

Beyond Inclusion: Ethnographic analysis regarding the precarity of disability and the need for belonging on UCSC campus

Evelyn Drake

University of California Santa Cruz

Abstract: Higher education campuses are a changing landscape both socially and politically, one which positions disabled life as increasingly precarious. The demographic of students receiving accommodations for purposes of reaching academic goals and reducing barriers to education is rapidly increasing. While there are many claims as to why this is happening, it doesn't change the reality; more and more students are receiving accommodations every year. While there is an honorable emerging push for inclusion (as intervention) for students with disabilities, this in its most reductionist form is nothing more than a retrofit and at its broadest, will never fully suffice in creating equal access for disabled students. Based on current ethnographic data, this article, which centers on university students with cognitive and psychological disabilities, examines the possible loopholes in the paradigm of inclusion and flaws of universal design while promoting an accompaniment, a radical acceptance that beckons the cultivation of belonging.

Key words disability, diversity, inclusion, psychological disability, cognitive, universal design, belonging

Introduction

Maria, a fellow classmate, stood at the blackboard in front of the class, behind her were misshapen and oddly arranged letters, frantic lines insinuating movement, but overall a mostly barren board, her assemblage for explaining her experience of dyslexia. Even she felt frustrated, trying to relay the way she walked through the world differently, both linguistically and in the flesh. What she described seemed nothing short of perilous in the landscape of higher learning. Even in this class focused on the anthropology of disability and difference, her description drew blank stares from the students as they attempted to comprehend something so foreign in this overlooked space that we had taken for granted, the literal ease of reading the writing on the wall.

This story intrigued me not only due to its aberrant nature but because of the difficulty in translating it. This sparked a quest, one to better understand the lived experience of dyslexia. How does one become dyslexic? How does one “do” dyslexia? I know how I do depression and how it can look like both a mish-mash of utterances and anger or a constant battle with losing my train of thought but this different and I wanted to know more. I began where we all begin now, Google, but it failed to produce the desired result. This moment in time was the birthplace of this project. One guided with the hopes of developing some educational experience that would enable users to be “dyslexic” and a plethora of other “disabilities” and to know them, sensorially. In order to breach the walls of empathy and understanding by being able to walk through the world in the shoes of someone with a disability may be too grand an undertaking at this point. Yet, I recognized a need. Initially, I thought the same thing many other students think, including my interlocutors, that the problems arising for students who receive accommodations is rooted in a

simply lack of education regarding disability. But throughout this project it turned out to be much more sinister and systemic. This realization came through 32 semi-structured interviews through which I collected individual narratives of the everyday life of “disabled” students on the UCSC campus.

On a campus that claims to hold to the tenets of social justice, students are often positioned in the archaic view of disability, not as the minority group they are, but as a problem to be solved, an inconvenience to be legally negotiated, as precarious minds poised for defeat, or just completely rejected. The University promotes an autonomous culture that presents the virtues of independence, competition, achievement, measurement, comparison, and perfection above all others, where admitting that you need help seems out of the question. UCSC provides a stark backdrop to understand how cultural values and institutional discrimination seep into everyday interactions for students who receive accommodations. By following the stories of Disability Resource Center affiliated students, I illuminate how stigma driven attitudes, ableist discourse, and microaggressions produce institutional neuroatypical oppression, further upholding neurotypical privilege. Daily oppressions become a mechanism, producing and reproducing the “common sense” hegemonic power of the academy through a “manufacture of consent¹” that discriminates which neurobodies are worthy of education in a continuation of hegemonic norms. In these everyday experiences that students who receive accommodations are repeatedly reminded that they don’t belong in higher learning and have no place within the ranks of the academy.

I address three main issues in this paper. First, in the *Politics of Normalcy*, I introduce the politics and theories that frame and support this paper and its arguments. Engaging with the anatomy of divergence and deviance, the current working ideas of disability, the ethics of

interventions, the definition of Universal design, and the theory of stigma. Secondly, in the *Embodied experience and formation of disabled identities*, I explore the experiences of students who are affiliated with the Disability Resource Center (DRC). By analyzing patterns emerging from my ethnographic data, I highlight disparities of both personal and intersubjective natures. Utilizing a macro lens, I look at the influence of family culture and beliefs on a student's sense of belonging and personal identity formation. Within this frame I witness the impacts of intersectionality and its permeating effects. Then, moving toward the micro perspective of intersubjective relations, I argue, by taking a nuanced look at professor engagement and the politics of disclosure, that through ableist discourse and microaggression, institutional neuroatypical oppression is perpetuated, upholding neurotypical privilege. This translates to an embodiment of antipathy while also providing insight into how students resist through micro-rebellions, in subtle often unseen ways.

Finally, I address the importance of *In/visibility*. In this section, I unpack the idea of disabled students being a threat to the prestige of the institution. I argue that the awareness of disabled students morphs a symbiotic environment into a parasite relationship filled with microaggressions that reverberate with the displacement and devaluation of disabled students. I show how students are rendered invisible, impeding chances for academic success, community organizing, meaningful life, and a sense of belonging. Through all of this, affiliated students remain unwavering in the notion that there is nothing wrong with them and speak to their desire for visibility.

I conclude with the notion that structural change and ideological change are part of the same struggle. Just as DREAMers (Nicholls 2013, 2014) have created a 'niche opening' to a continued reimagining of immigration, students who receive accommodations offer the

opportunity to reframe our cultural understanding of disability. By suggesting a counter hegemonic stance of radical acceptance, I will explore the possibilities for future research and open up a much needed discourse regarding an anthropology of belonging.

Although I interviewed many students across the spectrum of disability and difference, my focus will be on psychological and cognitive/learning disabilities for two reasons. First, I believe it offers greater insight to the structurally produced precarity of disability and disabled identity in this space. Secondly, often times disability is more easily recognized in its physical form and invisible disabilities remain difficult to comprehend. The social model, which states that disability is caused by the way society is organized, rather than by a person's impairment or difference, is applied with ease to physical disabilities due to their more obvious nature. When it comes to cognitive or psychological disabilities, the social model fails in its explanation of the personal experience. So, what does it mean to say the material 'outside' world and the structural organization is what creates a disability when its regarding cognitive or psychological difference, which often include intersubjective and sensorial difficulties? The university creates a field site that brings into view how the socio-political model of disability affects both cognitive and psychologically disabled students. We can explore how curriculum and classrooms are being created for normative minds and bodies leaving out those with spectrum disorders, psychological difficulties, learning disabilities, and sensory sensitivities. It is in these unseen spaces where I desire to shed some light.

While disabled people are culturally rendered invisible, they do exist and en masse, in fact, 1 in 5 people in America are disabled.² Due to increased impacts of poverty and the intersectionality intrinsic of disability, they become our most vulnerable people and with that the most oppressed and "marginalized" population (Davis 2002). At the same time we are currently

witnessing history unfolding, “a people yet to come”³ with the rapidly emerging population of people with autism, one that has seen exponential increases on college campuses over the last 10 years. This demographic is poised to continue growth, further impacting classrooms of all grade levels including higher education. It is important to note that for many, college is the gateway to economic stability and a way out of the impoverished life incurred by many people with disabilities.

Throughout the following paper I am arguing that disability is framed by an interplay of social structures as well as a multifaceted categorization paradigm that frames and medicalizes difference as problematic; something needing to be managed, hidden, treated, and solved. In universities, the oppressive attempts to “aid” mediates life chances according, not to individual ability, but a social order that is rooted in the neoliberal production and competition schema inherent in the academy, often rendering students who receive accommodations, statistically and systematically invisible. I hope to encourage a reframing of disability, one guided by the idea that human rights include the individual's pursuit of a meaningful life and a place at the table, not just the crumbs that fall; a move away from mere tolerance toward a culture of belonging.

Methodology

For this project, I began looking at the ethics of existing and emerging interventions as well as embodied and lived experiences of disability. While investigating the effects of currently available interventions, I looked to gather narratives to also assist in the University of California Santa Cruz Disability Resource Center’s efforts to increase accessibility as well as foster greater inclusion for the disabled students on the UCSC campus. My focus was looking at how interventions can promote exclusivity or negatively impact notions of personhood and identity,

creating a departure from the DRC's mission and intention. Through a series of extensive interviews I sought to gain an in-depth view of the DRC student experience and recommend modifications to better assist their students with accommodations and support while addressing the implications of a previously documented lack of inclusivity for the disabled population on campus. While looking to provide a greater understanding of the barriers for disabled students in getting the assistance that could support their educational pursuits, I was also interested in looking at how the DRC impacts self-identity when establishing the need for documentation along with the current method by which accommodations are handled between student and professor.

Working in conjunction with Richard Gubash, the current DRC director, I sought to provide detailed student perspective, input, and experience to assist with the current and future changes happening at the DRC by identifying and separating both individual user and group needs. It was determined this can only be done in conjunction with in-depth student input through ethnographic research. Mr. Gubash did not participate in the direct research process or data analysis but acted as a liaison between the DRC service users and myself by recruiting participants while protecting the privacy of affiliated students. Guided by a tenet prevalent in disability studies, "Nothing about us without us," it was understood that those with disabilities should be at the center of the new direction that the DRC is taking and without their honesty, candor, and confidence, the impending changes to the DRC program may miss this mark.

The very first step in the research process when working with human subjects is to petition for IRB approval. The IRB process is a necessary, albeit lengthy one. I went through multiple revisions over many weeks before finally being granted my approval. This very detailed and thorough process assisted me to develop my research questions, and gain a much deeper

understanding of what I was researching before beginning any fieldwork or interviews. It also granted me the opportunity to establish a preliminary rapport, guided by compassion and respect, with my subjects prior to meeting them. Placing myself in their shoes by empathically imagining any harms that could come to them through my questions, behaviors, or intentions, allowed me to refine my approach prior to engagement. This was a priceless gift, one that only came through my and the IRB reviewers' meticulous and unwavering commitment to the protection of human research subjects.

