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Internalizing Disability: If I Tell You, Will You See Me?

Intériorisation du handicap : si je parle de mon handicap, vais-je exister à tes yeux?

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Abstract
In this research, I take an autoethnographic approach to center my own Mad disabled voice. I reflect on personal challenges and understandings as I was introduced to medical sociology as an undergraduate and went on to pursue graduate studies in critical disability studies. Although my first attempt at a bachelor's degree was cut short due to disability 20 years ago, I had never thought much about what it was to be disabled or how it would affect the completion of my degrees. However, my return to college was marked with the need to assure others my disabilities had been acceptably resolved to even have the opportunity to learn. And disability—my own, my family's, others—has remained an impactful dynamic throughout my educational journey. Through an exploration of medical sociology, outdated models of disability, disability studies, and disability theories—I reflect on the personal, educational, research, and pedagogical implications these have had for myself, as a Mad disabled critical disabilities scholar. As I was introduced to each of these, I found my understandings of self, those I cared for, and interactions with medical professionals changing. When I found myself traversing new and increasing disabilities, my personal and academic journeys collided, as I advocated to establish myself as able with limits. I consider the educational and historical relevance of medical sociology and outdated models of disability for critical disability scholars, presenting a Mad disabled perspective on studying sociology and critical disability studies.

Résumé
Dans cette recherche, j'adopte une approche autoethnographique afin de centrer ma propre voix mad et handicapée. Je réfléchis aux défis personnels et aux compréhensions qui ont émergé lors de mon initiation à la sociologie médicale au premier cycle, puis au fil de mon engagement dans des études supérieures en études critiques du handicap. Bien que ma première tentative d'obtention d'un baccalauréat ait été interrompue par le handicap il y a vingt ans, je ne m'étais jamais réellement interrogée sur ce que signifiait être handicapée, ni sur la manière dont cela influencerait l'achèvement de mes diplômes. Mon retour à l'université a toutefois été marqué par la nécessité de rassurer autrui quant au fait que mes handicaps étaient suffisamment « résolus » pour que je mérite simplement l'opportunité d'apprendre. Le handicap – le mien, celui de mes proches, celui des autres –

est ainsi demeuré une dynamique centrale tout au long de mon parcours éducatif. À travers une exploration de la sociologie médicale, des modèles dépassés du handicap, des études sur le handicap et des théories critiques du handicap, je m'interroge sur les implications personnelles, éducatives, pédagogiques et de recherche que ces domaines ont eues pour moi, en tant que chercheuse mad et handicapée. À mesure que je découvrais ces champs, ma compréhension de moi-même, de mes proches et de mes interactions avec les professionnelles et professionnels de la santé s'est transformée. Face à l'émergence de nouveaux handicaps, mes trajectoires personnelle et académique se sont entremêlées, alors que je militais pour être reconnue comme compétente, mais avec des limites. J'examine enfin la portée éducative et historique de la sociologie médicale et des modèles dépassés du handicap pour les chercheuses et chercheurs en études critiques du handicap, en proposant une perspective mad et handicapée sur l'étude de la sociologie et des études critiques du handicap.

Keywords
Critical Disability Studies; Mad Studies; Autoethnographic; Disabled Academics

Mots-clés
Études critiques du handicap; études de la folie; autoethnographie; universitaires handicapé·es

Introduction

Education is a peculiar thing to consider, being that it is statically defined, yet, in most senses, organic in nature. We frequently talk about education, specifically formal education, in a past-tense sense as something we previously participated in during defined points in our life. But we also have a propensity to adapt our educational importances in support of our current selves. Sure, the facts stay the same, I started formal school at age 5 in 1988, but what 5-year-old me and current me have to say about that experience are worlds apart—yes, we've spoken; recently. Instead of behaving statically, education grows with our own understanding of who we are and the spaces we occupy in the world. This is my story, of how education, *madness*, and Mad disability collided, shaping my life and understanding of the world.

Beginnings

I was born Mad disabled but lacked the critical awareness and terminology to communicate that for a majority of my life. This left me isolated, cut off from Mad, autistic, and disabled communities, and the support they provide. In addition to being born Mad disabled, the traumatic and abusive environments of my youth facilitated the development of "*medicalized madness"* (Bruce 2021; emphasis in original) as I went *madder* to aid my bodymind's (Price 2015) survival. From a very young age, dissociation has been a pervasive and affective influence in my day-to-day life, shaping how I perceive and participate in the world. Like many Mad people who find themselves in the liminal space between assumed sanity/ability and lived Madness, I found myself to be invisibly VISIBLE: as a child, I was *labeled—weird—different—gifted—difficult—special—freak*.

I sometimes wondered what it was that was *wrong* with me, why I had learning *differences* and medical concerns when my peers didn't, but outside of that, disabled didn't cross my mind as something I may be. Instead of disabled, I had other words: diagnostic labels, medications, and therapy. When it came to my learning *differences*, well, those were just *differences*; and what did it matter given I was smart? *Hmm*. I sort of thought they mattered, my disabilities. It's why I kept trying to talk about and understand them. What I learned though, from my first conversations on disability and madness, was that I was the only one concerned I was existing in a reality filled with pain, darkness, misunderstandings, and voices. See, I've always known I was Mad, but no one believed me, so I learned to invalidate and hide my *madness*, especially within my own bodymind (Price 2015).

