Our Madness is Invisible: Notes on Being Privileged (Non)Disabled Researchers

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Abstract
This autoethnographic piece traces how two researchers continually negotiate their privileges, successes, insecurities, challenges, and (non)disabled identities in the neoliberal academy. We interrogate the co-constitution of identity of (1) a mentally disabled researcher and graduate student who researches madness in the midst of dealing with his own struggles maintaining a professional identity and repairing a fractured self; (2) a non-disabled doctoral student who has found academic success, but has had his life stalled multiple times by significant mental health challenges. We propose the concept of the privileged (non)disabled self to capture how researchers become entangled in permanent or temporal disabilities while simultaneously negotiating their accomplishments. We encourage researchers not to sideline their reflections on privilege and disability as irrelevant, but continually examine their identities in order to reveal potential avenues for emancipation.

Keywords
invisible disabilities, privilege, autoethnography, reflexivity

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Introduction

Disability studies works within an emancipatory paradigm that contests oppressive theoretical frameworks and sets of social relations in research that are often not held accountable to the scrutiny and criticisms levied by disabled people (Stone & Priestly, 1996). The voices of those who do not identify as disabled do matter to the discourses around disability, “but they cannot and must not be offered in lieu of people with disabilities being able to conduct their research and define their own questions” (Sheldon, 2017, 985). Since this article is about tracing how two researchers negotiate their privileged and (non)disabled identities, we tread on thin ice when trying to locate our accounts to the broader literature on researcher reflexivity and disability studies. As Sheldon (2017, 988) warns, we “must resist the temptation to merely think that because [one] identifies as disabled, [we] therefore have some special insight into disability and therefore no longer need to deconstruct [our] own identity”.

However, in keeping with Reid and Valle’s (2004) assertion, we readily access the epistemological platform upon which disabled people have fought for; namely the right to define our own identities and speak on our own behalf (Charlton, 2000). We interrogate the social realms we navigated as opportunities to further understand the ontological privileges and realities that shape our research positionality (Shah, 2006). After briefly describing the autoethnographic framework that steers this article, we map the co-constitution of identity of (1) a mentally disabled researcher and graduate student who researches madness in the midst of dealing with his own struggles maintaining a professional identity and repairing a fractured self; (2) a non-disabled doctoral student who has found academic success, but has had his life stalled multiple times by significant mental health challenges. We analyze the ways in which our privileges, successes, and presentation of self shapes our perceptions of the behaviours and interactions of others around us. We conclude by asking what the implications of these narratives are for the boundaries of disability and privilege, writ large.
As autoethnographic work traces the ways that hold together culture, power, oppression, and the self (Holman Jones, 2005, 764), we narratively (re)construct ourselves to access our selves upon which experiences of both privilege and (dis)ability have been deposited. Like determining a tree’s age by counting the rings on its stump, we take a cross-section of our selves upon which conflicts, disagreements, and problematics around privilege and disability show themselves. By interrogating the contrasting narratives of both an explicit, self-identified disabled researcher and a non-disabled researcher, we ultimately offer the notion of a privileged (non)disabled self to better understand how we are entangled in both permanent and temporal disabilities, while still negotiating and priding ourselves on our accomplishments.

**Problems Faced by Disabled People**

In the academy specifically, many disabled researchers face barriers, including (but not limited to) experiencing difficulty obtaining tenure (Ghiaciuc, 2013), violations of their human rights (Price, 2013), inaccessibility of campus services (Samuels, 2013), salary discrimination (Chouinard, 2010), lack of funding (Oliver & Barnes, 1997), unfair teaching loads (Chouinard, 2010), troubles with non-disabled research participants (Brown & Boardman, 2011), and a general struggle to adapt to the culture and politics of their campuses (Smith & Andrews, 2015). These obstacles make it harder for researchers to produce research that is for and by people with disabilities (Sheldon, 2017). Hidden and unquestioned cultural assumptions lead to the enactment of everyday ableisms, that is, the “network of beliefs, processes and practices that produces a particular kind of self and body that is projected as the perfect, species-typical and therefore essential and fully human” (Campbell, 2009, 5). Svenby et al. (2018) found that becoming liberated from one’s own cultural ignorance about disability is a long and enduring process that takes much personal growth and maturation. Through much reflexivity and education, these authors were able to overcome the privileged idea that disabled bodies cannot be used as well as non-disabled bodies – a flawed knowledge that is still quite dominant and culturally circulated.