Subject screening was done through a self-screening process dictated by the qualifications listed on the informational flyer that I provided to Mr. Gubash. Involvement was on a volunteer basis only. Nothing of value was offered to the participants in exchange for their time. No student identities were made known to me unless they contacted me directly, through email, after receiving the informational flyer. The flyer was circulated through email, by Mr. Gubash, and initially sent out to every current DRC student. After an initial round of interviews I felt there was a lack of data inclusive of the DRC's primary demographic so I prompted Mr. Gubash to resend the flyer to those students receiving accommodations for psychological disabilities, the primary demographic served at the DRC. The flyer was then sent out a third time after the passing of a few months and during a new academic year. The identities of these students were never given to me directly and again remained unknown unless the student contacted me. Privacy was a leading precept throughout this project.

The process began with developing a broad scope then funneling it into more directly focused inquiries. For example, "What are the barriers are for disabled students?" would guide me to establishing the following questions:

- is the lack of self-determination a barrier in getting assistance and accommodations that could be useful in students educational pursuits;

- how does the DRC inhibit a sense of holistic self-identity when establishing the need for documentation;
- how do accommodations impact the relationship between student and teacher and does the lack of anonymity create a questionable ethics;
- do students feel protected from professors who discourage the use of accommodations; and
- how does the DRC account for cross-cultural impacts when determining the needs of the disabled population on campus?

Establishing this scope allowed me to refine the set of interview questions I would begin with.

The initial approach I took with my subjects changed dynamically with each participant after gauging personality upon introductions. I used a semi-structured interview format which allowed me to change direction based on how they responded to different questions. Most of the time I asked some introductory questions like “how did you find out about the DRC”; “have you had accommodations prior to UCSC” in order to get the subject talking about disability but through the venue of accommodations and went from there, exploring the details of their own personal experiences while also paying close attention to body language and vocal discrepancies. I was able to change the course of questioning based on my subjects’ comfort whereupon I would move on or return to more sensitive subjects after I felt more trust had been established. I also made it clear to the interviewees that I, in no way, worked for the DRC, their accommodations weren’t at risk, and nothing they said would be relayed in conjunction to any identifying traits, at least to the best of my abilities.⁴

I took to heart everything I was told while also utilizing my position as an insider/native ethnographer. Easily recognizing experiences that were tantamount to my own. This guided me in my approach and informed not only how I went about this research but my understanding of unspoken moments that happen which may not have been so apparent to other researchers. The unique internal tension that manifests every time there is a potential for disclosure is something I understand quite well.

I had recently written my diversity statement that I would submit with my graduate school applications, and had begun by eloquently relaying the trauma and tragedies of the past. I took the reader through the rollercoaster and comeback story of my life. I submitted my vulnerability in digital form to my mentoring professor. Upon return, as I read through my mentor's edits I quickly stumbled and lost my breath as the most important part of my experience was rendered invisible on the page. She had removed "psychological disabilities" from the statements of downward trajectory from which I subsequently rose, the proverbial phoenix, leaving behind the academically acceptable battle with addiction firmly in its place. It doesn't take a genius to understand why she did this, and on a good day I can realize it as her mothering instinct to protect, wanting only but the best for my future. She knew that this was not a place for the brutal honest truth of life, only the one that people can accept without threat. These places allow only the perfectly crafted public persona, an exhaustive second job for those with disabilities, and one which keeps so many entangled in the untruth of their lives, rendering their self-image incomplete, broken, incapable, and invisible.

In the next section I will speak to the history regarding the categorization of normalcy and pathology of difference as well as the external political factors that work to influence the tensions of this discourse. Recalling different ways to look at the body and disability, including the social model of disability, I begin to suggest what it means to live outside the statistical mean of normal. By introducing the ideas of universal design and the ethics of interventions, I lay the groundwork to analyze and begin to question the political nature of inclusion.

Part I: Politics of normalcy

"Maybe the target nowadays is not to discover what we are, but to refuse what we are...the conclusion or would be that the political, ethical, social, philosophical problems of our day is not to try and liberate the individual from the state, and from the state's institutions, but to liberate us both from the state and type of individualization which is linked to the state." (Foucault 1980)

Bodies and privilege in the era of transhumanism

My chances of winning a gold medal at the Olympics are slim, and I'll wager the average reader's chances aren't much better. The likelihood is poor for a multitude of reasons. With deadpan precision and the heroic sacrifice that alchemizes privilege and fortitude into gold, it takes more than the "average" body to achieve these extraordinary feats. It begins with the privilege of opportunity and although we'd love to dream that any "body" could train to become that caliber of champion, we know differently. It becomes apparent that even those within the ranks understand this, as the public witnesses one after another, the top placed triumphant succumbs to the competition and concedes to drug use as yet another method to push their superhuman bodies to still unimagined feats.

The spectrum of human difference is vast. The ideal body is a fluid notion changing dynamically over time and space. With technological adaptations, gene splicing, biohacking and the future of molecular nanotechnology, some could worry we are embarking on another phase of eugenics, extending privilege to fewer and fewer bodies. How bodies are viewed and labelled, especially disabled bodies has its history in biomedicine. In the next section, I'll examine how 'disabled' became a type of person you can be while simultaneously rendering the disabled body as something needing to be fixed and controlled.

The anatomy of divergence and deviance

In 'The Normal and the Pathological,' Canguilhem (1989) gives a history on how divergence from the norm became pathologized. "The disturbance of this harmony, of this equilibrium, is called disease" (p 40). It is also suggested that it became necessary for 'normal' and 'pathological' to be diametrically opposed in order to create a system of medical study and of healing... "the formation of a theory of the relations between the normal and the pathological, according to which the pathological phenomena found in living organisms are nothing more than quantitative variations, greater or lesser according to corresponding physiological phenomena" (p 42). Hacking picks up where Canguilhem leaves off by exploring the ways in which instances of new categories take on a life of their own, feeding back into itself and creating categories of personhood which then loop back to the category itself.⁵ This creates an ever-changing category of person, in a process he refers to as "looping".

The way kinds of people or classifications come to be, he calls dynamic nominalism. "The claim of dynamic nominalism is not that there was a kind of person who came increasingly to be recognized by bureaucrats or by students of human nature but rather that a kind of person came into being at the same time as the kind itself was being invented. In some cases, that is, our classifications and our classes conspire to emerge hand in hand, each egging the other on" (Hacking 1986). This theory extends to categories or kinds of people that, in a way, did not exist before. This he refers to as "making up people", or the creation of human kinds. These labels and categories shape our realities but are also constantly evolving. It is important to recognize that this sort of category creation isn't passive. Hacking states "people classified in certain ways tend to conform to or grow into the ways that they are described but they also grow into ways so that the classifications and descriptions have to be constantly revised" (Hacking 1995). Webb Keane

agrees to some extent but also argues that “we always cooperate in the creation of each other” through what Keane call, ethical affordances (2016).

Both the categorization and medicalization of bodies is based on averages. Disability inherently suggests an existence outside the mean, as a place of deviance, something to be pathologized, studied, fixed and solved. So, how does one “become” disabled? The biomedical answer would suggest this happens instantaneously, at the point of injury, at the onset of symptomatology, and for some, at birth, creating a temporal binary between disabled and non-disabled neurobodies. By zooming outwards, it may be possible to view the formation of disability in two different ways.

First, ideas of what a body can do may shape what a body can do. Marcel Mauss argues that each society has its own special habits, a combination of biological, sociological, and psychological elements which create a bodily “habitus” or techniques of the body. These can vary between individuals as well as societies dependent on the vastly different education, propriety, fashions, and prestiges; meaning these learned techniques are dependent on who has the authority over the person. “The principle made possible a precise classification. The constant adaptation to a physical, mechanical or chemical aim (e.g. when we drink) is pursued in a series of assembled actions, and assembled for the individual not by himself alone but by all his education, by the whole society to which he belongs, in the place [and time] he occupies in it” (Mauss 1973). This is also age and gender dependent along with many other locally determined variables, creating what Margaret Lock would refer to as a “local biology” (Lock 1993). These techniques seem to impact all the ways a person moves through their world as well as behaves and engages with others, something I will refer to as *embodiment*. While Mauss does not directly apply this theory to disability, he is suggesting ways in which cultural norms of behavior are

produced, opening the door to discuss the reasons by which those who do not comply to such norms become ostracized.

Secondly, as disability studies scholar Lennard Davis suggests, there are no disabled people, only disabled moments and “physical minorities” (Davis 1995). What Davis is calling out, in part, is systemic notions of the “minority group” or “social model” of disability. The social model positions society as the causal factor of disability suggesting that the world is created for one body and any divergence from, begets cause for exclusion. Though often done inadvertently, “exclusion can become systemic, a taken for granted ground for structures of political and social inequality” (Keane 2017). I utilize both approaches to show that in academe, institutional ableism is highlighted by 1) requiring difficult to secure and often expensive medical documentation prior to receiving accommodations, 2) positioning disability as a problem to be solved through a series of retrofits which may create a temporary ease but simultaneously create alternate barriers, and 3) producing and perpetuating stigma suggesting students with disabilities fall short in the ever-increasing neoliberal production standards that buttress the prestige and financial support of academic institutions. While these models shift away from the bioethical question of whether well-being is inclusive of psychological health, they continue to uphold the fundamental distinction and intrinsic focus inherent in medical categorization, thereby perpetuating certain prototypes (Carlson 2009).

Some interventions may be easy to recognize such as sidewalk cuts for wheelchairs, while others remain hidden. Often they begin a game of ‘whack-a-mole’, offering a retrofitted solution to one issue while creating another, including continued marginalization and antipathy. Through seemingly inescapable medicalization,⁶ (which naturally emphasis intrinsic rather than external causes) accommodations are still framed as interventions for something that needs to be

fixed, helped, or solved without accounting for “how philosophical discourse can also perpetuate certain forms of oppression” (Carlson 2009). Moreover, still failing to recognize that “first, life with disability is not the unremitting tragedy portrayed in medical and bioethics literature. Second, the culprit ...[is] the social, institutional, and physical world in which people with impairments must function--a world designed with the characteristics and needs of the nondisabled majority in mind” (Asch 2001). Universities still define disability mainly in medical and legal terms composed of legal requirements. In attempts to save public face and legal battles, universities will uphold ADA regulations for new buildings while exploiting loopholes, often ones poised as financial burdens, to avoid others. The philosophy or concept of Universal Design is the next generation of intervention.