I have spent the majority of the last 7 years studying sociology, going madder and finally embracing my Mad disabled bodymind (Price 2015). School taught me life lessons that my parents could never be bothered to teach to me and helped me find my Mad disabled voice. As an undergraduate, I was introduced to theoretical frameworks of medical and educational sociology, and at the time I entered graduate school, this is where I expected my research interests to develop. Instead, over the last 4 years of graduate study, I've found myself rapidly shifting, defining and redefining myself as a—medical sociology scholar—disability studies scholar—disabled disability studies scholar—autistic critical disability scholar—and as of now: a Mad disabled critical disability scholar.

Formalities

This research, like most, started with a consideration: What is the place of medical sociology and outdated models of disability in the education of critical disability scholars? There are a number of ways I could have explored this question but in order to do so authentically, I felt it best to tell it as I've experienced it: as a fragmented authentically Mad disabled story, approached with post qualitative inquiry (PQI) and Mad anti-methodology.

PQI is an approach to research that aims to generate new ways of thinking-knowing-being in the world and rejects the idea that researchers should follow a predetermined methodological plan (St. Pierre 2021; Vagle 2021). As a Mad researcher, I view my own approach to PQI within Mad anti-methodology. As described by Smith (2017), Mad Studies offers, to those willing to risk engaging with it, an undefinable "anti-methodology that is crazy as a motherfucker," (Smith 2017:1).

I have no desire to define or cage Mad anti-methodology—its elusiveness is what allows it to "be whatever it is that it wants to be" (Smith 2017). This was not a preexisting methodological plan, nor is it a methodological map for others to follow; it is an autoethnographic exploration of the relationship between my Madness and educational journey, guided and theorized through my Madness, using Anzaldua's Borderlands and embodied feelings of cultural discord.

Anzaldua (1999) defines borderlands as literal and metaphysical spaces occupied by people who hold multiple, often conflicting, identities—race/ethnicity, sexuality, spiritual/religion, linguistic and gender. Borderlands are spaces which reject dominant cultural norms, making space for complex, non-binary contradictions. They are spaces—

literal and psychological—where those who hold multiple conflicting identities can find truth in their lived experiences outside of dominant cultural norms, but also allow for people to reimagine or retain aspects of dominant culture that influence their identities. In my own work, I expand borderlands to include those between ability and disability and sane and madness. Furthermore, for me, borderlands are a starting point for generating new thought and knowledge—disabled, Mad knowledge. Traversing borderlands happens when moments of cultural discord (these can be negative or positive) are experienced, and instead of defaulting to cultural norms, a person interacts with the discord and makes spaces for contradictory knowledge: the abled disabled, the knowledgeable Mad. My own experiences with borderlands are both intellectual (thoughts) and embodied feelings, and as such, both are present in this writing.

Politicized Bodyminds: Words and their Meanings

Disabled and Mad bodyminds are highly politicized and socially controlled bodyminds (Goodley et al. 2019). Throughout this paper, I use *italicized* formatting to capture feelings of distress with broader social meaning. I capitalize Mad/Madness at times to show respect and work to raise the status of all Mad people: those who identify as Mad, and those who do not. When using bodymind, I am following Margret Price (2015) and rejecting the western ideology that the body can be separated from the mind. Additionally, I choose to use ableism to discuss discrimination against the entire bodymind; over sanism, which feels divisive of the bodymind, by indicating the mind alone is the source of discrimination. *Grammar***.** As a Mad disabled writer, I firmly believe grammatical rules are a

form of silencing authentic marginalized voices—this is an authentic Mad research paper, and does not adhere to traditional grammatical constraints (see smith 2017)

Pronouns. My pronouns are she/her/hers, they/them/theirs, and we/us/ours. Additionally, I use both myself and myselves when referring to my bodymind. I alternate authentically between all throughout my writing.

Undergraduate Take One

My first attempt at college was from 2001 to 2004, but across those years, I only earned credit for 12 of the 29 classes I enrolled in. My first year of college went well, that's when I completed 11 of those classes. Most of my classes that year were with friends, helping to manage my social anxiety, and overall, my bodymind was functioning within ableist expectations: that is, thanks to daily narcotics. But as I entered my second year of college, everything changed as I found myself facing increasing levels of disability and nearly no *understanding*.

Pain

One of the physical disabilities I live with, cluster headaches, are often referred to as suicide headaches (Koo et al. 2021). Some have argued clusters headaches are the most painful condition known to afflict humans, and people afflicted with cluster headaches are 20 times more likely to committee suicide (Fletcher 2015). Cluster headaches get their name from the way they tend to occur in patterns, clustered together (Fletcher 2015; Koo et al. 2021). For me, this has nearly always been daily attacks, occurring over the course of a few weeks to a couple of months, followed by months with no attacks—with the exception of late 2002 through 2004. During these years, I found

myself relentlessly suffering with cluster cycles, having no more than a week or two at a time, headache free.