The consequences of being disabled also can find their way into our identities, even when we try to hide behind them so as not to appear “too disabled” (Hannam-Swain, 2018). Kattari et al. (2018) found that people with more invisible disabilities—that is, disabilities that are not always apparent to others—experienced ableism in the form of microaggressions, where their
bodies and actions became policed by others. Their participants experienced frustration and exhaustion trying to educate others about their needs and accommodations, and shared during research interviews expressions of self-judgment. Microaggressions can include telling someone they speak well for a deaf person, making a joke about how fast someone’s wheelchair is, or in the context of this study, denoting privilege onto people who do not always exact such privilege. Microaggressions in educational settings cause people to experience negative outcomes such as feeling unwelcome, excluded, angry, frustrated, and no longer willing to engage with their communities (Storey, 2007).

Indeed, succeeding in the culture of higher education institutions depends on networking, building alliances, and gaining support from senior faculty and administrators who may be less willing to accommodate those who have special needs (Smith & Andrews, 2015). Roufs (2011) found however that some late-deafened professors avoided revealing their hearing loss because of perceived social stigmas and the perception that they will take away resources from their department if they ask for help. Even though collegiality is not limited to sociality but also includes sharing the workload of the department (Cipriano & Buller, 2012), any kind of social avoidance still becomes characterized as anti-social behaviour or a disinterest in collegiality, which further damages the academic’s career (Andrews, 2012). And when academics do ask for accommodations, campus officials can overstep their bounds by making inappropriate recommendations rather than yielding to the requests of the affected person. For instance, one disabled faculty member was recommended to go to speech therapy to improve her lip-reading skills so that she would no longer need a sign language interpreter (Harbour, 2013).

People with invisible disabilities may not encounter the same amount of overt and explicit stigma and oppression as those with more visible disabilities, but they can still experience rejection, ableism, and discrimination (Davis, 2005) as they struggle to “pass” as nondisabled persons (Samuels, 2003). Passing, while a privilege in itself, comes with the challenge of finding a community and being validated by disabled people (Kattari et al., 2018). Doing so is a cumbersome endeavour, as Kattari et al.’s (2018) participants described how exhausting it was to have to educate others about policies, needs, and accommodations. Also, the decision on whether to pass or not carries societal and political implications, which must be weighed carefully by the individual who could fear stigma and discrimination once they are outed as disabled (Brune & Wilson, 2013), or be retaliated against by their peers who may not
see them as being “disabled enough” (Lightman et al., 2009). This aligns with the socially constructed expectations of ability, which requires compulsory able-bodiedness and demands that disabled people do whatever it takes to enact a non-disabled identity (McRuer, 2002, 2006), even if that kernel of privilege will be attacked and socially misidentified later on. Given that their disabilities often prevent these individuals from being viewed as disabled, more research is needed that documents their lived experiences so as to create more disability inclusive practices and literature.