Universal Design began as an architectural concept and is now being utilized for building curriculum and class structure. The intention is to design curriculum and class formats that are useful and usable to people with a diverse array of abilities, the premise being to find solutions that are more inclusive. The Disability Act of 2005 defines Universal Design, or UD, as: “The design and composition of an environment so that it may be accessed, understood and used: 1) To the greatest possible extent, 2) In the most independent and natural manner possible, 3) In the widest possible range of situations, 4) Without the need for adaptation, modification, assistive devices or specialized solutions, by any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability⁷.” While it is imperative to recognize the diverse needs of the student body, there is no one size fits all and I will address how this has the potential to become problematic later in this paper.

Other key concerns are the modes of power that exist not only between professor and student but between the state and the university. Foucault, Canguilhem, and even Goffman

would suggest, types of people are categorized and pathologized for the sake of surveillance, study, and social control. While in-part, this may be true in this time and place, I find that Gramsci's ideas regarding power and oppression more useful to understand how the academy works through subtle but pervasive forms of control and manipulation. Such forms of power create a looping effect similar to what Hacking discusses but one that perpetuates its own repressive structures and disseminates an ideology⁸ into the social body. This ideology produces a hegemonic power that legitimizes the hierarchical and oppressive structures of the academy and works to continue the "false consciousness"⁹ that disabled students find themselves in, one that suggests they are not equal, nor are they capable of the rigor of higher education.

"By hegemony, Gramsci meant the permeation throughout society of an entire system of values, attitudes, beliefs and morality that has the effect of supporting the status quo in power relations. Hegemony in this sense might be defined as an 'organizing principle' that is diffused by the process of socialization into every area of daily life. To the extent that this prevailing consciousness is internalized by the population it becomes part of what is generally called 'common sense' so that the philosophy, culture and morality of the ruling elite comes to appear as the natural order of things." (Boggs 1976)

Now consider stigma as an compounding influence, on the creation of categories, the medicalization of bodies, and the hegemonic power of institutions and how that becomes embodied. Goffman defines stigma as "a process by which the reaction of others spoils normal identity" (1963) while Link and Phelan define stigma as " 'the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination', stressing also that for

stigmatization to occur ‘power must be exercised’. Discrimination here does not simply refer to one individual’s treatment of another, but to structural or institutional discrimination” (Link et al., 2001). Stigma functions ‘at the point of intersection between culture, power and difference’ (Parker and Aggleton 2003). At this intersection, stigma produces and perpetuates a disabling environment that intertwined with medicalization both establishes and changes life trajectory. It is important to pay close attention to the macro-level social and economic structures while also recognizing the intertwining of the more personal micro-interactions, lest we miss the insidiousness of the structural reproduction of stigma particularly within microaggressions.

While this particular understanding is dated, there is still worth in understanding Goffman's (1963) categorical distinctions between those who are ‘discredited’ and those who are ‘discreditable.’ Students with physical manifestations of disabilities, both of deafness and mobility, fall into the discredited, who “possess a conspicuous or intrusive attribute that they cannot conceal”, whose principal challenge is to “negotiate or manage the (stereotypical) impressions that others have of and bring to their dealings with them.” While those with invisible disabilities are discreditable but retain passing “privilege.” This creates an opportunity for students to attempt to retain the ability to be treated as a “normal” student thereby avoiding embarrassment, and a lessened chance for career advancement (through lab and internship placements as well as job referrals.) However, the threat of being “outed” or having their disability revealed creates an increased vulnerability and compounded stress, pushing some students to avoid requesting their accommodations entirely, and for that reason they receive lower grades or fail out altogether.

Regarding Terminology

There currently exists a dynamically changing lexicon where disability as both a vernacular and an identity are in a constant state of flux and redefinition. “Defining terms such as *health, normality, impairment, and disability* continues to pose problems and cause controversy for bioethics and for disability studies. Their meanings are not clear, objective, and universal across time and place and are contentious even for contemporaries in the same culture, profession, and field” (Asch 2001 p. 300). Psychosocial disability, mental disability, difference, handicap, cripple, impairment, “Mad”, psychiatric survivor, mental illness/health, neurodiversity, and neurotypical/atypical. Some of these have the function to medicalize for purposes of insurance reimbursement, some categorize to invoke or call out modes of oppression, some historically are used to demonize, and now, some are used to produce a beckoning space for community and strength to arise. In order to honor this landscape, avoid misappropriation, and as an accent to the purpose of this paper, I will use a limited verbiage when talking about my interviewed subjects. I deliberately chose to use “affiliated”, short for ‘students who are affiliated with the Disability Resource Center,’ as it may include the embodied identities in all realms mentioned above or none at all. If a term is imperative to an individual's narrative or to the argument, I will use the phrasing determined by the student when speaking about themselves.

Part II: Embodied Experiences and the Formation of Disabled Identities

*“Wouldn’t it make sense from a biocultural perspective to consider minds as embodied, as constrained or enabled in their interpretative acts by the structure of brain and body in connection with a material environment always shaped or informed by culture?” - L. Davis, in *The End of Normal*, 2013*

Disabled Identity –

In this section, I include specific interview findings in order to weave together a dominant narrative.¹⁰ When observed in their entirety and allowed to harmonize and mesh, these utterances bring together a common story that exists for students affiliated with the DRC on UCSC campus. I'll show how disability becomes an identity shaped through medical and social interventions while simultaneously being reshaped for a new intention. These expressions highlight how that identity becomes embodied and interwoven with aspects of socialized discrimination and stigma until they are almost indistinguishable.

For affiliated students disabled identity takes many shapes and forms. Some refer to themselves as disabled, some don't, some only with family and some refrain from telling certain family members, some wish to avoid it all together, some will identify for sake of procuring help, and for some, it is just a parsed utterance of enumerated identity traits. The way affiliated students identify with disability is a vast a spectrum as disability itself.

“Lack of awareness is ableism!”-Jessica

With an undeniable smile and equally undeniable stature, she walked up, her long green dress exposing porcelain shoulders which were soaking up the mid-winter sun. I was honored by her willingness to speak frankly, answering whatever questions I had packed in my arsenal as we

sat in the open cafe, others students, staff, whomever walking by anonymously for over an hour. No diagnosis was discussed, instead we talked about Disability¹¹, ableism, and the formation of identity. Despite her short stature, multiple surgeries in her youth, and unrelenting daily chronic pain, she explains a refusal to categorizing herself as disabled. Medicalization refused to dictate her identity. Instead, she described how once denied a desired surgery, she felt a loss of agency and it was at that she point began claiming disability as an identity for herself. It was never the physical manifestations that determined identity for her, she choose to identify as a resistance and as a form of advocacy.

“I had surgeries from when I was in kindergarten to 10th grade on legs and back to strengthen them. Then at the end of my high school career, my hip really started hurting and I assumed that I would just have another surgery... but I would need a hip replacement and so you want to delay that as long as possible because hip replacements only last about 10 years, so the earlier you do it, the more you have to throughout your life. I really struggled with that diagnosis because to me it’s like, ‘just wait until you can’t stand the pain anymore and then we’ll do it.’ It was also the first time I ever asked to have a surgery and then was told no. I feel like I lost a lot of agency there. It was very frustrating for me to come to terms with what my doctor and what my parents were saying. One day, I realized that if this is what i have to deal with, I should come to terms with it, see my body for how strong that it is and all the things that i can do. and in the meantime, until I can get a miracle surgery that takes away all of my chronic pain, that I should advocate for myself to make the day easier. I think it was the fact that the one time I asked for help in the form of a surgery I didn’t get it, that lit the fire.

We continued discussing medicalization, categorization and labeling and how that negotiates the way one walks through the world and sees the nature of a space. *“The idea of labeling myself as disabled would automatically put limits on what I could do, whereas if I lived in my bubble of denial and didn’t say it, it wouldn’t be true... I just plowed through without asking for help... Which is, of course, not practical and actually ended up hurting me more and limited myself more rather than acknowledging what I can do and what help I need to do all of the things I wanted to do... By saying disabled, instead of putting me in a box, it gives me more power, acknowledging the struggle I go through and gives me the power to ask for help.”*

When I prompted what had changed she told me about a global realization. *“During my visits to graduate schools... I realized that accessibility is an issue everywhere whereas I had been making excuses for the institutions that I was a part of, like “they’re old”... It’s an issue everywhere and I could make excuses for every institution or I could realize it’s their responsibility.”* She also speaks about this in more generalized terms further applying this insight. *“People aren’t aware of how hard it could be. People just don’t think about it, but that too is ableism. I’ve stopped using that ignorance as an excuse and started labeling that as ableism.”* Though she doesn’t receive accommodations, she relays her experience at UCSC as a triumphantly positive one that speaks to a sense of belonging. *“The department I’m in here is so nice and liberal and friendly. I think being around people who are so supportive and don’t shy away from talking about how to make the department more accessible, that really helped me.”*

In the next section and series of interview excerpts, I will parse out the impact of early and ongoing personal relationships. Underpinning how a “habitus”¹² is constructed which in turn affects how one understands themselves and inhabits the world they live in. Often these

“techniques of the body” arise from our earliest interpersonal experiences, those with our families.

Culture is taught at the knees | The Personal

During the process of piecing together a schematic for how disabled identity arises, it became increasingly clear that family influence succeeds in laying the groundwork to how a disability becomes embodied. “We need to consider the ways in which interactions build up a sense of shared reality and establish people’s regard from one another.” Keane (2016) is suggesting that there is a mutual building of reality between two people based in part on an intersubjective regard, not empathy, but through “perceptible material forms such as body language, bodily deportment, etc.”(Keane 2017 p91) by which securing each other’s sense of self. A student’s sense of self is created, at least in part, through the materialized beliefs and perceptions of those closest to them. Regarding disability, students are engrained with the effects of social stigma alongside the combination of family pressures to succeed. Strong kinship ties often fail to provide confidence and instead add to the increased vulnerability the student feels. *“Depression is on me! ...My mom doesn’t believe that depression exists. Insomnia makes sense to her. Depression she can’t see.” –Laney*

The way their families see disability directly reflects on how students see themselves, as disabled or not, and often results in poorer moral and an impacted sense of dignity. Tension and confusion spawned from dissension leads to internalized culpability resulting in the student lying to their families about what their accommodations are for or simply avoiding the discussion altogether, thinning kinship bonds, further compromising their self-image. In the following vignette, Sophie shows how family beliefs influences talking about disability in general.