During the summer before starting college, I had a series of accidents that caused spine injuries, and in the process of having those treated, significant congenital spine abnormalities were found. If you know anything about the prescription opioid epidemic, you probably know it started with a rush of overprescribing during the late 1990s and early 2000s (Lyden and Binswanger 2019). I did not escape this fate and spent the majority of my first year in college, exceptionally high on opioids. For nearly a year, I took multiple controlled medications every few hours as instructed, waiting for my back to *get better*. Finally, one doctor told me I was never getting better, would always live with pain and nerve symptoms, and eventually, find my mobility severely limited.

For whatever reason, I went home that day and trashed all the pills. Withdrawal remains in my top-worst-never-recommend experiences, but trashing those pills was one of the best decisions I ever made. However, cluster headaches are creatures of habit: their own and the habits of those they afflict. And opiates are one hell of a habit to give up. In the weeks after recovering from withdrawal, my cluster headaches appeared with a vengeance. It's difficult to attend class the next morning, when you've been awake, in excruciating pain and in the emergency room all night, at least it was for me.

Access Denied: Ableism

I'll never forget the callus reaction of one professor. I had an A in her course, according to the work I'd completed, hadn't missed any assignments, and only a handful of class periods across the semester. For each of these missed classes, I had provided her a note from the emergency room, but she'd asked me to talk to her about the notes towards the end of the semester. The day I did, she told me she was sorry, but she wouldn't excuse absences based on notes covering the previous night, and not the day of class. Due to this, she was going to fail me for attendance, despite my having completed the course work. She could have told me this halfway through the semester: I'll always wonder why she didn't. This was only the first of many of these conversations, because really, all that makes this professor stand out among the others, is that she was the first to treat me this way.

Even though my disabilities were having significant negative effects on my life, I still didn't consider myself disabled. When the spine specialist spoke about loss of mobility, I imagined, briefly, I'd become disabled, but that felt like something to worry about later. Had I known or *understood* I was already disabled, and it was disability that was causing my academic difficulties, I'd have had access to disability accommodations and protections provided by the Americans with Disability Act (ADA).[1] But I didn't know, and no one else seemed to know or care that I was disabled either. They certainly never used the

[1] The Americans with Disability Act (ADA) is the main legislation in the US that aims to protect disabled people from discrimination based on their disabilities at work, school and in public spaces. (see www.ada.gov for more information.)

word. I only knew I was in pain and doing my best to keep moving forward. For two years, I continued to enroll in classes and as things would again fall apart due to my health andmissed classes, I failed all but one class. Finally, I was placed on academic dismissal, ending my first attempt at college.

Undergraduate Take Two

It took 14 years for me to decide to return to finish my undergraduate degree. During that time, a lot changed, and I had become rather acquainted with disability. I didn't hold a disabled identity, but I was openly discussing and accommodating my life around disabilities of my own, and those of my children, who have learning disabilities and are chronically ill. When I returned to school, my children were in the final 3 years of what ended up being a decade long diagnosis process, to finally have answers about their lifelong symptoms. A significant amount of their childhood was spent in doctors' offices, specialty clinics and hospitals.

During my time away from school, I'd been collecting life lessons. Like, I couldn't work a normal job of any sort and take my kids to 10 or more medical and supportive therapy appointments a week. So, I learned how to apply for Medicaid, food stamps, and utility assistance. When the medical bills kept coming, I learned about denials and billing codes and waiting endlessly on phone calls attempting to sort things out. Then I learned how to apply for medical charity programs, after finding out that in my state, employees of the state (my partner) and their dependents are banned from children's medical assistance programs, even when they financially qualify for them. After one of my children missed over 40 days of school two years in a row, I accepted some kids cannot manage

school and chronic illness in traditional settings. So, I learned how to homeschool. And how to teach in accessible ways for those with learning disabilities. I knew I wanted to do something with my degree related to making life easier for people living with chronic illnesses and learning disabilities, but I wasn't sure what yet. In order to go back to school though, my first task was to convince a review board at the university I'd been dismissed from, I deserved another chance. To do this, the review board requested I provide a detailed account of what led to my previous academic decline and assure them I had resolved those concerns. So, I *lied*.

I wrote a true account of what had occurred, but then I assured them my progressive spine conditions had been *resolved* and that my cluster headaches were under *control*. To document my *recovery* from my lifelong disabilities, I detailed how I was managing multiple consulting jobs, homeschooling my children, and managing their complex medical care. I may not have had the words to talk in critically academic ways about disability, but I damn sure knew how to distance the image of who I was from disability: *ability*. The dysphoria I experienced the day I wrote the letter, was mild, but I took notice of it. I remember thinking it likely had to do with the lie I had told, deciding I was anxious because I didn't want to get caught and it would pass,

Answers: Medical Sociology

They let me in. They put me on academic probation, limiting my hours and banning me from financial aid eligibility for a year, but they let me in. One class stood out that first year back, one I had to argue to be allowed to take due to the limitations on my hours and it being an upper-level course, that class was "Medical Sociology." Finally, I started learning

about theoretical concepts that brought meaning to my own excessive interactions with the medical-industrial complex and helped to bring understanding to all the life lessons I'd been collecting.