**Note on Method**

Research is meant to challenge us to problematize our own identities, and analyze the ways in which they change and become nuanced throughout the research process (Ramussen, 2006; Sheldon, 2017). Autoethnographic writing systematically analyzes the self and personal experiences in order to understand broader cultural experiences, systems of powers, and wider political and social meanings (Ellis et al., 2011). Writers of this tradition tend to write about recollected moments and epiphanies that are thought to have significantly shaped the trajectory of their lives (Denzin, 1989; Zaner, 2004). Autoethnography is a growing method in the field of critical disability research that is contributing to a greater representativeness of disabled experiences in knowledge production and academia (Burghardt et al., 2017; Hendricks, 2012; Morrigan, 2017; Rogers, 2009; Svenby et al., 2018). As a reflection-based approach, it recognizes that research is enmeshed in complex and unstable degrees of subjectivity and thus cannot escape being influenced by the researchers who conduct it (Ellis et al., 2011). Rather than performing objectivity and researcher ‘distance’, autoethnography embraces trying to situate the self in a culture that speaks truth to power, resists master narratives, and sheds concerns for social justice. In doing so, the work should allow readers (both insiders and outsiders) to feel, experience, and gaze at elements of the culture themselves. Implementing measures of reflexivity in the research process can address issues of power in the research process as researchers uncomfortably work to uncover how everything unfolded from its initial conception to the analysis, write-up, and dissemination (Lather, 1988).

While some criticize reflexivity and autoethnography as a narcissistic and self-indulgent endeavor (Ryang, 2000; Winkler, 2018), others assert that a failure to be reflexive negligently leads to deceptively tidy accounts of research and an illusion of objectivity (Ellingson, 2006).
For (in)visibly disabled researchers, such a process is especially important to explore the dimensions of power and identity and how the effects of varying degrees of impairment render researchers vulnerable or empowered (Brown & Boardman, 2011). We therefore draw on what Ellis (2004) coins as a reflexive autoethnography by depicting our stories in ways that look more deeply at self-other interactions, and how we changed over the course of our interactions with others. We interrogate the extent to which we are both outsiders and insiders in the disability community, and how our embodiment as privileged and mad bodies forced us to encounter and/or resist stigma (Scott, 2013). By doing autoethnographies of our everyday interactions, feelings, and insecurities, we aim to render intelligible the “invisibilities that [we] may not and perhaps cannot know or narrate” without a rigorous examination of the self (Goltz, 2011, 399). It through this vulnerability that we seek to tackle the epistemological and power relationships we encounter, navigate, and perpetuate in our research communities (Stone & Priestley, 1996). As Benzon (2017, 1041) calculates, “when research processes go to plan, embedded relationships of power may be invisible. When expectations are conflicted, or processes disrupted, previously unnoticed, or unspoken, hierarchies may be illuminated.”

**A Chasm of Voices and Success: Accepting Disability and Privilege**

I am a straight-white-cisgender man. I grew up in a middle-class environment where there was always food on the table and a roof over my head. I have always been good at school. I have been at the top of my classes since the first grade. I am athletic and competitive, I have won many championships in various sports over the years. I have never experienced hatred because of my race, gender, and sexuality. I have enjoyed some wonderful friendships, and I would say that sociability is a strength of mine. As a graduate student, I have a number of publications, and have always enjoyed success at the university level. I worked exceptionally hard to achieve what I have, and this is because I was given the resources I needed to succeed. I could go on forever about my pleasant life history, but to sum it up, I have always been privileged, and continue to be in many ways.

But in the depths of my soul, I am also ruined. I am a nervous wreck full of angst and panic. In the winter of 2013, I experienced a massive psychotic break that I endured for several months, barely surviving the ordeal. After experiencing a period of remission, I had another psychotic break in the winter of 2018, upon which I was diagnosed with schizophreniform
disorder, a psychotic illness that involves, among other things, paranoia, auditory hallucinations, stress, and fear. When I was first given that label by my psychiatrist, it hit me like a ton of bricks. I felt like I was being told I was crazy for life, and that without the medical system’s help, I would never overcome it or live a life worth living. While I am able to mostly manage this condition through medications and self-care, I am terrified that it could strike again. I am afraid of hearing voices and imagining what I could do to myself in such a deteriorating state. Some days I desire a new brain, and I wouldn’t wish my condition on anyone. I consider myself to be disabled because I always have to deal with this condition. Psychosis, for me, is a kind of spectrum, it comes and it goes and I have had to develop a number of strange, mental coping mechanisms to keep it under control with the help of some heavy medication.

