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The ripples, post-pebble: phenomenological explorations of disability through narrative

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Abstract This narrative analysis about meaning making and disability addresses the potentials of transgressing rigid conceptions of bodies and minds, of identities and selves. This analysis demonstrates the potential of blurring boundaries between body, mind, and sense making narratives of the mind/body amalgamation and argues that approaching disability through a tolerance of ambiguity can enhance understandings of experiences of disability. Disability narratives like this shed light on the lasting, often detrimental influences that policing of artificial boundaries between falsely dichotomized categories can have on individuals.

Keywords Disability · Severe traumatic brain injury · Learning · Body/mind · Narrative · Feminist

Introduction

Why am I compelled to write?

Because the writing saves me from this complacency I fear.

Because I have no choice.

Because I must keep the spirit of my revolt and myself alive.

Because the world I create in the writing compensates for what the real world does not give me.

By writing I put order in the world, give it a handle so I can grasp it.

I write because life does not appease my appetites and hunger.

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I write to record what others erase when I speak, to rewrite the stories others have miswritten about me, about you.

Anzaldúa in [2]

We are bound by language. Words spoken, written, carved, seen, and heard limit and emancipate us. We are simultaneously imprisoned by and liberated from our uniquely individual experiences of our bodies and minds through how we convey those experiences to others, making meaning of feelings and thoughts. Early on each of us is taught to communicate our thoughts through language and urged to quickly learn ways of expressing ourselves to one another with words. Expanding our vocabularies to more exactly communicate our feelings and experiences becomes necessary, as language grants us relationship to one another, connection through empathy, and opportunities to identify with those around us. Because of language, we do not face our realities in isolation. In any situation, our perspectives inform the language that we use to narrate our lived realities, and our interpretations of our interactions are only made possible because of our incarnations, our lived bodies.

The liaisons between mind, body, and meaning making through how we narrate our selves serve as the jumping off point for this analysis. My purpose is to demonstrate the potential of blurring these lines, to illustrate how this blurring can enhance understandings of disability experiences (intellectual, physical, and otherwise). Also, this analysis illustrates how narratives [11] of disability and illness shed light on the lasting, often detrimental influences that policing of artificial boundaries between falsely dichotomized categories can have on individuals. This analysis of lived experiences of disability unfolds through progressive stages of an imagined, metaphorical event: a

pebble being dropped into a pool of still water, causing a wave rippling effect. I begin with the section called "Once Upon a Body/Mind" to introduce how certain feminist scholars, such as Grosz [13], Braidotti [7], Bordo [5], and Cixous: The Laugh of Medusa [9], and disability theorists, such as Wendell [22], Oliver [14, 15], and Shakespeare [20], discuss the body/mind. I describe the interview context in the following section, "The Pool: Introducing My Methods and Ben." My analysis is presented in two parts, in "The Outer Ripples: Social/Emotional" and "The Inner Ripples: Existential." I conclude with a section I call "Next Steps: The Pool Returns to Stillness."

Once Upon a Body/Mind...

We navigate our world through bodies distinctively connected with minds [13]. Resisting the Cartesian view of the disparate body and mind (the medical model of disability exemplifies this mind/body dichotomy), I approach this analysis with an understanding of the body/mind as fused interiority and exteriority, a figuration that challenges dualistic ways of thinking about minds and bodies. This approach calls for what Braidotti terms a connection between the two, a way of thinking that treats discourse as "a positive, multilayered network of power relations" (60). Such a simultaneously cerebral and embodied relationship is one that "implies a strengthened connection between thought and life, a renewed proximity of the thinking process to existential reality" (Braidotti 60). As I illustrate in this analysis, power relations saturate discourse and our thinking and embodied experiences must be examined in since these are inevitably, invariably conjunction connected.

As is indicated in the narrative analysis that follows, a person whose body and mind are concurrently disabled is an individual on whose welded disabled mind/body power relations play out. For such an individual, meaning making can be done in various ways. This particular case study illustrates how one person's narrated experiences of their disabled mind/body are tied to their myriad understandings of their disabled body/mind. The narrative of this person's experiences through, with, and because of this unified disabled body/mind reveals how meaning making happens when someone is forced to come to terms with multiple impairments that influence the mind and body concomitantly, and in disabling ways.