I read about Talcott Parsons' sick role and how sick people were expected to seek care and recover, or to be socially vilified; turns out illness and disability are forms of social control (Goffman 1968; Parsons 1951). Parsons and other social theorists linked illness and deviance decades ago, contributing to the stigmatization of illness and disability (Goffman 1968; Parsons 1951). These views continue to contribute to American's understanding of illness and disability as a personal problem, with strictly personal causes, and most of all, as a problem that should be solved with personal resources. I began to understand why requiring public assistance was a common occurrence for Americans living with chronic illness and/or disability, and that my family fit a common pattern of being financially stressed due to high medical burden. Fundamental-cause theory expanded this understanding, providing the knowledge that economic status protects health, and poverty promotes the development of illness and disability through cumulative inequality (Phelan and Link 2013). Cumulative inequality results in socioeconomic health disparities due to a combination of toxic stress, poor housing and working conditions, environmental hazards, hunger, and lacking access to health care resources encountered by people who experience poverty (Merton 1988), and I'd had a lifetime filled with those things.

Medical sociology gave me words for the *anger* that had been building as I found myself increasingly interacting with the medical-industrial complex. With each

understanding, I found myself becoming critical of the value of the interactions with medical professionals, and began considering not only how it may help, but how it may harm. And while I wouldn't say my children were intentionally harmed, they were both subjected to excessive biomedical monitoring inclusive of exploratory tests/procedures, that had no impact on their treatment and only brought stress and pain into their young lives.

Voices

I began to understand the increasing frustrations of the doctors treating my children, were because they failed to conform to the medical model of illness and follow the expected pattern of illness, treatment, and recovery (Weitz 2019). Instead, my children found themselves in the ambiguous area of having a rare chronic illness. As the doctors were left with nothing but nonanswers and my children continued to go through cycles of significant illness, the doctors' frustrations became palatable. Some discharged my children from their care, others became suspicious it was a home toxin or mental health causing their symptoms, and a few actually continued to help my children work towards diagnosis. My understandings of the medical industrial complex had fully shifted to the sociological model of illness, especially regarding the political value of illness labels. It was at this point that I began to use my voice and occupy space during medical appointments. And more, I began to teach my children how to self-advocate and assert their autonomy over their own bodyminds.

After that first year in school, when my academic probation was lifted, I transferred somewhere new, where I have remained the last 6 years. One of the required courses at

my transfer school was an introductory level class on "Womanist Spiritual Activism." I was dreading this course, had no idea what to expect of it, but I knew I didn't want to take it. Or that is what I took from the feelings of anxious discomfort I experienced even reading it was a required class. I wanted to study sociology, not waste my time learning spirituality. Once I enrolled and read the syllabus, my feelings of *dis-ease* seemed to subside. Everything seemed fine, until a creative personal narrative of a story of origin was assigned.

See, I have a secret to share, I've been telling you a story, my story, but my autobiographical memory used to be missing. It's not that I didn't know what had happened to me across my life, but I couldn't think about it without disassociating. I couldn't remember much about being younger: I grew up, it wasn't great, the end. Even reading the instructions for the assignment caused me significant feelings of discomfort, and I would lose myself, unable to focus or even begin working on it. I couldn't make any sense of why I was seemingly losing time. Then, the day before it was due, I felt a pull, of deep seeded anger: *Who had the right to ask me about how I grew up for a class?! And if they feel entitled to ask this of us, then let us tell the truth, for once, let us tell the fucking truth*! And instead of running from that *Rage*, I embraced it:

> What is my story? Such a simple yet complex question; such a key component of essential self.
>
> My story,
> is the story of a forgotten little girl
> A little girl who was marked by tragedy

Who witnessed the destruction of a man from drug abuse and mental illness
A little girl who embraces **ANGER** above all else,
because it keeps her safe and alive
This little girl does not play
This little girl plans and **PROTECTS**
Her playroom is a closet,
that has a dresser,
that can be wedged in front of the door so it cannot be opened
Her dolls are a bit more demanding than most,
they are her own younger siblings
They are the burden she should never have known, yet they will be this girls salvation
She knows fear and abandonment She knows social workers and glass rooms,
for seeing people she doesn't want to see
She listens to people discuss her,
how **SHE** shut down in order to survive
She wonders what this means
This little girl is fairly certain that while her world was burning down all around her,
that **SHE** is the only thing that was working
She can **READ** to herself, **FEED** herself, **BATH** herself, **DRESS** herself
AND she can do all these things for her sister and brother
She can change diapers and make bottles
She is **SEVEN**

This little girl's life improves greatly for a while,
but she knows that what goes up must come down
She boxes this version of herself up

Stores her for when she will be needed,

because she **WILL** be needed again

This time, an emerging young woman seeks the knowledge of the forgotten little girl