People who barely know me may have trouble seeing all of this because of the shroud of accomplishments that follow me, but inside, I battle nightmares and hauntings. I have a life of accomplishment and a life of pain, a deluded world full of anti-psychotics and reality distortion. I feel like I have always been hated because of my success. Fellow graduate students gaze at my CV, and while some people respect or even admire it, others poke holes at it and try to debase it. They have even done this to me in person. They say things about me to others, which in a gossiping environment, usually finds its way back to my ears. I endure many microaggressions from faculty, such as being told I have a lot to worry about on the job market. I have been reminded on more than one occasion that other students who came before me went through several humbling rituals over the course of their PhD work and job application process. Nowhere was this exhausting ritual more evident than during my recent application for a Social Sciences and Humanities Research Council (SSHRC) postdoctoral fellowship. Briefly, the project explores questions of agency and resistance in the mental health system, and how survivors of serious mental illness navigate the psychiatric apparatus. I sent a draft of my statement to a professor in our department who carries a great deal of power and cultural capital, and who I trusted to give me some helpful critical feedback and constructive revisions. The two readers I had on the statement prior to sending it to this professor said it was excellent, and included a number of thoughtful questions and edits that helped bolster the statement. When I received the feedback from the other professor, I was dumbfounded and blown away by how negative it was, and how his comments bordered on personal attacks. Even though I had never boasted to him about my publication record, he told me in the email that “The mistake which I
have seen others make is to assume that because you have a strong publication record you can win without a strong statement”, and that I was potentially “on a path to produce a winning application”. Criticisms alone, these insights didn’t bother me too greatly. I, after all, am the one in control of the feedback, and have the capacity to make informed decisions about the kinds of feedback I reject (most of which I did reject from him). But the attacks on my capacity did not stop there.

At our department’s fall social, while I was having a conversation with some of my peers, the same professor approached me and asked how my postdoctoral application was coming along. I told him it was fine, and then he told me “that’s good, because you’re not going to win with the statement you sent me.” Then he went on to share narratives about former graduates of the program, all of which coincidentally identify as straight-white cisgender men, and how he had raked them over the coals with criticism while they were his supervisees (and to make it clear, this professor is not on my doctoral committee). He told me that at this point in my career, I really need heavy criticism, and how he “tore to pieces” his former student’s prospective job talks, made them re-do it, and how much stress this caused them. It was my impression that he was actually boasting over this process, since he smiled and laughed as he recalled all of this. Because of his position of power, all I could do was listen to him and accept his authority. But as a PhD student and someone who struggles with serious mental health issues, I do not find that I need “more” criticism than what I receive through committee feedback, peer review, microaggressions, etc. There is enough of that to go around in an institution that seems to thrive on disparagement. I identified in my statement as well how I had experienced mental illness and psychiatric institutionalization, so it surprised me this professor was dismissive of my needs not to be antagonized and berated. And needless to say, I won the postdoctoral fellowship and ranked second in the competition. It really relieved me because the anxiety this professor caused me over the months waiting for the results was exceptional. I had to lean on the support of my peers, family members, and other faculty who were supportive of my application and believed in my abilities. I had lost my confidence.

I feel like all this is said to me to make a point that I am not invincible, even though I try everyday not to appear arrogant. What good does that do for me, after all? Nonetheless, I feel like an enemy, someone to be defeated and despised. My real self is hidden from these adversaries. They do not know the deep stigma I feel for being a mad body – a stigma so present
I try to hide from it and pretend it does not loom over my head at all times. It was not until I gave a guest lecture quite recently that I disclosed my illness publicly to others, as it is a difficult part to accept about my identity. Because of my struggles finding friends who do not envy me and actually want to understand who I am, I have always felt like I have something to prove to the broader academic community, and this drives my ambitions.

