how others perceive self (Meyers, et al., 2011). The anger also returns along with sentiments of a "why me" thought process, particularly apparent in the thought "I was screwed from the beginning all because of my freaking eyes" (Meyers, et al., 2011). Using Gibson's model and my experiences, I want to give readers a tool to reference when considering the psychosocial aspects of disability. In sharing the intimate impacts of my psychosocial development, I hope the perspective I had informs future professionals and individuals of the importance of awareness around the socialization of disability.

TABLE 1: GIBSON'S DISABILITY IDENTITY DEVELOPMENT MODEL

Stage One: Passive Awareness	• *No role model of disability* • *Medical needs not met* • *Taught to deny disability* • *Disability becomes silent member of the family* • *Co-dependency* • *Shy away from attention* • *Will not associate with others who have a disability*
Stage Two: Realization	• *Begins to see self as having a disability* • *Self-hate* • *Anger; Why me?* • *Concerned with how others percieve self* • *Concerned with appearance* • *"Superman/woman complex"*
Stage Three: Acceptance	• *Shifts focus from "being different" in a negative light to embracing self* • *begins to view self as valid* • *Begins to incorporate others with disabilities into life* • *Involves self in disability advocacy and activism* • *Integrates self into majority able-bodied world*

RECOMMENDATIONS

With a model in hand and a narrative that helps contextualize the findings, I want to dissect common themes surrounding positive disability identity. First, I would like to say for other students in a similar position, **advocate for yourself.** If you do not do it, no one will.

In Dunn and Burcaw's (2013) exploration of narratives of disability, they identify six themes related to positive disability identity. For the purpose of these recommendations, I will focus on three. First, is the idea of positive disability identity and self worth, noted as "the idea that one values oneself and is dependent on an individual's ability to perform activities or tasks viewed as important to the self, others, and society more generally" (Dunn & Burcaw, 2013, p. 150). Second, is the idea that "discrimination entails awareness and recognition of an often direct experience with the fact that people with disabilities are the targets of biased, prejudiced, and unfair treatment within daily life" (Dunn & Burcaw, 2013, p. 150). Finally, "pride, refers to being proud of one's identity and, in the process, acknowledging possession of a socially devalued quality, such as a mental or a physical disability. Pride encourages people with disabilities to 'claim' rather than deny, mask, or hide disability, and to adopt the perspective that physical or mental impairments are normative within humanity" (Dunn & Burcaw, 2013, p. 150). To promote these three themes, I recommend the following ideas be considered:

1. Mandatory workshops for university and high school faculty (and possibly students) on disability and disability etiquette. These workshops would cover topics such as Person First Language, how to detect and disrupt ableism, as a friend, and professional colleague, and how to practice Universal Design. Universal Design is a phrase coined by Mace (1999) to describe the concept of designing products and the built environment to serve the needs of people regardless of their age, ability, or status in life. With these workshops available as professional development opportunities for high school and university faculty on a consistent basis, students with disabilities will have a better chance at being in a space with an accessibility ally present.

2. Disability workshops or seminars for incoming college students as part of orientation. This recommendation serves two important purposes. First, it connects students with disabilities to resources they can use in college during the initial onboarding process. This will ease the transition from K-12 to university. This transition is especially difficult because in K-12 disclosure and receiving services is the responsibility of the school. However, in college, the burden of seeking services and disclosure is the student's responsibility. This shift is often sudden, and students can be ill-prepared to make such a drastic shift.

3. Making sure disability is represented in marketing materials and webpages for schools, both in K-12 and higher education outside of disability-specific pages. A simple way for universities to aid in the normalization of disabilities and raise general disability awareness is to reexamine marketing materials and website images. Oftentimes students with disabilities are not included in university promotional materials, images, or webpages unless disability is the central topic of the material. This can present as though students with disabilities are reduced to solely their disability status. With more inclusive disability representation in university materials becoming standard, potential viewers will see disability as another component of diversity in the institutional experience.

4. Hiring professors and staff who identify as having a disability. Like other identities, representation matters. "The National Center for College Students With Disabilities estimates that 4% of all faculty members have disabilities. These numbers are discouraging, given that 22% of the general population has disabilities" (Grigley, 2017). This means that a majority of students with disabilities will complete their college careers without having a professor who can relate to their lived experiences. If more faculty and staff on campuses openly identified as having disabilities, students could have mentors inside the classroom who can offer advice around navigating being a new professional.