“people you interact with, shape how you feel about your disability” - Sophie

“If your parents believe certain things whether or not you agree with your parents you are going to replicate their beliefs in your life whether consciously or unconsciously...The [other] people you interact with, shape how you feel about your disability too!” She recalled *“my parents had sort of an archaic view of the meds...then once my mom saw the difference of me on meds vs off meds... she acknowledges that it doesn’t turn me into an unfeeling, unthinking robot, it just lets me get out of bed and keep living.”* She spoke of how both her father and sister are “repressed emotionally” and the way her father deals is it is to shut down and not feel. *“He’s neutral in it and just doesn’t talk about it to me.”* In contrast her sister vocalizes resistance and disbelief. *“I’ve had panic attacks in front of her [sister] before and she said ‘stop faking it.’ She’s not supportive of me, or my lifestyle.”*

Continuing, I asked, “Do you identify as disabled?” Sophie answers, *“It’s complicated, yes, but I have internalized guilt that I’m still working through that I inherited from my family. I would like to fully say that there are certainly ways that my illnesses affect me and make my life, and the way I go about life, different, like my best is different than other people’s best. ..I still have guilt that my illness is mental as opposed to physical. The hostility and the guilt that I’ve had about my mental illness has certainly created problems with my ability to come to terms with it and work through it. I like ‘differently abled’ as a term ‘cause I just have a different way of approaching things because what I’ve been through and because of the way my brain works. I’m in therapy, I’m on meds, I’m actively working on it. I think my answer would be different if you asked me a few years from now. But this is where I am now.”* –Sophie

Later in the interview I circle back to questions of identity and positioning them in conjunction to her educational pursuits asking, “How has getting accommodations impacted your

self-identity? Here Sophie discusses the difficulties in “passing” and how episodic difference creates a space for questioning. Further showing the complexities of accommodations and the instability of identity when it remains contested due to medicalization practices connected to questions of psychological ability.

“It’s given me the confidence to go through college. Mostly the way I feel about it all leads back to my internalized guilt. Sometimes I feel like I’m not worthy of it [her accommodations] if, for whatever reason, maybe if my meds are working well or if I’m doing really well in a class and then I have a depressed episode or I have an anxiety attack.. Then I’m like, oh shit I need this! That’s part of who I am and that is not going to change and I need to honor that part about myself by treating myself well and allowing myself to take advantage of these accommodations and do my work. ...I’ve tried to force myself through these feelings. Like if I wake up super anxious I’m like whatever, I’ll just go to class anyway... I’ve gone to section and become so anxious I’ve had to leave early. When I try to work harder, it gets to my brain.. it backfires on me pretty much always. What the accommodations have allowed me to do is to think more realistically about what I can accomplish with what I’m feeling and give myself the space and the time to grow and to accept certain things and also to get my work done. It’s made me more confident in my ability to do school.”-Sophie

When we assess a view of family influence on disability and identity cross-culturally, highlighting the influence of localized belief systems and honor codes, the mechanics of how culture shapes identity becomes strikingly more visible. The next few interview vignettes are from students with various ethnic backgrounds and speak to the strength of cultural views.

“..honor to the family, how are you going to do that with a disability?”

“When it comes to my Bengali culture, we’re very closed off so... we’re very sectional and compartmentalized with our families. Because of the way the social system is set up in Bangladesh, it makes it way harder for kids to talk to their families about these things. First of all, you’re probably poor, you’re probably a farm worker and you probably don’t have time to deal with the problems of your kid. There’s really no consent in our culture. When you’re thirteen-fourteen you get married off. There’s so much going on that they don’t really care about the individual diagnosis of their kids. It’s very draconian. You only care about what they can offer you. It looks bad in social status if you have a disabled son, people pity you and pity is not a nice thing [in this] culture. We want to be honored at all time. When you have a disabled child you can’t just marry that child off. Your family only cares what you can offer to them socially. If you get married off it affords them more power, as a family, more honor. If [they’re] disabled you say to your kid, ‘hey hide it because I’m trying to marry you off.’ If disability is found out later, that’s a dishonor. There’s a lot of factors that go into it. If you are a Muslim and you believe in marrying off your children[...] then it’s harder for you to talk to anyone... to connect to your family, harder for you to talk to your family about disability. It’s shameful in our family too. You have to bring honor to the family, how are you going to do that with a disability? When you are born into a family you have a purpose to play, if you have a disability you can’t play that purpose.” –Shagor

Floja

“In my own personal experience my family wasn't really used to having that kind of disability in the household. I have a Mexican background, my parents were born in Mexico, so were my

brother and sister. This is all very new to them. In Mexican culture, especially if you are the male, you have to be the strong one. It's something not talked about very often whether it's depression or anxiety, any kind of disability, it's always behind closed doors, it's never talked about. If you're disabled, you're weak. ..Or floja" (she translates as "lazy") - Estrella

While family cultural beliefs may pose a problem in reconciling ones identity, it can also be a strength. In the following vignette, Elijah shows how religious practices can be a venue for inclusion. He also presents his families understanding of the spiritual body as the imperative model of disability, being primary but also supported by both social and medical practices. Though he reveals he doesn't necessarily attend fully to the religious beliefs of his family, the view of disability, based on this spiritual model has been engrained in him.

"Well, the problem is, you're not praying!"

"The only person I probably wouldn't talk to, it would probably be my stepdad. My immediate family, they acknowledge different disabilities but they are slow to acknowledge it and when they do they'll think of it as something you can get rid of, that you can work on it, yourself. It comes from the way we feel about it in the south...my family is very religious and his [stepdad] view of religion adds to it. They think every mental and emotional condition has root in the spiritual. They kind of perceive it as something that through belief and prayer you can solve or at least manage every mental and emotional [condition] to a better extent. Weather that's in tandem with something you're using like from a doctor or just by itself, it's the go-to solution. If you aren't praying you're going to have a harder time. Personally, I'm not really religious so [when I say] I'm going to a psychiatrist for this and this he's like,.. 'well, the problem is, you're not praying!'

Spiritual intervention is primary... We have disabled people in our family, mostly with physical disabilities and we never stigmatize them because their family. You don't want them to feel like they aren't included...they're always part of every event. You're supposed to include them... cognitively trying to adapt to include them.” -Elijah

Elijah has been involved with community efforts that work to further disability inclusion and visibly, I see this as an influence from his families beliefs and actions. These kind of family beliefs then get embodied and can also work to predetermine a student's ability to utilize support and distinguishes their view of accommodations. Sarah's experience speaks also speaks to the influence of family but in a different way. Her story shows how the shame that families, as a unit, hold about disability can also disseminate. This lays the groundwork for internalized guilt and shame to become easily exploited by university staff and faculty.

“...they feel bad that I was born that way”

“My family is one that's a mental health denier. I grew up with the ideas that my ADD definitely was a weakness. When they finally admitted I had ADD, they took me to every kind of psychiatrist trying to find the right medication to “fix” me which is kinda ironic cause it's a condition I live with, not something that can be fixed. The way my family feels... heavily influences my deepest feelings about it, even though logically I don't think those things are true. But if I've grown up feeling that way and it's hard to shake that...they feel bad that I was born that way.” [It's apparent how this becomes embodied in a later statement.] ...I have a complex about going above and beyond to prove that I can do things that any normal person without disability [can do] to almost to diminish the effects of my ADD. I've guilted myself places... I

could have stepped back, I've been harder on myself in those situations to show that my level of achievement could be the same.” –Sarah

The mentality of needing to over-achieve to compensate, that Sarah is remarking on, is common for affiliated students and articulates the patterns of internalized shame and guilt they suffer with. She also speaks to another pattern, illuminating distinct disparities between what is seen as disability. Often psychological and cognitive differences aren't understood as disabilities. This reflects broader social cues which provide increased visibility for physical disability, in both media and sports, as well as increased accommodation efforts like cut curbs or designated parking spots and signage.

Psychological disability is still the most stigmatized spectrum of disability in our society. Often media attention exploits mental illness in conjunction with violence including mass shootings. This didactic perversion is apparent to affiliated students as well, often with psychological differences being viewed as a personal fault. Many students with mental illness or psychological disabilities don't see themselves as disabled. When medications are working well and the student experiences a reprieve from symptoms or isn't feeling a significant negative impact, the reason for accommodations may go unrecognized, almost forgotten about, leaving the student in limbo and questioning if they “truly” need their accommodations. This adds to the questioning regarding the validity of accommodations for psychological disability and further suppresses the students need to identify as disabled. This sort of waxing and waning is typical with episodic type disabilities, both of a psychological nature as well as chronic illnesses.

On the other hand, cognitive or learning disability, with its strong roots in neuroscience and the existence of calculable symptomatology and a “definitive test,” it is regarded more as a

palpable, physical disability than a subjective mental one. One student who identifies with experiencing both ADHD and depression discussed this division in the social view while recall a trip to the Urgent Care.

“Adhd is never questioned by medical doctors but the depression diagnosis and meds are always questioned. Even random doctors at urgent care ask, “Is it really recurrent?!? And say “since you are sleeping well, maybe you can go off of these now.” They never question the ADHD medications. My new doctor instantly agreed that [the current medication] was the ‘perfect’ medication for ADHD (“yep, that’s the perfect one for ADHD”) but questioned the depression med.” -Laney

However, this division between psychological and cognitive disabilities doesn’t fully mediate the influence of stigma or fully intervene in the negative embodiment it produces in fact, often guilt will arise. Multiple students suggest this through utterance like, *“I don’t want to be seen as this girl who claims to have ADD and gets special treatment” -Sarah* or *“I wonder if my accommodations are unfair.”-Anne*. All the while, students recognize the importance of their accommodations to their success even if it simply allows the student to feel more confident in their abilities or lessen the deafening stress unique to higher education and what one student refers to as *“genius cultures.”* In the next section, I’ll show the increased precarity of intersectionality and how affiliated students navigate “genius culture” while simultaneously fighting social myths of deficiency.

A minority like no other.