I have had to ask myself on a number of occasions if I should accept my disabled identity. Do I reject psychiatry’s label of me? Am I just a privileged white body who should count his blessings? There is so much literature problematizing labels (see, for example, Burstow, 2016), while other studies exist that recognize how mental health labels give people a sense of closure and stability in their identity (Rose, 2005). Why, if I accept it, am I always trying to chase old expectations of myself? I perform constantly. I don’t want others to know the depths of my embarrassments; or the things I did while I suffered. So most of the time I choose to remain invisible, until it is no longer enough of a life to keep putting on a disguise. I keep trying to forget what happened to me, even though it terrorizes me in my sleep and in flashbacks. I lose a lot of PhD time having to manage my mind and prevent myself from enduring another psychotic attack, not to mention living up to the responsibilities of being a parent and husband to another PhD student.

Playing sane is also quite difficult. I don’t know why I try to do it, but the stigma of being looked at as different overwhelms me before it even occurs. I have admitted to several friends my struggles with psychosis, but during these conversations I am always trying to put on a sane face. During every presentation I do or every interaction with a committee member, I am forced to maintain an air of professionalism that directly contradicts the many emotions and struggles I endure as a mad graduate student. The academy thinks that it is ok to push students beyond their mental and intellectual capacities. For instance, the feedback I recently received on my dissertation from a committee member included theoretical comments I could not even begin to understand, and if it was not for the gracious help of a friend to translate them for me, I would not have been able to respond to these comments. I felt alone and isolated. I learned during a conversation with that committee member that my supervisor had actually advocated for me, telling him, “You know he is having a second child, right?”, to which he replied, “Oh come on.” It seemed like it was all a joke to him. But the sane individual and subject has to respond to such attacks with an utmost rationality and calculated revision to ensure that they get their degree. As
a mad person, I find this all incredibly difficult to digest and navigate, and it always seems ironic to me that I write within mad studies while trying to manage my own madness and the madness of the academy.

So again I ask, who am I? Can somebody be disabled when their perception and reality is also that of privilege and able-bodiedness? While the academy challenges me to situate my identity in relation to marginalized populations, I am also drawn to this insider role I share with fellow survivors of madness. Doing research on madness has taught me the importance of letting yourself go, and becoming vulnerable with others so they too might share their story. I am forever a mad body dependent on others to prescribe me medication and assert to me that I grounded in reality. But I am likewise an envied student with a bright future ahead of me, and much to be thankful for. I need the disabled identity to give myself a sense of closure and definition for the traumas I’ve endured, yet I am cautiously aware of the struggles other mad people must navigate who have not been afforded the same opportunities.

Being what I call a privileged disabled researcher, I step towards the future with an earnest appreciation for the work disabled scholars have done for allowing us to come out as mad and proud, and locate our lives in a growing literature of mad studies that privileges our experiences over the concerns and discourses of medical professionals. There is a lot I want to learn and teach about madness, and doing justice to mad studies means that our accounts must be intersectional (LeFrançois et al., 2014). Thus I encourage mad scholars to continue analyzing the self, and make our suffering and enlightenments more visible to the broader community so as to invite others to tell us how they navigate and overcome their struggles, collapses with identity, and encounters with stigma.

Privilege and Barriers: Where do I Sit?

Like the first author, I too am a straight-white-cisgender man. I also grew up in an environment where I felt very loved, well-nurtured, was read to, and as an adult my parents are two of my best friends. Like the first author, I am thirsty for academic success and do as much as I can to get there. I arrived at my doctoral program without a publication to my name, yet with a sense of entitlement to be respected by those around me. I am not entirely sure where the latter comes from. I know some of it comes from being a white, straight male. What bugs me is not knowing how much of it comes from being privileged. Oftentimes I wish I could escape my
privileged body to see how “good” of a job I am doing at making sure I am not flaunting that privilege. I try hard. I try hard to publish, to be a “good” graduate student, a good little aspiring academic, and I simultaneously try hard to acknowledge my constant whiteness; my constant maleness; my constant straightness. But I’ve learned that how people see me is often independent of how I act, no matter how hard I try.