I root this analysis in the social model of disability [14, 15] that identifies society's negative attitudes and exclusionary practices that disable people who have impairments. Similar to the interactive model of Shakespeare [20], this disability narrative analysis puts the mind and body in conversation with one another. A goal of this

analysis is to exemplify how one individual's interpretations of their own disabled body/mind illustrate the interconnectedness and interdependence of consciousness and embodiment. Another goal of this analysis is to illustrate how becoming disabled can necessitate reconceptualizations of one's relationships to one's body/mind. A third aim of this study is to show how our minds are forever embodied and how our bodies are constantly experienced through our minds. Our identities, as illustrated here, result from our interpretations of how we navigate the world in and through our bodies/minds, as well as how others interpret and discipline bodies/minds. I root my analysis in the feminist perspective of bodies as being not mere vessels of our minds, but as what permit us access to our environments. Our bodies serve as surfaces on which "the central rules, hierarchies, and even metaphysical commitments of a culture are inscribed and thus reinforced through the concrete language of the body" (Bordo 90). I exemplify this by showing how the disabled body/mind as a site saturated with socio-political power relations.

Feminist poststructuralist critics (whose approach emphasizes the discursive and contingent nature of identities), like Cixous [9], define the body as a cultural construction. Wendell, for instance, explains the body and body parts as "symbolic forms in a culture" (324), while Bordo calls the body "a powerful symbolic form" as well as "a medium of culture" (90). By considering the body a literal medium, bodies can be interpreted as substances that convey to others ideas, effects, and forces. Bodies are constantly interpreted, read, deciphered, and redeciphered, like language, and bodies also exist in relation. Like paint used on a canvas to tell a story, bodies "must be heard" [9], they are mediums of culture. This understanding of bodies facilitates showing, in this analysis, how coming to terms with one's multiple disabilities concomitantly influences an individual's mind and body as well as their constant renegotiations of identity. As I illustrate here, disability influences one particular individual in social-emotional (I couple these to explore their intersections synchronously) as well as existential ways. This analysis interrogates how existential and social-emotional influences co-exist and fluidly overlap in making meaning of disability.

The pool: introducing my methods and Ben

Like a pebble's impact on motionless water, becoming disabled sometimes often happens abruptly, and without warning. Experiencing an impairment and subsequently becoming disabled in society can completely transform an individual's life. Like waves rippling, being diagnosed with a disabling condition or suddenly becoming impaired can impact a person's life in numerous, often overlapping



ways that have enduring effects. This analysis centers on one individual's account of what having multiple disabilities has meant for him. I draw from feminist theories of the body, scholarship by Wendell [22], Bordo [5], and Braidotti [7], among other theorists, to critically consider particular instances in Ben's¹ narrative in which his multiple disabilities influence him socially/emotionally and existentially.

This analysis is part of a larger project on students' narratives about their experiences with learning differences and disabilities in high school and university learning spaces. Because individual student narratives about disability and education have been largely untold, their experiences have remained markedly under-examined. This particular analysis is of Ben's narrative since his emerged as uniquely relevant to body politics and corporeal feminist work, scholarly areas to which I am particularly drawn. Through this analysis, I intend to illustrate Wendell's point that people with disabilities "have a great deal of knowledge about [various] aspects of bodily experience [and] should [thus] be major contributors to our cultural understanding of the body" (326). I consider narrative gathering and oral history research powerful and necessary to develop feminist theory. Narratives about difference contribute to social justice and facilitate understandings and coalition building among different marginalized groups [17]. Such narratives have the potential to change our attitudes and behaviors by highlighting perspectives that have been historically under-examined. Here, Ben's experiences illustrate the complex ways that having multiple disabilities can impact one's life. This unique case illustrates the transformative nature of personal narrative for both the person experiencing it first-hand and the readers experiencing it vicariously.