Pivoting away from the singular imprints of family acceptance, cultural belief systems, stigma, and medicalizing, the next section more deeply explores the compounded aspects of intersectionality. Working with Lennard Davis's notion of disability as a minority, the following section shows the added complexities that occur when affiliated students are also members of other marginalized minority groups. Both James' and Shagor's stories show how disability works to reinforce existing racial and gendered stereotypes rendering it unique against the backdrop of repressive ideologies.

"[In] my own experience being a brown man with a disability, it's definitely a lot harder. First of all, you're not as believed. There's some privilege that comes with if you have a disability and that goes away if you aren't white." If you are disabled and you're white, it's easier for you because if you say you're disabled, people believe you... Ethnicity plays a lot into believability and credibility... You are more credible if you aren't a person of color." -Shagor

On UCSC campus, disability creates an avenue for a multifaceted and debilitating experience of intersectionality. Affiliated students don't just experience discrimination solely via racism, sexism, homophobia, transphobia, and classism. These are compounded and magnified through the ableism that they also encounter. Often appearing through microaggressions in their daily living, this discrimination in turn produces an internalized oppression and lack of belonging resulting in increased feelings of displacement and shame. This constant and unwavering categorization negotiates what a student believes they are worthy of accomplishing and creates a

secondary barrier of fear which keeps them from pursuing their dreams. It also works to keep students from seeking accommodations which can assist their success. Archaic cultural delusions¹³ that seep through the skin and into the soul, myths regarding intelligence or productivity, work to deter students from requesting accommodations, often to their detriment. Students will choose to fail out before adding “disabled” to the continuous stereotypes they have already been prescribed, perpetuating the cycle of poverty and upholding stereotypes of failure and ignorance. This is especially true of cognitive/learning disabilities. In next vignette, James, an older student, provides insight into how much things have changed and how much they are still the same in a “post-racial” world while expressing how myths about race impact a student’s desire to get accommodations.

“..it just reinforces that stereotype..”

“I was in special education for the majority of my life but when I was going to school there was no term ‘dyslexic.’ Either you were just slow or you weren’t trying hard enough. Once you were labelled and put in those classes, it’s hard to get out. There’s a social stigma that leaves with you, when you’re not in class, into society. It kills your self-motivation and the image of yourself. For me, once I was labelled with it, it made it better for me... because I knew I wasn’t stupid. I was able to point at it, I was able to research on it. It helped me as far as looking for new ways how to learn. I didn’t feel like I was the only person in the world going through this. I know there was nothing wrong with me, I knew that I learned a little different.. But the main thing that happened to me was my motivation and my self-esteem. People constantly telling me I couldn’t do anything, I was scared to step out of my comfort zone... Being a minority, in my school most of the students were black or minority in the class and there’s already a stigma especially if you

are black or a minority. A lot of society judges us as not being smart enough. And oh my god, if you got to go to the DRC, it just reinforces that stereotype, so a lot of people that may be struggling with disorders but that's just like the ultimate 'yes, you were right' so a lot of them would rather avoid that and almost flunk out of school other than to being treated. “-James

However, from my findings, students with long standing IEP's (Individualized Education Program) tend to exhibit a diffusion to the social stigma of learning disability that newly recognized (aka diagnosed/tested) students do not. This is to say that students who experience early interventions are more likely to self-advocate and resist negative cultural stereotypes and criticisms. The issue that arises here is that people of color are still often forced into poorer school districts with less resources and often do not receive proper interventions through testing, diagnosis, and evidence based instruction until much later, if at all. Even if they do, students of color are still rendered vulnerable to common accusations of lying and cheating.

Autism as a second job

Psychological and cognitive differences require a kind of “double bookkeeping”¹⁴ which entails a balancing act of two separate but mutually aware realities. In one reality, one part of their being is aware that they learn differently or experience acutely heightened sensory responses while in contrast they are also living with the acute awareness that they need to portray a normal neurobody, or as close to a normal neurobody as possible. Producing the need to work, often to extreme measures, to succeed in a type of “covering”¹⁵. For one of my subjects, Allison, this took the form of hours and hours of training. She referred to it as her ‘CBT’ or ‘Cognitive Behavior Therapy’, a method of behavior treatment popular with psychologists. Training herself how to overcome what came naturally for her, in order to present a more “normal” neurobody. In

Allison's case one of the things she worked on was the ability to maintain consistent eye contact, something that would "out" her if she did what came naturally. She does this in order to maintain relationships which hinge her success, mostly with professors. With goals of medical school, she can't risk her ability being questioned. For Allison, autism is a second job.

"I can perform neurotypical"

"I take a CBT approach to all of my disabilities which is basically training yourself out of it [using accommodations] and because I take this approach I try to not rely on a lot of things that people in my situation do take... I'm autistic and I don't want people to know, it's to the point where I can perform neurotypical so I won't tell anyone because there is a stigma on it. Everyone generally accepts ADHD as being a challenge. They're generally more willing to be accepting of ADHD than they are about anxiety and autism. I'm perfectly fine saying I have ADHD to someone.[Explaining that with autism] You just see it and you don't know what kind of face they're making, It just like looks like people are making a funny face. But you can use different stimulus to understand what people are saying too. I don't think it works for everyone but I was able to train myself to learn different stimulus, train myself to look [in a way] that should be understandable for everyone."

The Precarity of Disclosure | The Intersubjective

Neuroatypical students call into question some of the most cherished tropes of the academic discourse including productivity, collegiality, and rationality. (Price 2011) Disability is ultimately devalued at the university level. This is recognizable in the microaggressions between student and professor and at the macro level in the sudden substantial drop in accommodation

rates from high school to college.¹⁶ Legally determined and university sanctioned accommodations produce an inevitable need for disclosure. During methods of disclosure, the preexisting power dynamic between professor/student yields what I would refer to as a multi-level series of microaggressions further establishing the students 'disabled' social status.

Goffman (1967) conveys it like this:

“evidence of social worth and mutual evaluation will be conveyed by very minor things and these things will be witnessed, as will the fact that they have been witnessed. An unguarded glance, a momentary change in tone of voice, an ecological position taken or not taken can drench a talk with judgmental significance.”

Currently, after a student request for DRC affiliation is processed, the student needs to request accommodations for each class through the website. From there the student will receive an email correspondence which includes a form they are directed to give, (often suggested to do directly and in-person as a form of forced self-advocacy), to their professors. This in-person method opens the door to direct discrimination, disregards student privacy, and creates a forced discussion around the students private (medical) information. This often takes place in front of the class as students hope the professor will avoid asking further questions, however often times it is still seen as an invitation to do so, and now in front of other lingering students. Often this interaction creates a compelling pressure for students to further disclose personal information, often in the form of diagnosis, and explanation on their difficulties to “justify” their “special privileges.”

This disregard for a student's privacy is one of many microaggressions students face. Professors leaving identifying accommodation forms in the classrooms upon their departure,

blatantly saying “oh, you won’t need these” regarding their accommodations, or flat out ignoring them with a shifted gaze and bit tongue are also commonplace. Asking for doctors notes for something covered in accommodations has also been known to happen. Another common issue that arises is forgetting to book separate testing facilities then rushing to do so last minute producing a feeling of dread and burdensome inconvenience directed toward the student. Information like corrections and clarifications which are given during exams are often not communicated to students in the rooms for testing accommodations. More than poor judgement, at the rate I heard these stories and with such similarity, I would argue intention.

“You need to be careful who you reveal it to.”

“It actually took me awhile to register with the DRC and seek accommodations because I definitely was afraid of the stigma that it brought with professors. I get accommodations for ADD and I know that some people hold beliefs about that and I don’t want them associating me with anything except my intellect and so I was afraid of being judged by professors if I got accommodations. I don’t want to be seen as this girl... who claims she has ADD then gets special accommodations. You need to be careful who you reveal it to. Some faculty won’t understand and see it as a weakness...Especially with some professors I respect a lot and truly care about what they think about me...or think I want to do research with them or get a letter of rec...The admittance that I have a disability as a weakness that in their minds may detract from their view of me.” -Sarah

This power dynamic provides a venue for the severing of or truncation to the reciprocal relationship of the student and professor when seeking opportunities like internships, lab

positions and job referrals. It becomes clear that students are at the mercy of their professors but sometimes even more impacted by the interaction with Teaching Assistants (TA's), given they do the grading and run the sections. This comes up repeatedly in my interviews. TA's often treat accommodations and those that receive them as a less than subtle nuisances, scoffing at requests covered by accommodations and sidelining the dynamics and difficulties of writing and reading aloud for those with learning disabilities like Dyslexia. TA's aren't often made aware of a student's accommodations by the professor which adds to the problem.

It is through this series of political and social defeats that the student begins to embody the notion that they don't belong. They internalize the idea that they are not like the others (students and professors) and therefore don't have access to the same life chances. This further perpetuates the ableism inherent in cultural myth and stigma by creating a dividing line between the conscious ways they view themselves and the reciprocated view of the university. It is the university's purpose to imbue the student with the skills to be successful, not to perpetuate preexisting ableism and social norms of exclusion.

My data, especially those double-major, cross-disciplinary students, strongly suggests a distinct disparity in the occurrences of microaggressions between departments with a stark difference in the way professors in the STEM departments react as compared to the Humanities and Social Science. The recognition of emergent data regarding different learning methods is apparent to and utilized by professors in the Humanities and Social Science. Students speak to how some professors have already begun accommodate for this in their style of teaching. However, the STEM departments are entrenched with competition and perfectionism which seemingly is attained through one standardized method only, something spawned from the disciplines themselves. This environment fully consumes the other students as well, pushing

them to seek out weakness and vulnerability in each other. Learning disabilities threaten and shake these idealist foundations, seen almost as an direct assault on the scientific method itself.

“The disciplines take different approaches to learning which sounds really strange but everyone in the psych department has been trained in how to learn. They design the class dependent on how students learn the best. I often don’t need to hand in my letters [accommodations request forms]. The hard science classes and math classes, they... they’re not aware of it as much. So like me saying I can’t take your test within the time given sometimes doesn’t make sense to them because they’re like ‘oh, it’s super easy’ but I’m gonna put a 3 where there needs to be a 2 and a 2 where the 3 needs to go and maybe add a 4. Sometimes, I forget to pay attention to the numbers that I’m writing down. So I’ll be looking ahead and I’ll just write down the completely wrong number. They’ll just be [professor] ‘But you understand the material, you should do fine!’ -Allison The student witnesses the professor’s awareness of her comprehension of the material while concurrently dismissing her need for accommodations in order to perform under the very specific circumstances of the exam.