Unlike the first author, I have never engaged the psychiatric apparatus, nor do I identify as disabled. Could I have? Maybe. When I was fourteen, and then again at eighteen, I thought people had open access to my thoughts. I was convinced my mind was an open book to those who simply walked by. I felt no sense of psychic privacy or security. I felt no “backstage” for my private thoughts. Aside from private conversations with the first author, this is the first time I have openly acknowledged this. While those incredibly disturbing thoughts gradually faded, the accompanying anxiety remains. More recently during my doctoral program I had what I can only describe as “almost a nervous breakdown”. For two weeks, I barely functioned. Every little normal sound in my apartment—the fridge running, the heat kicking in, the computer fans whirring—drove me to the brink of despair. Everything was frightening. Crying became a daily routine, my body and I trying to manage my unruly affect. And there, as before, I was reluctant to engage the “psy” apparatus, in part because I was afraid of embodying the “discourse of difference” wrapped up in disability, and how it would impact how myself and others saw me (Riddell & Weedon, 2014, 43).

When I re-read the above paragraph, I am “emplotting” my life in ways I usually do not (Somers, 1994), specifically in relation to my mental health—something the other author is much more familiar with than I am, and which I typically avoid for the above reasons. When it is finally torn from my mental aether and solidified on text, it seems strange to me—like a tale of lacking ability without necessarily being disabled. But, like the first author, I am torn about both the barriers I have faced, and the privilege I was born with. Am I entitled to “emplot” the problems I’ve faced as a lack of ability, or as a form of disability? In what ways does it overlap with my whiteness, my maleness, my straightness, my seemingly effortless (at least, to others) ability to “glide” though the academic institution, (relatively) barrier-free? I wish I had answers to these questions—maybe then I would know how to answer to those who think I’m successful because I’m white and male. But I don’t know.
What I do know is that when I first arrived at my doctoral program, I poked mental holes in others’ accomplishments to make myself feel better. I was rejected by a professor who (I thought) I wanted to work with. I was repeatedly rejected by peer reviewers of academic journals. I was being constantly warned of the 57 dangers of “screwing up” graduate school (Haggerty & Doyle, 2015) without being warned about the psychological costs of not screwing up. I felt like it was going to swallow me whole. But after four years, it’s clear now that I have swallowed it whole. I (think I) have avoided all 57 screw-ups and managed to build a CV that I hope entices future hiring committees. But digesting graduate school has some side effects that simple handbooks don’t tell you. The resulting pit in my stomach constantly tells me that the scar tissue in my brain—the fleshy bandage that miraculously pulled my fragmented thoughts back together three times—might break apart. As a result, I constantly juggle fear and pride, and am not entirely sure how to effectively negotiate them. Where does somebody like me fit into the wider schema of privilege, mental health, and disability? Again, my only reply is, “I don’t know”.