In 2011, Ben was a 25-year-old undergraduate student at a large state university in the southeastern region of the United States. In the fall semester of 2011, I distributed a recruitment email to students through the university's students with disabilities services office. The email requested that students contact me if they were interested in sharing their experiences, memories, and perspectives about education and having learning disabilities and/or learning differences. Ben was one of the first and most willing respondents. Deeply enmeshed in what turned out to be an extremely rich and memorable conversation, Ben and I spent approximately 2 h talking about his experiences with multiple disabilities. When I transcribed the interview, I came to understand that Ben experienced what I interpreted as social-emotional and existential effects of having multiple disabilities. Ben's narrative about these effects of

¹ I use the pseudonym "Ben" to maintain confidentiality and ensure anonymity.



having disabilities illustrates what it means to Ben to navigate his world with disabilities. His narrative also shows how sense making is a reiterative, fluid, and interminable process.

The outer ripples: social/emotional

"So, when I was in...Ist grade... um... I was diagnosed ADHD. You know? Big deal. A lot of people are" (Ben).

The first post-pebble-drop ripples of Ben's narrative are what I term "social/emotional" effects. In his narrative Ben frequently describes finding himself in social situations in which he must determine how, when, and with whom he feels comfortable discussing his multiple disabilities. For me, these are social influences and responses that Ben experiences as a result of his multiple disabilities. I define the "emotional influences" as what Ben's describes when he reflects on how and why he chooses to respond to his disabilities in particular ways and in various social settings. I enter this narrative analysis via social-emotional experiences that Ben describes.

Ben was diagnosed Attention Deficit Hyperactivity Disorder (ADHD) when he was in first grade. Attention Deficit Disorder (ADD) and ADHD diagnoses have been on the rise over the past two decades, and both are extremely common diagnoses for children. According to the American Psychiatric Association [in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)], 5 % of children have ADHD and approximately 11 % of children 4–17 years of age (6.4 million) have been diagnosed with ADHD as of 2011 (Centers for Disease Control and Prevention [8]). The same data reveal that boys (13.2 %) are more likely than girls (5.6 %) to have ever been diagnosed with ADHD, and boys are 2.8 times more likely to take medication for ADHD than are girls. Ben was put on Ritalin when he was in first grade:

I hated it. Like, you know, like, I was like, I didn't ever get hungry. You know. Like I wasn't eating. And... I was like a zombie... you know? Like, some people, like, [sic] take Adderall and Ritalin and ...well...they think it's like speed or something? But, to me... to me? It...zoned me out. Yeah.

Even though he disliked taking his medicine, as he describes above, Ben took Ritalin every weekday from the time of his diagnosis in first grade until he was in ninth grade. At that point, he decided to stop taking his medication because he felt physically better when he was not taking the pills. He explains that he was more "awake" when he was around other people, and his appetite returned when he was off of his medicine:

I wasn't a zombie anymore! Yeah! I could eat whenever I wanted, you know, like, um... my social skills improved! ... Definitely! I felt like I could interact better, just... um, it was better for me!"

After Ben chose to stop taking his Ritalin in ninth grade, he did not take it again until he graduated from high school. He made this decision, he said, because the medicine changed his personality. It made him feel "zombie-like," and less social when he was around his peers. Ben told me how early on in his life he refused to allow his disability (he defined this as his ADHD) to determine how he interacted with others; his social life and sense of identity as an individual were not dictated by his diagnosis. He resisted such a possibility by refusing to take his prescribed "corrective medicine" (as he referred to it, using air quotes) in order to preserve particular aspects of his personality that permitted him to be comfortably social with his peers. In this way Ben did not allow his disability to define him.

Disability scholar Avery addresses negotiations that happen between people and their disability. She describes her personal negotiation with her disability as a dance. "Ultimately," she says, "there's a tango this disease has me doing. How much do I pull toward arthritis, how much do I push it away?" [3, p. 263]. Like Ben, Avery asks herself, "Do I claim the title of 'disabled' for myself, or do I reject it? If I claim it, is it permanent? Can I give it back?" [3, p. 263]. Avery asks, "Will I have to explain to more obviously disabled people why I label myself disabled?" [3, p. 264]. As he explained to me, early on in his life, Ben rejected the "disabled" label. Ben's later experiences reflect similar tango-like relations with his disabilities, and his attitude shifts after he is diagnosed with manic depression and experiences three major, life-altering accidents involving vehicles. One of these incidences involved his being dragged behind a vehicle used for landscaping/clearing, and two were car accidents.