Another student reveals. *“Engineering students will try to discredit anything.”*¹⁷ Suggesting a group effort to protect the “ideal” engineer, upholding the notion that if you come out of this population you also have to exhibit this sort of cognitive perfection. When you don’t, you are displacing the entire group in social representation. The ability of the group as a whole infuses the identity of the “super human” of engineering. “Professors aren’t open to accepting ‘excuses’ about why the student can’t ‘hack’ it.”

I speculate this is influenced by the differences in how the university is funded across the departments. The humanities and social sciences derive the majority of their funding from

student tuitions and fees while the STEM departments retain outside, heavily competitive private contracts as their main monetary source. And while I can't prove it, I would strongly suggest that universities and professors look at how the capitalist driven neoliberal politics, which are buttressed by stigma filled notions of incompetency, are infused into their daily interactions and teaching styles and determine how this might push our most vulnerable students further into economic and social precarity.

Part III: In/Visibility (and the “privilege” of passing)

"These powers, by their nature, were of moral and social order, they took root in the madmen's minority status, in the insanity of this person, not his mind. If the medical personage could isolate madness, it is not because he knew it, but because he mastered it, and what for the positivism would be an image of objectivity was only the other side of this domination." (Foucault, 1967)

In *Pedagogy of the Oppressed* (1970) Paulo Freire suggests that it is the responsibility of the oppressed peoples to rise up against their oppressors, however many don't even recognize the conditions that bind them. He refers to this as a false consciousness, a barrier of denial to realizing how subjugated they actually are. I've set aside a separate section for this topic because of its importance as it speaks to disability justice and directly affects the implementation of universal design. This lens further informs our understanding of the systemic oppression affiliated students and the disabled minority at large experience and speak to the need for belonging.

Prestige and the threat of the disabled student

Prestige also exists as a source of institutionalized oppression and covertly creates structural vulnerability. While a professor at Princeton, famed anthropologist Emily Martin suggested to Princeton's head psychiatrist that perhaps she could facilitate the formation of a support group for students struggling with Bipolar disorder. In response she was told, "students with those kinds of serious mental problems would simply not be able to function in the intellectually demanding environment at Princeton" thereby suggesting there was no need. She knew for a fact this was not true, having had many of her own students disclose and herself having incurred the diagnosis. However, she recognized the brutal truth that "if you say you have manic depression, you may well be categorized as a nonfunctional person, as a less than a fully rational person" (Martin 2009).

While more prevalent in the STEM majors, statements like this are not rare and populate the mindset of faculty at UCSC. This is apparent to affiliated students through patterns of remarks and actions they experience. It is within these microaggression that the notions of prestige are reproduced and transformed into stigmatizing oppressive remarks. The moment a student requests accommodations they become positioned as an oppositional other, one who needs special attention or gets additional help seen as "hand out" or a "leg up." Students further become aware of these resentments when professors fail to book testing rooms or relay timely information to those rooms. Comments like "oh, you won't need it" (when asking for accommodations) or "aren't you getting enough help already" present as personally directed and laced with bias. To the student these actions and statements communicate a profound lack of belonging and furthermore, due to the ideological hegemony of the "ideal" student¹⁸ that persists within higher learner institutions, an endangerment to the professor. The affiliated students

divergence from the ideal student, one who can uphold the prestige of the university, renders them as a threat. One needing to be removed, ignored, and rendered invisible. With the student positioned as a threat, the institution shifts from a mutually beneficial, symbiotic environment to a parasitic relationship.

The gap in the progress narrative

With the social push and demand for diversity, UC campuses like UCSB claim to strive “to create an environment that is welcoming for all sectors of our state’s diverse population and that is conducive to the development of each individual’s highest potential. ... since equal opportunity fosters the best conditions possible for the enhancement of research, creativity, innovation, and excellence.”¹⁹ But while diversity, even with its superficial markers, by all standards includes disability²⁰, any recognition of disabled students is at best difficult to find on any public facing sources for universities. UCSC is no different. While demographics suggests the university moved to rectify the oppression and discrimination of the past, there is apparently still no place for disability at the table. UCSC, with its large Latinx demographic is a lighthouse for the arrivals of more Latinx students, a beacon of belonging. While visually praising how diversity creates a better university, students with learning, psychological, cognitive and physical disabilities are rendered absolutely invisible. This erasure is not unique to UCSC but is obvious when scanning the websites of most colleges and universities. Age, gender, geography, ethnicity, sexual preference, economic class...all create selling points for belonging. You want to know why they feel they don't belong? Disability is perpetually left out of the diversity rhetoric. The flagship of the UC system, Berkeley provides a bit more visibility for their disabled students and staff. But while aspiring to be a leader in diversity, disability is still

reduced to 16 words in a 12 page brochure, (the 2013 diversity snapshot)²¹ in addition to one bar graph and ~20 words on their diversity data dashboard.²² For universities, it seems diversity is a great selling point unless it's regarding disability.

A flawed design

Universal Design (UD) is often proposed as a great catch all. One that has the potential to help many especially those who may not realize they could learn more efficiently and with greater ease in alternative ways. This broadening of the recognition of learning behaviors is no doubt, universally beneficial. However, it is imperative to recognizing the impact of the professor/student relationship and take this view into consideration when proposing future interventions. What could this mean for UD? Is UD a question of integration or mainstreaming rather than true inclusion? How can we frame UD without invoking legal or ethical need but as a solution oriented toward belonging? These findings would suggest the following:

First, there is no one size fits all. Affiliated students will continue to need special individualized attention and because of this could be pushed further to the margins, creating an increased resentment by their professors. Especially when they have already gone above and beyond by reinventing their class structure and curriculum toward something deemed “universal.” Further discrediting those who may have previously invoked their passing “privilege” in certain instances by positioning their disability as something that needs even “more attention.”

Secondly, students will still be at the mercy of their professors. Universal design is not a hard and fast set of rules. It is an open ended platform which leaves all decisions up to the discretion of the producer, who in this case are the individual professors. While this may change

as the concept of UD becomes more mainstream and standardized, my intuition suggests we will still see a divisive opposition to UD in the STEM departments, furthering the exclusion of disabled students in STEM. The above issues of resistance may be diffused by recognizing the increasing demographic that universities are poised to serve in the rapidly approaching future.

“Lack of awareness is ableism!”

One of the suggestions that I fielded throughout the interviews was, “if the DRC provided honor cords for commencement, would you be interested in wearing one?” Honor cords are worn in addition to a cap and gown to signify ones affiliation with and/or belonging to certain campus clubs, honor societies, fraternities, or sororities. The response was overwhelming. I even had a student say she loved the idea so much that if the DRC didn’t offer them, she would make her own. My initial working assumption of the significance was twofold. First, the ability to render the students affiliation visible during a moment of achievement could work as a “coming out” for some. A moment of pride that expressed to the unspoken hardship they endured to get there. Second, to assist others by creating an identifiable mark, that proved to those in the audience who may also experience difference that they were not alone, granting visibility to an invisible community.

What I didn’t realize till later in my research was that while these were still true, the real significance was that this proved affiliated students do not wish to be invisible, they want to be seen and recognized as students who exist with difference. This speaks to the power of the institutional ableism and the academic hegemony that forces students to lie about who they are in order to feel like they have a chance at success, even when *they* refuse the notion that anything is “wrong” with them. While the rigors of higher learning may be more difficult for them, they still

wish their success to be seen, not in spite of and not because of, but through their differences. This goes against the universities suggestion that students would prefer to remain private and speaks to the depersonalization and forced obscurity of difference as well as the bias that dominates the institutions discourse. At the end of the day, affiliated students prefer to be visible and it is the institution that renders them a threat.

Conclusion

"It seems to me, that the political task in a society such as ours is to criticize the working of institutions which appear to be both neutral and independent, to criticize them in such a manner that political violence which has always exercised itself obscurely through them will be unmasked, so that one can fight them."
(Foucault as used by Rabinow, 1984)

A rightful place at the table.

Disability rights, advocacy, accommodations, and the ethics around interventions are all social justice issues. To change the public perception of difference, the UCSC college campus is an imperative place to start. Not only is this an age group that experiences the onset of debilitating psychological differences, these discommodities can be encouraged to surface due to increased stress as well as a lack of support while being far from home. Besides psychological differences, many students experience temporary disabilities due to accidents²³ (with an increase during spring break) and injuries. In order to better support our current and future students we need to better understand their needs and develop systems that further break down the barriers to education, including social stigma. This is our responsibility and it all begins with education for students, professors, TA's as well as the student's families. I would highly encourage more

support for this type of research as it has the ability to encourage visibility and change social perceptions of disability. Difference is an integral and necessary part of human existence; we need to understand *us*, talk about *us*, support *us*, include *us*. At all levels of society.

Structural change and ideological change are part of the same struggle. Until the majority refuses the “common sense” notion perpetuated by ideological hegemony that there is no place for people with cognitive or physiological differences in higher learning, we will remain stuck in a loop of tolerance and retrofits. While many will continue to complain and seek reformations, what is ideally needed is a cultural shift realizing the importance of and right to a meaningful life and a sense of belonging for every citizen. What is needed is a complete overhaul of the cultural dis/beliefs of disability and the value system underpinning the institutions of higher learning.

Universities offer a place to change cultural perceptions by offering a sense of belonging for all those who breach its walls, especially the public schools. Seeing as we spend 15-25 years of our lives in school, it is easy to see how social issues can be rooted in the educational experience. Also by positioning teachers as dismantlers of myth, they harness the power to shape social views one classroom at a time. On these campuses, I see the opportunity to “unravel” stigma and its impacts by approaching difference as a continuum of human experience. I refrain from suggesting we create new norms, as there is always an opposition to an emerging category or label (Canguilhem) instead I offer a simple desire to undo the hindering binary of social norms and Cartesian dualism that buttress forms of oppression and create false realities.