She unboxes this part of herself and understands

She understands that shutting off essential emotion is necessary

She understands what is coming

She opens doors for fugitive swat teams and DEA agents

She picks up the pieces of a broken house left ransacked from people searching for what isn't there,

for people who have long abandoned her

She finds solace only in the fact that she will soon be an adult

That there is an expiration to this roller coaster from hell

Then, this young woman's life is changed forever by three events

She has long known abuse,

But now

NOW, the most remarkable thing happens

This young woman learns what love is

TRUE UNCONDITIONAL LOVE

The love of a father

And the love of a boy who still stands by her side as a man twenty years later

The third event almost destroys her in spite of this love

Her own brother, who she now understands she has always loved unconditionally is **SICK**

He is sick like the man she watched self-destruct years ago

She knows she will bury this boy before he can become a man

> And she does
>
> Before this woman can even legally drink, she knows sorrow that most never will
> Not sadness, sadness is fleeting
> Sorrow is all consuming
> Sorrow is raw, animalistic
> Sorrow is lying on a shower floor screaming in pain as the water turns from hot to cold
> But this **WOMAN** has the help of a forgotten little girl
> A little girl who knows how to get up when it seems impossible
> A little girl who is the epitome of resilient
> So she yields to this inner child
> She learns from her, and she picks up the pieces (excerpt from assignment 2019)

Well *fuck*. The sensations I experienced when writing this are, nearly indescribable. I could feel myselves shivering from the inside-out, up and down my spine, a visceral shaking that had nothing to do with being cold. They were desperate to be heard and terrified to be known. I didn't know it yet, but this was the first time I was listening to my Madness, inviting it back in, and offering to interact differently than our long-established history of traumatic dissociation. The only problem was, once I started remembering, I couldn't seem to stop remembering and I didn't have a clue what to do with the nightmares that were now filling my days and nights. I don't really remember much else about completing my undergraduate degree, other than my final semester being Spring of 2020 when COVID-19 hit. I graduated in May 2020 and took a semester off, to ride out the pandemic.

Graduate Studies

If you've ever wondered whether you or someone you know may be disabled, it turns out there is nothing like a global pandemic to bring clarity. During the pandemic, life was turned upside down for my family, as we were following strict isolation guidelines up until vaccines were available for all ages. When you're locked inside because everyone in your household is at an elevated risk of infection and poor outcome, well, you realize how different you are. It was *surreal* to watch my husband work from home the entire school year of 2020–2021, on ADA accommodations; someone who no one, including himself, views as disabled. But here we were, all living with disability during a global pandemic. Experiencing these difficulties solidified my decision to move forward with graduate studies in medical sociology. So, in January of 2021 I went back to school again.

Access: Mentorship

My first year of graduate studies taught me a few things, and one of those, was that if I wanted to be successful at graduate school, I was going to have to start *accommodating-my-own* disabilities and Madness. When I was younger, I had accommodations at school until 5th grade, and I knew from my own children's time in school that disability accommodations existed, but I didn't know how to *prove* I deserved access to accommodations. What I did know, was how to teach to learning disabled children. So, I identified where I was struggling and figured out how I needed to work and be taught.

The first thing I knew I needed were written instructions; my memory kept getting worse. It was never good, but I was losing days at a time, unsure of what I'd done that

week. It was disorientating, but I was in quarantine, had started graduate school, and one of my children was in the longest flare of their chronic illness they've ever had. So, I figured I was stressed. Written instructions were easy for assignments, as most were online, but what I was struggling to keep up with was understanding hidden curriculum: *how to fit in at neoliberal universities*—I found and continue to find the *beyond the classroom* aspects of graduate school absolutely confounding, and terrifying.

But I had a professor. Whose class materials were accessible to me, and I seldom misunderstood. The few times I'd asked him questions, he had provided detailed written responses, without seeming bothered by doing so. He also sent these really long sarcastic class announcements and talked about being disabled himself.[2] So, I took a chance, and instead of making an appointment for advising, I sent him a 1,000+ word, overly detailed advising email—which scared the hell out of me, but worked out rather well:

> Oh wow this is a long email. I'm proud actually. Normally I'm the only one sending books as emails. (personal communication 2021)

It's funny what sticks with you, small words or moments—feelings of being seen and welcomed into a space. All I could do was smile and breathe a sigh of relief, as the entirety of my overly long email was addressed in matched detail. By the end, I found myself laughing, realizing, maybe I could pull off this PhD after all. I was learning to *listen* to my

[2] While the US does not require ethics approval for autoethnographic research, ethical scholarship is of the utmost importance to me; every person mentioned directly in my writing has read this work and okayed their inclusion in my story.

needs, to welcome my Madness into my educational space—and it was empowering; I was starting to trust myselves.

While formal disability accommodations do exist, they are primarily envisioned with the idea of taking a less than complete disabled person and making them abled. This work out okay, when the issue at hand is physical building access, but less so when the disability in need of accommodation cannot be accommodated away—disability can and often does come with limitations and honoring those limitations is true accommodation (Lyman et al. 2016; MacFarlane 2025). It has been my own experience that formal accommodations are not able to create inclusive learning spaces for me, and that I am left to find ways of self-accommodating to gain inclusivity.