In twelfth grade, Ben was working as a busboy in a restaurant after school a few times a week. He began exercising lot more than usual, staying up later at night, and getting fewer and fewer hours of sleep at night. This continued for weeks:

No one really noticed it. You know, I didn't really *tell* anybody? Cuz I didn't- I was just like, 'Ah! I feel *good*! I feel really, *really* good!' And then one day... I'm just like, 'Oh my god... this is euphoric.' You know, like, euphoric feelings? And then, one night, while I was working, I was bussing tables, and ...all of a sudden, I just went to the bathroom—and I had only had like 3 h of sleep the night before—and I went to work, came home, went to school, worked

out, and then went to work—and I was only working until 10...and then... like...

I just started bawling my eyes out...you know...in the bathroom. And I was like, 'What's wrong with me?' You know ... all of a sudden there was this shift in my- in my, uh, brain. I was just like, 'Something's happening, this is not right, you know? Yeah, something's way off.' And so, I walked out, and went to the manager, and I was like [sic], 'I'm not feeling well,' and he's just like, 'Okay. Look Ben, just tell Ralph to bus your tables.' And Ralph was like, 'But we're so busy!' And I was like, 'I just gotta go man.' And he could tell that I was not okay.

And so I went out in the parking lot, sat on the curb, and just started *crying*. Like, I don't know. I tried calling my mom. I tried calling my dad. I called my sister. No one picked up.

The following week Ben was diagnosed with manic depression, a condition that his father shares with him. Ben continues his narrative by explaining how his father's manic depression is "well-managed" and "well-controlled." Ben told me that evidence of this is due to the fact that his father is such a productive man who "gets his work done" and was able to get advanced, professional degrees to further his career goals. Ben tells me that his father "doesn't like to be asked" about his manic depression because "his is controlled." While "he knows, he doesn't tell anybody because ...he gets his shit done, he's a super productive guy, you know? Doin surgeries and things? And...and like, he doesn't want people to find out. You know ...you don't *have* to disclose that...you know?" Ben describes in his narrative that decided to follow his father's lead by "not disclosing [his manic depression]," except to his immediate family and one friend. In contrast with how Ben refused to take his ADHD medication (because it alters how he interacts in social situations), Ben's negotiating and meaning making of his other disabling condition—his manic depression—illustrate his internalized anxiety about "outing" himself. He articulates a desire to "pass" as nondisabled. Bartky explains internalization of something as what happens when "it gets incorporated into the structure of the self [...] those modes of perceptions and of selfperception which allow a self to distinguish itself both from other selves and from things which are not selves" [4, p. 145]. Ben structures his consciousness of his disability through seeing himself from the perspective of non-disabled people. In other words, Ben chooses to not "come out" to many people regarding his manic depression because he thinks that non-disabled people assume that being a "manic depressive" implies being an unproductive, unstable, and possibly unpredictable person.



The other part of Bartky's definition of internalization is "the sense of oneself as a distinct and valuable individual [being] tied not only to the sense of how one is perceived but also to what one knows, especially to what one knows how to do" [4, p. 145]. Whatever its effect ultimately is, Bartky explains, "discipline can provide the individual upon whom it is imposed with a sense of mastery as well as a sense of identity" [4, p. 145]. Internalization that Ben experiences exemplifies how complex it often is to be forced to socially navigate through and with disability when it is mostly not written on the body/mind (when it is not visible). The examples that follow show Ben choosing to disclose his disability/ies to specific people and in limited circumstances; if he "came-out" indiscriminately, he explains, he feels he would be judged, accused, and otherwise disciplined for his otherness. Ben chooses to act in ways like this because of how he makes sense of his disability: through acknowledging the policing, disciplining, and monitoring of others in response to their (non-)disability status.