5. Creating disability studies programs or courses centered on disability in social contexts, i.e., disability in media, disability culture, etc. According to the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) department at the University of Washington (2019), Disability Studies is "an academic discipline that approaches disability from an interdisciplinary perspective and uses multiple theories to define disability and understand the disability experience. Disability Studies programs are being formed at universities nationwide and at all levels of scholarship. There are undergraduate minors and majors, as well as master's degrees, certificates of advanced studies, and PhDs available in this new field."

Programs of study like these offer classes and electives that explore the socialization of disabilities, the development of disability culture, disability movements, and policies that shaped the social and physical spaces that individuals with disabilities inhabit. Having courses like this available to students will normalize disability. It will also offer students studying in fields that work with individuals with disabilities class options that will greatly impact future interactions in their careers. Programs like these bring disability into the classroom in a way other than academic accommodations. They offer conversations about disability that extends past the conditions, and that is important to campus climate for individuals with disabilities. If beginning a new degree track is too large for your institution to undertake, offering courses like "Disability in Literature" or "Disability in Film" in English programs as electives or "Person First Language" courses in Communications departments is a way to incorporate disability into existing programs. Some universities that have good programs to base your own on would be The University of Washington, Temple University, Syracuse University, Ohio State University, University of Hawaii at Manoa, and the University of Illinois-Chicago. These institutions offer a wide range of degrees, certificates, and programs in disability studies that can be a solid foundation for fledgling programs to take note from.

For family members I have a few recommendations as well. These recommendations are centered on personal education for the family members. As a family member of someone with a disability it is important to educate yourself, advocate for your family member when appropriate, and facilitate open dialogue with your family member.

1. Incorporating Person First Language into your daily rhetoric. There are multiple positives to using Person First Language. The user emphasizes the person ahead of the disability and communicates a sensitivity toward disability. Furthermore, it acts as a replacement for potentially offensive language a family member may not be aware they use. For example, my brother and mom used to say the phrases “disabled parking” and “disabled restrooms,” but after learning about Person First Language use the phrases “accessible restrooms” and “accessible parking.” They also used to say they were “normal” or “healthy,” whereas now they just say they are people without a disability or able-bodied. This simple change in the way my family communicates about disability has helped me feel more comfortable discussing disability because it is more respectful. I advise that families make this simple change when discussing disability until they know specifically how their family member wants to be addressed. This is important because preferences can vary. So, until you are sure how your family member wants to be addressed, Person First Language is a respectful default.

2. Respect and honor their experiences. If a family member recently gets diagnosed with a disability, be aware and respectful of how that disability impacts the individual. This advice may seem simple, and you may think that the impacts are obvious; however, it is important to remember that there could be ways a disability impacts someone that may not be immediately apparent. For example, because of my restricted visual field, if I want to see someone’s entire face as I talk to them, I have to look down slightly. People often think I am distracted or refusing to look them in the eye even though I am paying attention and present. Without having a conversation with me this impact of my disability is not immediately apparent. I also recommend having a discussion about the ways their disability impacts their life. Letting the individual with the disability detail exactly how it impacts them. This is because while two people may have the same disability it may impact them differently in the way the interact with their environment and severity.

Ask in which ways you can assist, so that you can have a personalized understanding of your family member’s disability and be on the same page when accommodation or modification is necessary. This conversation also includes the individual with the disability in the conversation and, at least in my case, provided a sense of autonomy over my disability and set clear boundaries.

3. Be prepared for lifelong learning. Language, accommodations, laws, and the way your family members disability impacts them can all change over time. This means that it is important for family members of individuals with newly diagnosed disabilities to be committed to learning all that they can about disability, be informed on the legal protections and accommodations applicable to their family member, and have semi-regular discussions about whether your family member has been impacted by their disability in an area of their life they hadn’t previously been aware of. If you commit to lifelong learning, you can ensure that a respectful and accessible environment will be provided to your family member and can advocate for them when they need it. That being said, please remember to let the individual with the disability be the expert on their disability.

CONCLUSION

Overall, I now have a better relationship with my disability and a better self-image, but it was not an easy journey. I had to combat ableism from myself, my family, and my professors. I also can see exactly how society builds these attitudes and views about disability that cause such a negative disability identity experience. However, I found that people with disabilities are more likely to recognize ableism when they had a positive disability identity and endorsed the social model of disability. Unfortunately, disability is often minimized and is not considered an identity that deserves sensitivity like gender and race. This lack of sensitivity and education means that it is the individual with a disability’s job to educate and advocate for themselves to classrooms, workplaces, peers, mentors, and colleagues. This work is never complete and now more than ever is essential to the retention and support of students and young adults with disabilities.

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