Disability Studies

My second year of graduate school, I was formally introduced to disability studies and since then, it has defined my research and theoretical interests. The two dominant models used for theorizing disability in western academic research remain the medical and social models of disability. The medical model of disability is based on biomedical conceptualizations of disability as an abnormal bodymind, in need of treatment by medical professionals, and claims the only desirable outcome is full resolution of disability (Bones, Gullion, and Barber 2022).

In contrast, the social model of disability sees disability as socially constructed, not necessarily undesirable, and accommodatable by society (Bones et al. 2022; Shakespeare 2004). The social model of disability provided me with an introduction to academic disability culture. I was enthralled with exploring research representative of people who

lived similarly to me. But as I read, I felt dissatisfied with certain aspects that seemed to be missing or underdefined. I wanted to know more about the nuanced details of living with disability and what it was like for others to live publicly disabled lives, not because they couldn't conceal their disabilities, but because they *choose* to make them part of who they are. Those feelings of excitement began to be accompanied by feelings of *agitation* and *invalidation*. So, I trusted those feelings and began exploring what else had been said about disability, beyond disability studies.

Disabled Identity: Crip Theory

Thanks to the readings, I was introduced to McRuer's (2006) *Crip Theory* with, it felt like a homecoming; I had found my people. Ellen Samuels' (2017) "Six Ways of Looking at Crip Time" helped me embrace my own disabled ways of learning-knowing-being. I started working with my Madness, listening to what felt authentic and what made me want to puke when it came to academic work. Margaret Price's (2015) "The Bodymind Problem and the Possibilities of Pain" encouraged me to embrace my bodyminds needs and limits, and to honor my pain and that of others. The more I read, the more I felt disability was a defining part of who I was and the spaces I occupy in the world: I was finally internalizing my disability. And it was a good thing, because things were about to get messy again, very fucking messy.

Those memories, of my childhood… they had kept building, and I wasn't sleeping much, or I was sleeping too much. I was forgetting weeks and months of my life now. Unable to account for how I'd completed schoolwork or kept myself alive, but I was faced with the evidence of having done so daily. I began to consider I could have brain tumor, or

be dying, something incurable. Then I started hallucinating the memories: movies enacted in current space. And then, all the sudden, the house of cards collapsed, and I found myself fragmented into thousands of selves, unable to focus-read-function-think-work. I was lost in *madness* and the only way out, was going to be getting intimately familiar with myselves in ways I'd never imagined possible. For the first time in my life, I found myself undeniably afflicted with "*medical madness*" (Bruce 2021) and unable to conceal that from others.

Accommodations

My own experiences with formal disability accommodations at my university can be described as lackluster to mildly harmful. There is a difference in true access, as I discussed my mentorship providing, and accommodations that masquerade as access. I believe the people at my university who work in these areas do the best they can, but "despite all this access, ableism still managed to make my life absolutely fucking miserable," (Smilges 2023:4). I have encountered so many instances of ableism at my university that I no longer care to count them. My accommodations have been fully ignored, I have been degraded in emails, accused of being dishonest, sat through ableist and invalidating trainings and lectures; these encounters with ableism have been pervasive, coming from peers, my students, coworkers, and professors.[3] Each of these instances *screams* that my Mad disabled bodymind isn't welcome within ableist neoliberal

[3] I would also like to acknowledge the invaluable knowledge and kind support of most peers, students, coworkers, and professors at my university. When I was profoundly disabled after my descent into *madness*, I was truly accommodated and protected.

academic spaces. But instead of listening to that voice of marginalization and rejection, I've learned to listen to the *uncomfortable-angry* parts of my Madness, the parts that push back, and say fuck-it, we've never fit anywhere in our entire life, this is no different. Every setback I've faced, I kept pushing forward, and I kept adapting education to fit my Mad disabled bodymind, over twisting my Mad disabled bodymind into ableists expectations.

Critical Disability Studies

A critical flaw in both the medical and social models of disability is that medical care is not an equally accessible resource to all people. Race, socioeconomic class, gender, sexuality, age, occupation, and educational attainment all influence a person's access to medical care, disabled knowledge, and disabled identity (Bones et al. 2022; Lovern 2022; Retief and Letšosa 2018). By failing to consider intersectionality, the models have failed to break free of colonial systems of oppression. I join critical disability scholars who have come before me and assert that both the medical and social models of disability aid in the recreation of ableist culture, helping to perpetuate existing social systems of marginalization through the reproduction of colonialism and all systems of oppression within colonial binarism (Flynn 2021; Goodley et al. 2018; Goodley et al. 2019; Lovern 2022; Spirito-Dalgin and Bellini 2008).

Where traditional disability studies felt theoretically limited and focused on colonial values, critical disability studies (CDS) rejects them. Formed as a critique of disability studies, CDS defines itself as interdisciplinary, with theoretical influences including feminist, queer, critical race, postcolonial, and Indigenous theorists (Goodley et al. 2019). Further, CDS provides an open methodological framework to think within that is focused

on advancement of disability theory, situates research within applicable economic and sociopolitical contexts, and aims to generate cultural knowledge that contributes to global understandings of disability, helping to improve the everyday lives of disabled people (Goodley et al. 2019). CDS provides a space that not only allows, but demands researchers be aware of systems of colonial oppression, and work to dismantle them.