Ben rarely discusses his manic depression with people outside his family, and he intentionally chooses to only tell a few friends about his Severe Traumatic Brain Injury (STBI) that he suffered because of his accidents. Choosing to do this for strategic reasons, Ben explains in his narrative why he likes to "keep [his disabilities] separate" when he decides disclose them to certain individuals:

You know? Yeah...just cuz like...there's a lot of layers to me...you know...there's like *quite a few* problems. But...I mean...it just...you have to pick a...a special kind of person that can *understand*, you know? And not...not *judge* and not just be like, 'Okay... manic?...crazy. Depression?... sad.' You know, like, 'Brain injury?...Like, what the fuck.' You know, like, I can't...deal with *that*. You know?

Ben explains to me that he thinks people often jump to conclusions regarding what it means to have multiple disabilities, particularly when referring to disabilities that influence one's mind and emotions. He attributes this jumping to conclusions to non-disabled people's often having many stereotypes and "biases against people that have...mental disabilities." Ben describes how he feels comfortable only telling certain individuals about all of his disabilities because of his anxieties surrounding how people assume things about him because of his specific disabilities. Disability scholar Samuels [18] illustrates the constantly shifting and opposing meanings of disability that exemplify Ben's hesitancy to "come-out" about his disabilities in particular circumstances. Samuels details this complexity as being often most evident in "the uneasy, often self-destroying tension between appearance and identity," and "the social scrutiny that refuses to accept statements of identity without 'proof'" (233). Ben hesitates to disclose and explain his disabilities to others because of anxiety. This apprehension illustrates the shortcomings and violence that can be done by sense making through our limited (and quite limiting) Western tendency to often exclusively rely on what we see (what is visibly marked), what is visually intelligible as "disabled." As in theories and practices of identity formation in Western culture, "the logic of visibility" (Samuels 236) frequently reigns absolutely in discourses surrounding disability. Ben's reluctance to "out" himself as having disabilities exhibits how much is at stake if disability discourse remains within the confines of what can be visibly read as "disabled" bodies.

Examining Ben's case through a Foucauldian lens, the social and emotional impacts of having disabilities and navigating the world with them epitomize how "punishment is uniquely situated in a certain 'political economy' of the body" (Foucault 25). Returning to theories of power, discipline, and body/mind Foucault [10] explains that the "power to punish derives its bases, justifications, and rules; from which it extends its effects and by which it masks its exorbitant singularity" (23). Even if the punishment is not violent or bloody, but is instead social, "it is always the body that is at issue—the body and its forces, their utility and their docility, their distribution and their submission" (Foucault 25). In combination, Ben's disabled body that resulted from nerve and spinal injuries that he received after his extremely violent vehicular accidents, his ADHD, his manic depression, and his severe traumatic brain injury (STBI) epitomize Foucault's "body that is at issue" (1995), or docile body. Ben's body/mind is "docile" not because he might seem "damaged" by disability, but because he is under multiple layers of surveillance due to his having both a "disabled" body and a "disabled" mind. The excerpt below shows how Ben is externally and internally disciplined (self-disciplined) because he occupies what many deem a problematic (since it is disabled) body/mind.

Ben tells me that when he spent several months in a "mental hospital" (the language he uses in our interview talk) he felt isolated from most of his friends since none of them visited him in the hospital. When they came to his house after he left the hospital, many of them "distanced themselves" from him. He tells me that this behavior was because they did not understand what he was going through, why he was behaving in the ways that he was, and why he was saying the things he was. He explains the situation:

I would just be talking about the CIA or the FBI or whatever, and ...um...and they'd just kinda be like... 'That's weird...' And they'd talk to my *mom*, and my mom was like, 'Well, Ben is not *doing* too well right now...'



While some of his friends were aware that he had experienced an STBI, Ben recounts that none of them knew that he had manic depression. He had chosen to not tell his friends about his manic depression because he feels that people often quickly jump to conclusions about what it means to have such a condition. He explained that people have clear "stereotypes, for sure," as well as "biases against people [with certain disabilities]." Since those fears led Ben to choose to avoid disclosing that part of his disabled identity to his friends, this, in turn, may have contributed to their lack of understanding about what was going on with Ben after his STBI and mental hospital stay. In response to Ben's deciding to keep his manic depression to himself at that time in his life—even though he is fully aware of it and explains how his particular "mental disability affects [his] learning and everyday life"—his friends disciplined him by distancing themselves from him, leaving him to recover with only this family and medical professionals as support.