The problem with the solution

As Jay Timothy Dolmage explains there is no “solution” needed unless disability is seen as a problem to be solved. Interventions, even with the best of intentions, still frame disability as

something to be managed which carries its own vivid implications of production and continuous threat to prestige. Therefore the “solution” will ever be reached through policy alone. Only through a formulation of counter hegemony or what Foucault refers to as “strategic reversibility,” and directly challenging assumptions and categorical norms will this oppression be lifted. Creating a cultural acceptance that students with cognitive and psychological differences *belong*, unequivocally, on college campuses, continues a trajectory toward a more just society. This begins by embracing a *radical acceptance* and by understanding that these students have been here all along.

Both historian Robin Kelley and anthropologist Laurence Ralph suggest that the path out of oppression is to dream bigger, to push our imaginations further, to think differently, creating new unrestricted visionary ideas of a utopian future. I dream of a future with increased empathy regarding the dreams of all students, unharnessed by perceived culturally designed ability and recognizing that while those dreams may manifest in different ways, they are all valuable. Equal access only equates to equal ability to ‘aspire’ to, while equal ‘privilege’ equates to an equal ability to achieve a meaningful life. In order to achieve a culture of belonging, where these dreams can be realized, it will be necessary to work to bridge the divide between access and privilege. To create and support innovations that are centered on belongingness, it is imperative to move toward building ‘collective’ and community to further support, not just the educational needs but the social needs of affiliated students.

The following are some my suggestions for systemic changes focused on visibility and community support that will lead to an increased sense of belonging for affiliated students on UCSC campus (see appendix A for an extensive numerated list). First, rectify social invisibility by providing public facing visibility including demographics and stories of students, staff, and

professors with disabilities creating a visible platform that speaks loudly they are not alone. Secondly, create pride and begin to fully resonate, "You are one of us", period, no caveat. One way to begin this would be to encourage professors and staff to self-disclose their own disabilities and differences, in conjunction with struggle or not, creating role models and increasing visibility that current and future students are not the only ones who have ever gone through this. There doesn't need to be a huge discussion around it, just simply creating space for that radical acceptance and belonging to occur. In this vein, throughout my interviews it was shown that peer advisors would be extremely useful to work individually with affiliated students, providing the wisdom and acceptance from someone who has actually been there, and succeeded. Thirdly, my research also suggests a strong need for an educational video that would work to increase empathy, demystify, and destigmatize; one geared toward staff, students, TA's professors, and families that explains the wide range of affiliated students on campus and highlights what accommodations mean and entail. With this there is also a need to call out professors just as you would in instances of racism. They should lead by example, not by ego and fear. "Lack of awareness is ableism" and it's no longer an excuse.

On an Anthropology of Belonging

"As anthropologists, we can strive to do more than simply mobilize real-world messiness to complicate—or serve—ordered philosophy, reductive medical diagnostics, and statistics-centered policy approaches. Both the evidentiary force and theoretical contribution of our discipline might be intimately linked to giving creative form to people's arts of living. ..In ethnographic writing, specific human stories can illuminate larger social processes as well as people's capacities, irreducible to any philosophical concept, to endure or transcend, humbly or grandly, the weight of history and control. This is the immanence of lived experience, which always includes forms of sublimation, however marginal or obscure. These impulses, as deeply human as the institutional forces that constrain them, need social recognition and care in order to be sustained and to acquire political value." - Biehl and Locke, 2010

As interest regarding the social determinants and influences on the health and wellbeing of the population increase, this research suggests looking at belonging as both a source of ailment and of healing. Disability provides a lens to greater understanding of the root causes of stigma and the impacts of culturally determined standards of productivity. Where often the conversation begins and ends with visible or assumed impairment, these differences do not become embodied as “problems” until they come in contact with a suggestive force outside the persons being. Or better said, no one I interviewed feels there is anything fundamentally “wrong” with them, though they all acknowledge their deviation from socially and medically defined norms.

I call attention, with a profound urgency, to center disability in hopes of increasing structural competency and creating a more just society through acknowledgment, visibility, inclusion, radical acceptance, and a change to the cultural perception regarding differences of all kinds. I wholeheartedly suggest that instead of striving for an inclusive society, we would achieve greater success by promoting belongingness. Not only is this a place for policy and social change but also a lush field site for anthropologists looking to better understand disability, personhood, and becoming. A sense of belonging beckons to the instinctual need we have as a social species in order to survive. Humans are not by nature individualistic and although neoliberal ideas would suggest otherwise we need each other, and not only to survive but to thrive. Our sense of belonging stabilizes us, suggests our value to the whole, and propels us with sense of duty and a recognition that we are not alone. It is at the nexus of the fear that we are ultimately alone in the world, that creates the deepest departure from how we understand ourselves as human.

Every person wants a place where they belong. A place they intrinsically understand they fit in, where they find solace in the utterance "you are one of us." For many people that feeling arises and is manifested in the ideals of higher education. Their dream of a meaningful life begins at the gates of the university. They know, just know, this is where they belong and they see people just like them, thriving in these spaces. For disabled students who harbor that same dream, the path remains narrow. Disabled students often are compelled to hide their disabilities, pushed to overachieve to compensate, and are positioned to suffer constant microaggressions in silence, all in order to fight for their belonging in these same spaces. This is a battle which is rendered, like them, invisible to the masses.

Notions of belonging tend to be constructed by both identity and place, the university campus is well positioned to offer refuge without othering. Disability is diverse and distinct but that does not mean it needs to be divisive. As Andrew Solomon boldly suggests "it's our differences and our negotiating of differences that unite us." If the university is truly the producer of societies greatest thinkers, how disability is addressed there will lead to changes across the world, resonating the belonging of disabled citizens everywhere.

Acknowledgements

I am grateful and honored to say that this project was made possible with support from the UCSC Blum Center and the guidance from Dr. Nancy Chen. I feel this work falls perfectly in line with the Blum Center's mission to deepen the understanding of the impacts of poverty and to build a more inclusive society by fostering participatory governance and letting all voices be heard. I truly hope that the data uncovered in this project can better illuminate the depth of the financial burden of disability as well as the structural vulnerabilities that are propagated even within systems that are in place to help. It's also important to realize the impact of poverty on those with disabilities and how economic security also provides early diagnosis and intervention, a stronger support system, and works to lessen the impact of social stigma. That is to say that poverty works to deepen the negative impacts of disability and diminish life chances, in fact, it can make all the difference in the world.

Bibliography

- Abu-Lughod, Lila. 1986. *Veiled Sentiments: Honor And Poetry In A Bedouin Society*. Berkeley: University of California Press.
- Asch, Adrienne. 2001. Disability, Bioethics, and Human Rights. *Handbook of Disability Studies* edited by Albrecht, Gary L.; Seelman, Katherine D.; Bury, Michael, Thousand Oaks, CA: Sage Publications, chapter 11, pages 297-326.
- Baker, Bernadette. 2002. The hunt for disability: The new eugenics and the normalization of school children. *Teachers College Record*, 104(4), 663-703.
- Beauchamp-Pryor, Karen. *Disabled students in Welsh higher education: a framework for equality and inclusion*. Rotterdam: Sense Publishers, 2013.
- Biehl, Joao, and Peter Locke. 2010. "Deleuze and the Anthropology of Becoming." *Current Anthropology* 51. p317-51
- Boggs, Carl. 1976. *Gramsci's Marxism*. London: Pluto Press.
- Canguilhem, Georges. 1989. *The Normal and the Pathological*. New York: Zone Books.
- Carlson, Angela Licia. 2009. *The Faces of Intellectual Disability: Philosophical Reflections*. Indiana University Press.
- Davis, Lennard. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; Verso.
- , 2002. *Bending over backwards: Essays on disability and the body*. NYU Press, 2002
- , 2013. *The End of Normal: Identity in a Biocultural Era*. Ann Arbor, MI: Univ. of Michigan Press.
- Dinishak, Janette, and Nameera Akhtar. 2013. "A Critical Examination of Mindblindness as a Metaphor for Autism." In *Child Development Perspectives* Vol 7, Number 2, 110-114.
- Dolmage, Jay. 2017. *Academic ableism: disability and higher education*. Ann Arbor, MI: University of Michigan Press.
- Dreyfus, Hubert. L., & Paul Rabinow. 1983. *Michel Foucault: Beyond Structuralism and Hermeneutics*. Harvester Press.
- Farmer, Paul. 1997. "On Suffering and Structural Violence: A View from Below." In *Social Suffering*, edited by Arthur Kleinman, Veena Das, and Margaret Lock, 261-83. Berkeley: University of California Press.
- Foucault, Michel. 1998. *Technologies of the Self: A Seminar with Michel Foucault*. Amherst: University of Massachusetts Press.
- , 1995. *Discipline and Punish*. New York: Random House.

- Freire, Paulo. 1970. *Pedagogy of the Oppressed*, New York, Herder & Herder.
- Garcia, Angela. 2010. *The Pastoral Clinic: Addiction and Dispossession along the Rio Grande*. Berkeley: University of California Press.
- Garland-Thomson, Rosemarie. 2009. "Staring: How We Look." New York: Oxford University Press.
- Giddens, Anthony. *Sociology [Giddens, 1997]*. 3rd. ed. Cambridge: Polity Press, 1997. xiv, 625s.
- Goffman, Erving. 1963. *Stigma: notes on the management of spoiled identity*. New York: Simon and Schuster.
- Good, Bryon. 1994. *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- Goode, Jackie. 2007. 'Managing' disability: early experiences of university students with disabilities. *Disability & Society* Vol. 22, Iss. 1.
- Goodman, Rachael D., and Cirecie A. West-Olatunji. 2010. "Educational hegemony, traumatic stress, and African American and Latino American students." *Journal of multicultural Counseling and Development*, 38(3), pp.176-186.
- Gramsci, Antonio., 1971. Selections from the Prison Notebooks, Hoare, Q and Nowell Smith, G (eds.), New York: International Publishers.
- Green, Mara. 2014. *Building the tower of Babel: International Sign, linguistic commensuration, and moral orientation*. Cambridge University Press.
- Hacking, Ian. 1986. "Making Up People." In *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought*, edited by Thomas Heller, Morton Sosna, and David E. Wellbery, 222-36. Stanford: Stanford University Press.
- , 1998. *Rewriting the soul: Multiple personality and the sciences of memory*. Princeton University Press.
- , 2002. Historical ontology. In *In the Scope of Logic, Methodology and Philosophy of Science* (pp. 583-600). Springer, Dordrecht.
- , 2003. *The Social Construction of What?* Harvard: Harvard University Press.
- Hart, Brendan. 2014 "Autism parents & neurodiversity: Radical translation, joint embodiment and the prosthetic environment." *BioSocieties*, Vol 9, Number 3, Page 284
- Herman, Edward S., and Noam Chomsky. 2010. *Manufacturing consent: The political economy of the mass media*. Random House.