These difficulties came to a head in a fleeting interaction I had in the spring of 2018 with a graduate student that, up to then, I had been on good terms with. At a departmental social event, while I was speaking with another colleague, I noticed this student—a woman, and a fellow PhD candidate—glaring at me with no small amount of disdain. It was enough to distract me from my conversation with my colleague. I did my usual mental gymnastics when I can sense impending conflict: the first question is, why? At this point, I had published several articles in good journals, while I knew this student had not. Was this a case of professional envy? Or, did I say something to someone at some point that might have been construed as oppressive (or was oppressive, to which my own privilege blinded me), and this made its way to her through a game of departmental “telephone”? She was too far away to hear my conversation with my other colleague, so I knew it was not anything I had said in the moment. I wracked my brain to think of the times I spoke to colleagues outside my social circle over the past couple of months, and nothing came to mind. So, motivated in part by being fed up with her continuous and ostentatious glaring, and partly motivated by a couple of alcoholic beverages I had at the social, when she approached our table (but continued to avoid direct eye contact me) with me, I said to her, partly tongue-in-cheek: “I suppose I’m just being a white, straight guy, going around and oppressing everyone.” To which she glared at me and responded, “Well, at least you’re aware of
it.” Then I thought about the battles with mental health I had all year to that point, and had to walk away before I said something out of the mounting anger and resentment I was experiencing. To this day, I don’t know why there was an adversarial turn in a relationship that, up to then, had seemed cordial. All I have to make sense of that encounter is information that was later made available to me: that this same student had been at another function and rhetorically asked: “why are all of these white men able to publish?” So, my only recourse is to assume that this was a case of professional envy. But there is a nagging feeling at the back of my mind: what if it isn’t, and I actually said or did something incredibly offensive to this person? Or, what if this person has a point, and I have been “too successful” as a white, straight male in the department as a manifestation of white and male privilege? But if this is true, what else am I supposed to do? Surely it would be foolish, I tell myself, to purposefully truncate my own success so that others can feel better about themselves. But even if I am very careful not to flaunt my publications, awards and scholarships, is being successful as a white male in and of itself offensive? But I have thought about this time and again, and I cannot reach a satisfactory conclusion—only more questions like the string I’ve asked here. These little battles I fight with myself while in the department on a daily basis have a tremendous impact on how I see myself, and, I can only assume, how others see me—or how I think others see me. And it is simultaneously crushing and anomic to know that, despite the battles with mental health I have discussed above—which are not visible forms of disability—that many people view me as not being entitled to draw on discourses of (dis)ability to help me make sense of my own situations, even to myself.

So, when it comes to issues of privilege and issues of mental health, I constantly feel the crush of Alexandra Jaffe’s (1993, 65) ethnographic paradox: “I can neither escape nor completely take part in the politics of knowledge in the community I study.” My privileged body and precarious mind force me to participate in this discursive community, constantly wondering what tools I am entitled and/or “allowed” to use to make sense of my struggles, my challenges, and my successes to both myself and others. But even as I write this, I am afraid of appearing like another spoiled white male, complaining of a cut on my finger when others have entire chunks of flesh missing. Someone always has it worse. In fact, in this very article alone, someone has it worse. Inverse to Hannam-Swaim’s (2018) fear of appearing “too disabled”, I myself fear being advised to shut up, be happy that I was born in a privileged body, and that I am
“not disabled enough” (Lightman et al., 2009) to warrant complaint or reflection. How much
disability is enough? I don’t know. And I wish someone was able to tell me.

What I do know is that both the first author and myself sit on either side of the “formal
disability” line, textually reaching out to each other across a chasm of struggle and privilege. The
only constant in both contexts is our strained, collective attempt at reconciling our successes,
privilege, and permanent/temporal (dis)abilities. We feel the difficulty in trying to “settle” our
identities, constantly agitated by outright and implicit accusations of success because of our
white, male straightness, and (in the second author’s case) being “not disabled enough”. We
suggest that this constant movement, this back and forth of negotiating privilege and disability—
ever really being able to find a satisfactory fusion of the two—culminates in a privileged,
non(disabled) self. We share this self, though it manifests for each of us in fundamentally
different ways. Echoing the first author, I encourage others with similar invisible barriers to
share how a privileged, (non)disabled self problematizes taken-for-granted assumptions about
how privilege and (dis)ability intersect.