I have little control over how I am formally taught but what I do have is control over, is what I study independently and how I teach. Teaching undergraduates was one of the things that I was apprehensive about but has ended up being one of the most rewarding parts of my education. The classroom has become a place where I can be my true self and help others find their own stories. I have intentionally worked to crip my classes, through the development of student-centered teaching pedagogy that aims to facilitate successful outcomes for all students by focusing on the development of ethical assignments and grading practices, inclusive of accommodating all bodyminds to the best of my ability. I intentionally aim to acknowledge the complexity of my own positionally as a privileged educated white person alongside my marginalized status as a Mad, disabled, neuroqueer academic in an effort to create learning spaces where students feel empowered to connect their lived experiences with academic concepts. I have worked closely with students, helping them find ways to advocate for themselves within the neoliberal university system and gain access to needed resources and disability accommodations.

Freedom: Mad Studies

My aforementioned descent into *madness* coincided with the completion of my thesis prospectus, and I spent the next 18 months, trying to regain the balance within my

bodymind and conducting qualitative research on internalizing disabled identity. My thesis and Madness were intricately linked and until each were sorted out, neither could find balance. To face my thesis, I had to face myselves:

> I know I've been all over the place with this—it's (thesis) grieving—this is the last thing 'old-unaware-less-disabled-us' ever did—we'll never return to this level of function or ignorance—it's grief. [...] for me the joy/accomplishment of this paper is missing—I cannot access the me that wrote the proposal, only follow the shadows of what she left—parts of self remain frozen in time, never growing—fragmented experience/reality. (personal communication 2024)

This is from one of the final emails I sent to my mentor regarding my thesis. I almost quit more times than I can count, but in the end, we managed it, and it was finally time to move onto new research, and the final semesters of our PhD. Our only way forward is by honoring our Mad disabled bodymind and finally caring for it as it wants-needs because we fought like hell to survive and make a space for ourselves within the neoliberal university, we intend to use it.

Listening to my Madness has guided my research and teaching pedagogy to Mad studies. Here, I have found people like Bruce (see Bruce 2021) who embraces his madness, leaning into it as he works, and making space for it within his work; and Phil Smith, who writes in a poetic style that makes my Madness squeal in excitement and joy: seen-validated-welcome-knowledgeable. The lacking adherence to neoliberal academic grammatical structure and spelling are refreshing beyond words (see Smith 2017).

Mad studies occupies a unique space, at once allowing all who identify as Mad to be Mad, but also allowing each of us to define how we identify with our Madness—I am a psy-complex *user* and *survivor*. At times, I use my *labels,* even identify with some of them, like autistic. See, there are few rules here in Mad studies, and there is also no required or limited definition of Madness. We're all welcome.

Endings

So, what is the place of medical sociology and outdated models of disability in the education of critical disability scholars? I believe the place of each of these for CDS scholars, is to understand their place for all university students. If we do not understand the current state of academia, academic literature and continue to work against research and teaching pedagogy that recreates colonial systems of oppression, we are failing. As we work to deconstruct ableist systems of oppression, I believe we will watch these old models and theories fade into the background, becoming nothing more than a history of harm, but I believe CDS may have let these theories fade into the background too soon, as they are still foundational components in many academic programs.

For me, the journey of my education has been intricately tied to the embracing of my Mad disabled bodymind and has included ableism across its entirety. Ableism put an end to my first attempt at college, and without (formal and self) accommodations, I would never have been able to be successful at school. The reason my second attempt at my undergraduate degree was successful, was because my classes were online. This allowed me to have written materials and communication: accommodation and access. And within

a semester of graduate school, I was self-accommodating, before gaining access to formal accommodations.

Ableism is rampant and is unbelievably harmful to all bodyminds, not only disabled ones. Disability and Madness remain marginalized because society continues to recreate and tolerate marginalization. There is no reason I or any student needs to sit through a lecture that praises the work of bias theorists and harms our sense of identity. Just as we are not forced to sit through lectures on outdated biological theories of race or gender roles, we should not be forced to do so for outdated theories of madness or disability. What is harmful is defined by those who it harms, not the intent behind the harmful action.

In one of the first conversations I had with my mentor, he asked me a question that has stuck with me, "*Do the intentions behind the act matter more than the outcome?"* It has taken me years to reach a conclusion, but no, the intentions behind the act do not matter more than the outcome, not even when the intentions and outcome are both positive. My education has included needless ableism, and my resilience does not dismiss that *harm*. While I am proud to have found the resilience needed to persevere, no one should need resilience to be successful in education.

References

Anzaldua, Gloria E. 1999. *Borderlands/La Frontera: The New Mestiza, Second Edition*. 2nd ed. Aunt Lute Books.

Bones, Paul D. C., Jessica Smartt Gullion, and Danielle Barber. 2022. *Redefining Disability*. Leiden, Netherlands: Brill.