- Kerschbaum, S. L., Eisenman, L. T., & Jones, J. M. 2017. *Negotiating disability: disclosure and higher education*. Ann Arbor: University of Michigan Press.
- Kittay, E. F. 2001. When Caring Is Just and Justice Is Caring: Justice and Mental Retardation. *Public Culture* 13(3), 557-579. Duke University Press.
- Kleinman, Arthur. 2000. "The Violences of Everyday Life: The Multiple Forms and Dynamics of Social Violence." In *Violence and Subjectivity*, edited by Veena Das, 226-41. Berkeley: University of California Press.
- Kleinman, Arthur, and Joan Kleinman. 1994. "How bodies remember: Social Memory and Bodily Experience of Criticism, Resistance, And Delegitimation Following China's Cultural Revolution." *New Literary History* 25 : 710-11.
- Kohrman, Matthew. 2003, Why Am I Not Disabled? Making State Subjects, Making Statistics in Post-Mao China. *Medical Anthropology Quarterly*, 17: 5–24.
- Kumari Campbell, Fiona. 2008. "Exploring Internalized Ableism Using Critical Race Theory." *Disability and Society* 23 (2): 151-62
- , 2010. Introduction to Ordinary Ethics: Anthropology, Language, and Action, edited by Michael Lambek, 1-36. New York: Fordham University Press.
- Ladd, Paddy. 2007. "Colonialism and Resistance: A Brief History of Deafhood." In *Open Your Eyes: Deaf Studies Talking*. Minneapolis: University Of Minnesota Press. p42-59
- Lefebvre, Henri. 1991. *Critique of Everyday Life*. Vol. 1 New York: Verso.
- Lock, Margaret. 1993. *Encounters with Aging: Mythologies of Menopause in Japan and North America*. Berkeley, CA: University of California Press.
- Luhrmann, Tanya. 2007. Social Defeat and the Culture of Chronicity: or, Why Schizophrenia does so Well Over There and so Badly Here. *Medicine and Psychiatry* 31: 135-172.
- Martin, Emily. 2009. *Bipolar expeditions: Mania and depression in American culture*. Princeton University Press.
- Mauss, Marcel. 1973. Techniques of the Body. *Economy and society*, 2(1), pp.70-88.
- Nicholls, Walter J. 2014. From Political Opportunities to Niche-openings: The Dilemmas of Mobilizing for Immigrant Rights in Inhospitable Environments. *Theory and Society* 43, no. 1, p 23-49.
- Nicholls, Walter J. 2013. *The DREAMers: How the undocumented youth movement transformed the immigrant rights debate*. Stanford University Press, 2013.
- Ochs, Elinor, Tamar Kremer-Sadlik, Olga Solomon, and Karen Gainer Sirota. 2001. Inclusion as social practice: Views of children with autism. *Social Development*, 10(3), 399-419

- Parker, Richard, & Peter Aggleton. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, 57(1), 13-24.
- Price, Margaret. 2011. *Mad at school: Rhetorics of mental disability and academic life*. University of Michigan Press.
- Ralph, Laurence. 2014. *Renegade Dreams*. Chicago:University of Chicago Press
- Rapp, Ranya and Faye Ginsburg. 2001. Enabling disability: Rewriting kinship, reimagining citizenship. *Public Culture*, 12(3), 533-556.
- Schweik, Susan. 2010. *The History of Disability: The Ugly Laws*. New York: New York University Press.
- Scheper-Hughes N. 1990. Three propositions for a critically applied medical anthropology. *Social Science and Medicine*. 30:8.
- Solomon, Andrew. 1994, August. "Defiantly Deaf." The New York Times.
-----, "Love no matter what." 2013. TEDMED. Posted April 2013.
https://www.ted.com/talks/andrew_solomon_love_no_matter_what.
- Spade, Dean. 2015. *Normal life administrative violence, critical trans politics, and the limits of law*. Durham, NC: Duke University Press.
- Stubblefield, Anna. 2009."The Entanglement of Race and Cognitive Dis/Ability."
Metaphilosophy 40, no. 3/4,. pp. 531-51.
- Tremain, Shelley. 2015. *Foucault and the government of disability*. Ann Arbor: University of Michigan Press.
- Wool, Zoe. 2015. *After War: The Weight of Life at Walter Reed*. Durham: Duke University Press.

Appendix A

The following is a list of key suggests regarding university policy, as well as suggestions for the DRC and ideas to broaden inclusion to provide a greater sense of belonging.

1. Graduation Honor Cords
2. Peer advisors/support
3. Encourage profs to self-disclose
4. Public facing demographics
5. Disability scholarships
6. Disability studies (classes)
7. The DRC to provide a large more inviting, community space that's separate from the office (Perhaps in conjunction with the Cove?)
8. DRC run and proctored testing rooms
9. Disability speaker series (especially stem!)
10. Education video exploring the range of disabilities served on campus and what accommodations are. (This would work to demystify and destigmatize. It could also work to inform faculty and staff how to properly handle requests and how to make their classes more inclusive. Would include subtle reminders of the second life led by students who receive accommodations, what accommodations cover and why disability demographics on campus.)
11. Sensory stability rooms in each college
12. Student Accessibility Auditors
13. Support groups/mixers with food
14. Disability safe space stickers (Increases visibility acknowledgment and acceptance)
15. Cohorts (this is being done in other colleges and showing a decrease in drop-out rates for at risk groups)

The following are the most imperative changes that can be made to class structure

1. Webcasted lectures (with Video conferencing)
2. Slides and notes online
3. All materials to the DRC or already available in digital form prior to first day of class
4. Exam formats/location available digitally (can be without access to internet)

¹ This term was first used by Antonio Gramsci to explain how hegemonic control of ideas and norms were maintained through a system of indoctrinating consent. The idea has been furthered by Noam Chomsky in relation to mass media: “The beauty of the system, however, is that such dissent and inconvenient information are kept within bounds and at the margins, so that while their presence shows that the system is not monolithic, they are not large enough to interfere unduly with the domination of the official agenda.” (2010) I’m using it to show how discrimination of disabled students in higher learning goes all but unnoticed due to the unquestionable power of the professors. It also speaks to the importance of prestige in hegemonic power of the university. Prestige is what renders the power of the professor and their actions as warranted and unquestionable. It’s through this power that the “common sense” notions that cognitively disabled students don’t belong in the ranks of the best and the brightest is populated.

² according to the CDC

³ (Biehl and Locke 2010)

⁴ There is however, a false completion as this sort of research methodology doesn't provide an honest and complete view. Cultural norms suggest the interlocutor may provide a more sunny (disposition) view of the issues than is true. Trust cannot be built in a hour. Especially when people with long term disabilities fall into the sick role and are often social accused of making things out to be worse than they are. This compounded affect can translate into a "everything is great/fine" when more insidious issues lurk below the surface. Long term ethnographic participant observation at this or similar field sites would be encouraged.

⁵ like a living organism birthed from the medical establishments need for constant pathologizing and surveillance.

⁶ There still exist a gap in the discourse at the intersection of biology and the social body. The lack of cohesion, failing to recognize the impacts of both intrinsic and external causes of suffering makes understanding and speaking about disability difficult. I would argue that both the social and medical models have merit but often are placed in diametric positions.

⁷ <http://universaldesign.ie/What-is-Universal-Design/Definition-and-Overview/Definition-and-overview.html>

⁸ “shared ideas or beliefs which serve to justify the interests of dominant groups” (Giddens 1997.)

⁹ This term, though often attributed to Marx, was never used by him. Other Marxist scholars including Gramsci, Lukács and Marcuse have furthered this idea in their work. I’m using it in this paper to suggest a cognitive distortion used to justify oppression by maintaining a false order of facts.

¹⁰ All names are fictional pseudonyms to protect the identity and privacy of my interlocutors.

¹¹ Here I allotted to use “Big-D” to speak of being part of disabled culture rather than disability as a medical condition following the similar usage in the Deaf community. Capital D is often used by Deaf people to refer to being part of Deaf culture, the “little-d” deaf to refer to the medical condition of deafness.

¹² A concept from Bourdieu referring to the deeply ingrained habit, tastes, and dispositions we physically embody which arise due to life experiences or due to the “way one is raised”. Street smarts is an example.

¹³ Here I’m referring to historical beliefs that positioned women and racial minorities as less capable and less intelligent which led to systematic discrimination against specific racial groups.

¹⁴ Louis Sass, Emil Kraepelin, Eugene Bleuler, and Emily Martin as noted in Martin 2007

¹⁵ Also attributed to Goffman who observes that “persons who are ready to admit possession of a stigma. . . may nonetheless make a great effort to keep the stigma from looming large.” (1963) While “passing” pertains to the visibility of a characteristic, covering pertains to its obtrusiveness. For example, he relates how F.D.R. stationed himself behind a desk before his advisers came in for meetings.

¹⁶ according to Jay Timothy Dolmage less than 10% of previous recipients

¹⁷ Michael (pseudonym)

¹⁸ As understood during a time of standardized tests and often with a prevalent focus on cognitive qualities. A student who is well positioned to reciprocate honor back to the institution as an alumnus.

¹⁹ <http://diversity.evc.ucsb.edu>

²⁰ legally, not till the ADA, the Civil Rights act and affirmative action did not include disability

²¹ Prepared by the office of the Vice Chancellor for Equity & Inclusion Fall 2013

²² <https://diversity.berkeley.edu/reports-data/diversity-data-dashboard>

²³ There is a significant increase in injuries over spring break shown in the increased need for accommodations