

NANCY LA MONICA

SURVIVING OR THRIVING IN ACADEMIA: AUTOETHNOGRAPHIC ACCOUNTS
OF NON-VISIBLY DISABLED GRADS' EXPERIENCES OF INCLUSION AND
EXCLUSION

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Abstract

Using autoethnography, combined with qualitative data collected through innovative online methods, this dissertation explores the experience of navigating the emotional geographic space of graduate school for non-visibly disabled students such as learning disabilities, and mental health disabilities at two southern Ontario universities. Autoethnography merges tenets of ethnography and autobiography to allow researchers to prioritize their own experiences as valuable data and “making it possible to construct the ethnographic scenes that happened and the fictional scenes that didn’t—but could have” (Ellis, 2004, p. xx). As such, the work produced by autoethnography is “expressive rather than representational” (Kiesinger, 1998, p. 74) This dissertation is a narrative based on real and fictionalized events told through dialogue between the author, a composite character, and six co-participant graduate students who provide their stories through e-mails and a collaborative blog. Academic literature, observations, areas for future research, and recommendations are woven into the dialogue and layered throughout the dissertation in non-dialogic sections. Davidson and Milligan (2004) posits, “Our emotional relations and interactions weave through and help form the fabric of our unique personal geographies” (p. 523). By focusing on unacknowledged and misunderstood “emotional labor” (managing emotions in paid work environments) and emotion work (managing emotions in unpaid work environments) (Hochschild, 1983), this dissertation demonstrates how non-visibly disabled students must perform “extra work” that distinguishes their experiences and the effort required to navigate the spaces and places of

academia. With a specific focus on the process of acquiring and implementing academic and workplace accommodations, it draws on the literatures and theoretical insights of emotional geography and critical disability studies to demonstrate how these disabilities are misunderstood and stigmatized, which results in an accommodation process that is both humiliating and inadequate to support non-visibly disabled graduate students. Thus, understanding the emotional geography of the accommodation process is vital to creating effective academic and workplace accommodations for non-visibly disabled graduate students.

Acknowledgements¹

And just like that, it's over! I passed D-Day—final defense day—or what I commonly referred to as “the death of me”!

To celebrate, Mom and Dad surprised me with a Rocky (Balboa) themed party—yes, there's even a Rocky cake that stands at least 16” tall. I'm overwhelmed with everyone that filled the room. I usually don't like to be the focus of attention, but surviving D-Day is a huge milestone, so I'm excited my folks invited everyone who accompanied me on this journey. This is everything I could have imagined it to be.

My niece and nephew, Tessa and Julian, are the first to greet me, rushing over to hug me. Right behind them are my brother Paul and (his wife, my sister-in-law) Sandra. I am so happy I'm having a hard time holding back my tears. They both reach in for a hug, “Congrats sis!”

Bonita is awaiting a few steps away with the biggest smile on her face. I know she's just as relieved as I am that this is finally over. “I couldn't have done this without you, B. I'm still not sure how I survived, but you definitely helped me pull this together. Thank you from the bottom of my heart!”

Standing beside her is my supervisory committee: Vera, Ann, Rob, and Geoffrey. “Group hug anyone? I know this thesis was challenging at times, especially since I didn't do anything in a ‘traditional’ academic way, but you each believed in me enough to support it and here I am. Your feedback throughout this process has been invaluable. Thank you for supporting me through this work.”

I reach in to speak with Ann and hug her again. I can't defeat the tears. They roll down my face. “I couldn't have made it without you. The countless Skype sessions, coffee meetings, and email check-ins got me through, especially since the crash. There were many times I was ready to just give up, but you assured me that this would work out, and sure enough, it did. There are simply no words for me to describe what you mean to me. I look forward to your continued mentorship and our friendship, Ann.”

Standing next to Ann is Karen. “*A refreshing read,*” I excitedly say to Karen, as I reach in for a hug. “Thank you so much for such a glowing review of my work and for making my defense an outstanding experience. I am really blessed to have had you as an external.”