The disabled body/mind that Ben is forced to make meaning of, with, and through—and finding himself in social situations where he must determine when and if to "come-out" about his disabilities—characterize his as a "docile body of modernity," a "body that is at issue," and a body/mind that is constantly shaped and reshaped by disciplinary practices [10]. For his "problematic" body/ mind, Ben socially and emotionally experiences his body and mind like a prisoner might experience incarceration in Bentham's design for the Panopticon, the model prison that perfectly encapsulates what disciplinary societies entail [10]. Like Ben's experienced sense of alienation from his friends after he is discharged from the mental hospital, each prisoner in the Panopticon is "alone, shut off from effective communication with his fellows, but constantly visible from the tower" (Bartky [4, p. 131]). The inmate thus experiences overwhelming isolation and a distinct sense of being constantly visible, judged, and monitored. This ensures that each prisoner takes on the role of serving as his own jailer. The automatic functioning of power, in these ways, concurrently ensures that the body and mind of every prisoner are under constant disciplinary control. In addition to being socially isolated by his friends, Ben experiences other forms of control: his perceptions about his disabilities (i.e., his internalized definition of what it means to be "disabled") that render him hyperaware of his disabled identity in particular social settings and result in his renegotiating his identity as disabled.

The inner ripples: existential

I kind of ... didn't pay a lot of attention to school because I was so... preoccupied. This new part of my

life, I was like, 'Wow, I have manic depression.' I was like, 'That's what's wrong.' Like, 'this is what defines me. Which I know now, it doesn't. You know, [but at the time I felt that it was kind of my identity], that I was crazy. You know, like... there're some people that are really smart and can handle it, [but at the same time] I felt that it defined me and I was like, 'Now I'm part of this crazy population.' (Ben)

Shifting from the outer ripples of social and emotional influences of disability on identity formation, reformation, and renegotiation, we migrate inward. Later in his narrative Ben explains instances in which disciplining no longer comes from the outside. Ben tells me how he self-disciplines when he acts in self-preserving ways. He undertakes these self-protective measures, he explains, to avoid standing out too much, to avoid being stigmatized [12] or ridiculed, and to avoid even being accused of lying about his disability (since it is often not visually apparent to many that he has disabilities).

One examples of this is when Ben returned to college after his STBI. He explains that he did not speak when he was assigned to work in groups during his classes because he did not feel comfortable doing so, he "was *scared* to give his input." He details what this was like:

For a long time I was *scared* that...I was *stupid*. That I was... you know, just like when I felt like manic depression defined me, I thought [my traumatic brain injury] was gonna define me. After a brain injury you think that too. Like, 'Am I gonna be inside of this person who's disabled for the rest of my life?' You know? Just like, I'm cuz [sic] I have to park in handicapped spaces, you know? Does that mean I'm a handicap for the rest of my life? Like...no it just means that, you know, like, that I have this special condition that I need...accommodations. And so ... when I first started with groups, I really thought that... I was still battling with that brain injury, traumatic brain injury. Of course not everybody knew, but like, [I thought,] 'Is my input valid?' 'Does anyone even wanna hear from me?' Like, they don't know that I had a brain injury...

Later in his narrative Ben explains that he now realizes that he works extremely well in groups. However, when he first returned to college after his brain injury, he had very little confidence in what he had to contribute to small group or classroom discussions. Ben explains that his "so many insecurities [were] always on his conscience," and he was constantly afraid of "how [others] would misinterpret [what he might say]." Ben was always worried about being "on the same page" as his peers, and so he chose to not speak, even when he had something to contribute. His fear