**Conclusion: Coping with a Privileged, (Non)disabled Self**

Using autoethnographic methods, we have identified how and why we both find it
incredibly difficult to “settle” into an identity when we are constantly at war with ourselves, and
with others, in negotiating the boundaries of how we can discursively construct ourselves in the
academic world. In this struggle, we have oscillated between disability and non-disability. But to
be clear, neither of us has been implicitly or explicitly discriminated against in the way that
racialized, gendered, or visibly/physically disabled persons experience, sometimes daily. We
make no claim to knowing how these discriminations, both conscious and unconscious, feel and
impact the psyche of someone trying to find success in academia or elsewhere. Let it be known
that we both absolutely “pass” as fully privileged bodies and individuals with nary an obstacle to
our names. But we should add this thought offers little solace while in the midst of a psychotic
break and/or a psychological episode that is, put simply, scary. It is terrifying to live through. It
is petrifying to think that these episodes may revisit us. And, most of all, as the first author has
demonstrated through his experiences, it is scary to think of the potential fallout if and when that
happens.
We are reminded here of how Denzin (1992, 91) describes how shifts in identity “from one social world to another” occur through epiphanic experiences and ruptures. In exploring these moments of constant self-transition—that is, this discursive game of back-and-forth between disability, ability, and privilege we constantly play—we have revealed and prodded what is usually taken for granted in relation to normativity and privilege (Galvin, 2005). We have proposed the concept of a “privileged (non)disabled self” to capture how researchers become entangled in permanent or temporal disabilities while simultaneously negotiating their successes, challenges, and accomplishments. Our narratives remain in a continual state of self-reflection as we work out who we are while acknowledging that our stories are relational and therefore being understood by observers in ways we cannot fully fathom or account for (Scott, 2013). In attempting to carve out a coherent self, we recognize that our narrative may contain examples of dominant discourses, however in choosing to become vulnerable we have sought to create a sense of community with other researchers whose invisibilities make up the very fabric of their lives (Kattari et al., 2018).

During the process of this article’s review process, one referee astutely asked us to consider the ways that this very article renders more visible our disabilities—something we individually thought about but did not explicitly discuss until prompted. In short, our feelings on this issue are mixed. Rendering ourselves vulnerable through text is something of a double-edged sword. On the one hand, our ability to “pass”—and with such flying colours, as white, straight, heterosexual men—will necessarily change if and when our colleagues, friends, and family decide to read this article. There might be a shift in the way that our networks use a “discourse of difference” to make sense of our behaviours (Riddell & Weedon, 2014, 43). One example—which is something that we have discussed at length ourselves—is that our ability to find success in writing and publishing is borne of the same forces that cause us our “craziness”. There is some discomfort involved in laying bare the internal conflicts we have faced during our dissertation programs, especially if it leads to others treating us or thinking of us as “crazy”. However, we believe this is a fair price to pay for the hope that this article will effect some change in the conversations we have around privilege and (dis)ability. Our experience with academia is that others’ assumptions of being privileged can paper over the profound gaps we both fear and experience in our overall well-being and in the continuation of our already unstable identities as “becoming-academics” (Aitchison & Lee, 272). We hope that by exposing some of the internal...
lives we have lived, we also expose invisible obstacles to ability writ large, and that these may begin to circulate in the thoughts and discussions others have about us—and by extension, others out there who are like us. It is not an expectation, but an honest plea.

In closing, identity negotiation affects our relationships with participants, colleagues, families, and friends, and thus we encourage researchers not to sideline their reflections on privilege and disability as irrelevant (Brown & Boardman, 2011). By reflecting on the normativities we subscribed too in the neoliberal academy, we were able to reveal a strategy for emancipation (Galvin, 2005). We are no longer confined to the identities ascribed to us in processes and encounters with relationality, but through autoethnographic writing, we have taken control of our narrative to reveal personal senses of imbalance, breakdown, and resiliency. It is in these moments of rupture that we have swung back and forth on the pendulum of oppressor and oppressed, thus complicating the tendencies of others to affix labels of privilege as always/already static and unchanging. Within this space of dissonance we have likewise exercised our capacity to identify ourselves as subjects, define our own reality and identity, and tell our story (bell hooks, 2015). If disabled identity functions as the “pivotal turning point to the norm” (Galvin, 2005, 408), we have tentatively accomplished this by exposing invisible vulnerabilities as well as the external, structural, embedded oppressions that continue to shape ontology.
References


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