Bruce, Marr Jurelle. 2021. *How to Go Mad without Losing Your Mind: Madness and Black Radical Creativity*. Durham, NC: Duke University Press.

Fletcher, John. 2015. "Why Cluster Headaches Are Called 'Suicide Headaches.'" *Journal of Neurology & Stroke* 3(3). doi:10.15406/jnsk.2015.03.00092.

Flynn, Susan. 2021. "Corporeality and Critical Disability Studies: Toward an Informed Epistemology of Embodiment." *Disability and Society* 36(4):636–55. doi: 10.1080/09687599.2020.1755237.

Goffman, Erving. 1986. *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Touchstone.

Goodley, Dan, Rebecca Lawthom, Kirsty Liddiard, and Katherine Runswick-Cole. 2019. "Provocations for Critical Disability Studies." *Disability and Society* 34(6):972–97. doi: 10.1080/09687599.2019.1566889.

Goodley, Dan, Kirsty Liddiard, and Katherine Runswick-Cole. 2018. "Feeling Disability: Theories of Affect and Critical Disability Studies." *Disability and Society* 33(2):197–217. doi: 10.1080/09687599.2017.1402752.

Koo, Brian B., Ahmed Bayoumi, Abdalla Albanna, Mohammed Abusuliman, Laura Burrone, Jason J. Sico, and Emmanuelle A. D. Schindler. 2021. "Demoralization Predicts Suicidality in Patients with Cluster Headache." *The Journal of Headache and Pain* 22(1):28. doi: 10.1186/s10194-021-01241-7.

Lovern, Lavonna L. 2022. "Indigenous Concepts of Difference: An Alternative to Western Disability Labeling." *Disability Studies Quarterly: DSQ* 41(4). doi: 10.18061/dsq.v41i4.8468.

Lyden, Jennifer, and Ingrid A. Binswanger. 2019. "The United States Opioid Epidemic." *Seminars in Perinatology* 43(3):123–31. doi: 10.1053/j.semperi.2019.01.001.

Lyman, Linda M., Charles R. Beecher, Andrea C. Griner, Marla M. Brooks, and Teresa

Callahan. 2016. “What Keeps Students with Disabilities from Using Accommodations in Postsecondary Education? A Qualitative Review.” *Journal of Postsecondary Education and Disability* 29(2):123–140. Retrieved June 25, 2025 (https://eric.ed.gov/?id=EJ1113021).

Macfarlane, Katherine. 2025. “SELF-ACCOMMODATION.” Dx.Doi.Org/10.2139/Ssrn.5243830. doi: 10.2139/ssrn.5243830.

McRuer, Robert. 2006. *Crip Theory: Cultural Signs of Queerness and Disability*. New York, NY: New York University Press.

Merton, Robert K. 1988. “The Matthew Effect in Science, II: Cumulative Advantage and the Symbolism of Intellectual Property.” *Isis; an International Review Devoted to the History of Science and Its Cultural Influences* 79(4):606–23. doi: 10.1086/354848.

Phelan, Jo C., and Bruce G. Link. 2013. “Fundamental Cause Theory.” Pp. 105–25 in *Medical Sociology on the Move*. Dordrecht: Springer Netherlands.

Price, Margaret. 2015. “The Bodymind Problem and the Possibilities of Pain.” *Hypatia* 30(1):268–84. doi: 10.1111/hypa.12127.

Retief, Marno, and Rantoa Letšosa. 2018. “Models of Disability: A Brief Overview.” *HTS Teologiese Studies / Theological Studies* 74(1). doi: 10.4102/hts.v74i1.4738.

Samuels, Ellen. 2017. “Six Ways of Looking at Crip Time.” *Disability Studies Quarterly: DSQ* 37(3). doi: 10.18061/dsq.v37i3.5824.

Shakespeare, Tom. 2004. “Social Models of Disability and Other Life Strategies.” *Scandinavian Journal of Disability Research: SJDR* 6(1):8–21. doi: 10.1080/15017410409512636.

Smilges, J. Logan. 2023. *Crip Negativity*. Minneapolis, MN: University of Minnesota Press.

Smith, Phil. 2017. “Defining Disability Studies and Its Intersection with Madness.” *Disability Studies Quarterly: DSQ* 37(3). doi: 10.18061/dsq.v37i3.5940.

Spirito-Dalgin, Rebecca, and James Bellini. 2008. “Invisible Disability Disclosure in an Employment Interview: Impact on Employers’ Hiring Decisions and Views of Employability.” *Rehabilitation Counseling Bulletin* 52(1):6–15. doi: 10.1177/0034355207311311.

St. Pierre, Elizabeth Adams. 2021. “Why Post Qualitative Inquiry?” *Qualitative Inquiry: QI* 27(2):163–66. doi: 10.1177/1077800420931142.

Vagle, Mark D. 2021. "Post-Intentionally Considering Post-Qualitative Inquiry." *Qualitative Inquiry: QI* 27(2):201–9. doi: 10.1177/1077800420931129.

Weitz, Rose. 2019. *The Sociology of Health, Illness, and Health Care: A Critical Approach*. 8th ed. Belmont, CA: Wadsworth Publisher