of saying something that was "totally off-base [and doing so] because [he] had a traumatic brain injury" prevented him from participating fully in his classes. Ben's self-disciplining in social settings such this left him "down in the dumps" when he first returned to college after his STBI. Through this instance we see that Ben participated in meaning making for himself through such behaviors; he changed himself in anticipation of other people's negative responses to his disabilities. He performed, as many people with disabilities do, in order to match his mind and body that are internally "in commotion" (in their impairments) with the surrounding environment in order to pass as unimpaired [19]. After his STBI diagnosis, Ben participated in self-surveillance and self-discipline as he was forced to renegotiate his relationship to his mind/body as well as his relationships with his peers and in classroom settings. As this instance illustrates, existentially, Ben was aiming to reassign meaning to his own life and body/mind in the aftermath of his disability diagnoses. When viewed with power relations in mind, Ben's self-disciplining measures bring to light the workings of a process similar to what Butler describes as an "exclusionary matrix by which subjects are formed" [6, p. 237]. According to Butler, this matrix requires "the simultaneous production of a domain of abject beings, those who are not yet 'subjects,' but who form the constitutive outside to the domain of the subject" [6, p. 237]. The subject is constituted through forces of abjection and exclusion. Since he first returned to college, Ben explains, his ability to speak out in group settings has been "slowly but surely progressing." Through this, Ben begins to allow himself, once again, to become "a body that matters" (Butler [6, p. 237]). Ben's anxiety about being misinterpreted because of how his STBI might impact his processing is waning.

Following Ben's STBI and manic depression diagnoses, Ben describes how he found himself in a situation in which he felt he had to internally reconceptualize his relationship and interpretation of his own body/mind as disabled. While his body/mind was previously unmarked by disability (since ADHD is not visibly marked), Ben came to a conscious awareness of his body/mind as "damaged" through disability after he experienced his accidents. Similar to how Murphy explains the ways in which illness negates a "lack of awareness of the body in guiding our thoughts and actions [since] the body no longer can be taken for granted, implicit and axiomatic, for it has become a problem" (taken from Wendell 326), Ben's inability to walk long distances because of the nerve and spinal damage he experienced during his accident led him to a new awareness of his body/mind through numbness. Ben arrived at this new awareness when he realized that he now had to both contend with and find accommodations for his newly disabled body. Wendell's disability work illustrates how such new senses of awareness result from new confrontations with "pain, discomfort, [and] physical difficulty" (326). This is apparent in Ben's justification for having a "handicapped tag" that he details in the following discussion.

Halfway through our interview Ben offers an account of why he has, and uses a "handicapped tag" even though he identifies as an athlete and loves sports, he said. He explains that "standing on [his] feet for a long time" is a problem for him because of the way that his muscles paralyzed. He is unable to use part of his feet because, he explains, his do not work the same as other people's feet work: "everything is sitting on [his] ankles, all the weight is on these two ankles." Ben explains that his feet start to hurt him if he is required to walk long distances but running or bike riding, for instance, are not issues since the pressure is different since it is more dispersed. From his explanation, and his use of the word "justify," Ben shows that he feels the need to "explain" his behavior and his use of a "handicapped tag." His showing me his ankles during the interview and explaining—by using his hands to point out each muscle in his legs that was numb to him-to me his reasoning for using such an accommodation illustrate Ben's feelings of anxiety about being perceived as using accommodations that he might not visually seem to need.

Ben continues his narrative about his new "disabled" body/mind identity by then quickly switching the discussion from his physical limitations, as he explained them during his "handicap tag" explanation, to sports. Specifically, he told me about his personal connections with bicycling. Ben explained to me that he loves bicycling because "no one knows that [he has] a disability when [he's] on that bike." He told me that he has participated in rider groups and his "favorite part about riding all of time with the others was that no one knew! It was great! I loved it! I loved it! I just like it when no one knows, you know?" Ben then details that he "hates it when people find out [about his disabilities]...and there are mixed reactions." Ben told me about this to describe instances in which people do not know how to respond to knowing about his disabilities. From his descriptions, Ben's least favorite responses relate to pity, overly dramatic congratulations for "surviving" such violent accidents, and quiet discomfort. Ben tells me that he prefers when people are unaware of his disabilities, and he prefers this because he likes to "pass" as non-disabled, he explains. Ben's preference to not "come-out" as disabled, in contexts like this, indicates the ever changing, fluid, and concurrently public and private negotiations that Ben participates in regarding his disabled body/mind. Examples like this illustrate that Ben is forced to be constantly hyper-aware of other people's potential interpretations of his body/mind, their surveillance of him because of his disabilities.



Through his increased awareness of non-disabled people's surveillance and the potential assumptions that are made about individuals with disabilities, Ben monitors himself because of people's potential responses to knowing about his disabled body and mind.

Next steps: the pool returns to stillness

"Man, like all the other animals, fears and is repelled by that which he does not understand, and mere difference is apt to connote something malign" (Walker [21, p. 169]).

Ben's narrative shows the body and the mind as interdependent, as one experienced through the other. The negotiations between them, the meanings made through one another, sinuously shift like waves in a pool. Reimagining relationships between falsely dichotomized categories such as disabled/non-disabled and body/mind necessitates a call to blur lines. Such a reconfiguration requires reinforcing unions between cerebral and embodied. Anzaldúa's concept of "mestiza consciousness," an in-betweenness (1997), is a useful approach such a blurring of lines. In striving for a tolerance for ambiguity, Anzaldúa reminds us that, "rigidity means death" [1, p. 235]:

All reaction is limited by, and dependent on, what it is reacting against [...] At some point, on our way to a new consciousness, we will have to leave the opposite bank, the split between the two mortal combatants somehow healed so that we are on both shores at once and, at once, see through serpent and eagle eyes. (Anzaldúa [1, p. 235])

This new mestiza idea is a call to move beyond binaries and challenging such dichotomous thinking about race and ethnicity, though this idea can help interpret disability experiences differently and illustrate how blurring lines between mind and body might help us recognize their interconnectedness.

Disability narratives like Ben's show how the mind and body operate in complex, nuanced ways, and how people who have disabilities are often forced to go about making meaning of their embodied experiences and of their changing identities. As is evident in Ben's narrative, power relations materialize on and through bodies/minds, and especially those marked by and with disability. The mind and body cannot be examined separately; they are enmeshed, and necessarily so. This exploration of disability through narrative is a small step in the direction toward blurring lines of, or queering (Peterson [16], "Queering Language"), (i.e., resisting categorizations) how narratives of disability are analyzed in disability and feminist studies. Approaching disability through a tolerance of ambiguity

can lead to developing "new paradigms of identity, representation, and social interaction" (Samuels 234), and thinking and naming new paradigms can alter what is possible. Shifting approaches to how disability experiences are understood and discussed can positively influence lived realities of disability.

Ben concludes his narrative by explaining how he wishes he could be a part of a traumatic brain injury (TBI) club or organization. He wants this, he explains, so that he and other people with TBIs could be able to talk about their experiences with each other. Ben's desire to be a part of a community of individuals who have similar experiences with STBIs, or other disabilities, shows the importance of communities of disability. Like Ben's narratives about experiencing difference, about change, about that which many people do not understand are essential, for they build community through fostering support and through raising people's awareness about experiences of living with disability. Breaking silence disrupts fear. Narratives soothe anxieties by creating opportunities to better understand difference. Narratives also cultivate expanded notions of inclusivity. Intentionally blurring lines, embracing intersections, and breaking silences through storying and restorying experiences of disability can resist understanding disability through reductive binaries that segregate. As Ben's narrative indicates, highlighting the problematics of artificially dichotomized categories of disabled and nondisabled, and of body and mind has significant potential.

At this point I revisit the role that the existential plays in Ben's narrative; it emerged as the frame through which Ben's disabled identity was formed and reformed. This frame is necessary for other embodied experiences to take on meaning. It also epitomizes the body/mind union indorsed here. Like Shakespeare [20], I argue that examining existential effects of living with disabilities—through negotiating and renegotiating one's identity-and false dichotomies in disability scholarship is crucial. Perhaps one of the greatest challenges of living through, with, and in the disabled body/mind is a more invisible, abstract, and existential one rooted in the necessary fluidness of reimagining and redefining oneself and what is possible. While it might seem divergent from much theory on disability, existential explorations emerged in Ben's narrative as a resounding influence of having multiple disabilities.

Existential effects must be recognized as what frames and reframes embodied experiences. To conclude, I align my scholarship with that of Shakespeare [20] and invite disability scholars in a new direction, to turn away from unanswerable debates on body/mind as disparate and oppositional. Instead, I encourage future scholarly discussions about experiences of impairment and disability that exemplify engaged, nuanced, and interdisciplinary approaches.



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