Next up are Fady and Chels and another group hug! “I couldn't have asked for better friends. Fady, there are simply no words to describe our friendship. We've shared tears,

¹ This scene, in keeping with the rest of the dissertation, is also creative non-fiction and never actually happened.

laughter, and even moments of wanting to throw each other off a plane or train around the world. I would never change ‘us’ for anything.” I turn to Chels and say, “The same goes for you friend, minus the throwing each other off a plane or train bit. Your friendship and support means everything to me. I didn’t think I’d make it this far, but you assured me that I would get here even after all the times I called you a liar. When I was at my lowest points during the process, you said I would get through this. Guess you’re not a liar after all!”

It’s at this point that the tears just begin like waterworks. *Where’s the tissue?*

To my right, is Halifax. I walk over to her as I see Stan is taking a nap. Halifax gives me the biggest hug and I say, “Thanks Halifax, you always believed in me from the minute I met you during my undergrad. Your support, mentorship, and friendship mean everything to me. Talking to you before my defense was so reassuring—your hidden pink labour never goes unacknowledged, at least not to me.”

I feel a sudden tap on my shoulder and hear a familiar voice: “Can I get a hug too?” “Oh my gosh, Tony! You’ve been such a source of inspiration and you’ve never let me down since the day I met you three years ago in Texas. Throughout this process, you always made time for me. Thank you so much.” Seeing Tony has me thinking about Carolyn, Art, and Lisa, whose work has influenced how I wrote this thesis. Of course, I can’t forget Patricia—she always has something motivating to say. Her creative knowledge sharing and support has helped me along the way. Thanks Patricia!

I get another tap on the shoulder, “Nanc, I told you, you got this!” “Kim, thanks for being an incredible sounding board when I needed one. I appreciate you taking the time to read and comment on various drafts. I turn around and see Sheila smiling away at me. I reach in for a hug. “Oh my gosh Sheila, we’ve been through a hard road together for almost two years now, and I couldn’t imagine making it through without you. Thank you for your friendship.”

As we near the end of the night, I decide it’s time to make a toast to thank everyone. I can’t possibly get to each and every one of my family and friends, who has come out to celebrate with me. I could be here for hours and I am too exhausted to even try:

Friends and colleagues like Jenny, Stacey, Maria, and Susan. Thank you for reading various drafts of this work and offering critical feedback. Susan, I appreciate all the help you offered me as I prepared for the defense. You made this process a lot less anxious for me. Friends like Alexis, Kat, Katie, and Keri. You’ve been there for me through some of the hardest moments of this journey. I am thankful that I had you to lean on when I needed to vent, cry, or just needed a good kick in the ass! I sure am lucky.

To my long-time supporters and friends like Carmela, Elena, Silvia, Annette, Lori, Tania, Tina, Sheryl, Neita, Caro, Carmelo, and Laura. You are amongst the list of people who

have been rooting me on since I was accepted into my doctoral program. I really appreciate your never-ending support. I laugh as I recite the most memorable text I received from one of you, “Nancy I have every confidence that you're going to kick ass at this. You don't know how to fail.” You were right! Thanks for all of your support, especially near the end.

I simply can't formally to get to everyone. Instead, I pick up my glass of Baileys, as I fight back tears, and ask for everyone's attention. I clear my throat and begin my toast:

“To each and every one of you here today, both near and far, especially those of you who have privately messaged me on Facebook to cheer *me on*, and cheer *me up*, for the Rocky memes you shared on my page, for the endless messages of ‘YOU GOT THIS!’; to all my family especially my aunts, uncles, and cousins, who have supported me along the way despite me giving you the dirtiest of looks every time you asked: ‘So you done school yet?’; and to my angels in the sky who never gave up the good fight; and mostly to my Mom and Dad who have never stopped believing in me. I wouldn't be here without your love and support. Dad, you can now say you have a ‘doctor’ for a daughter,” I joke as I smile at him knowing full well that both my parents still have no idea what a PhD is, but they sure are getting close, “I love you more than you could imagine!

By this time, I'm really getting choked up. I'm not one who enjoys all this attention, but tonight I am soaking it all in. I continue,

“I cannot forget to thank my new-found supporters who've accompanied me on this rollercoaster ride since the crash, like Yvonne and Sandra. You two have believed in me since the day I met you. I especially appreciate all the laughs. I'm so grateful that you came into my life when you did.

“Thank you Umesh for all of your support during my time in grad school. Also, thanks to Debbie, Kathi, Justin, and Kristen. You've been an invaluable team to work with.

“A special thanks to Shauna! You've helped me through some of the hardest decisions I had to make since the crash. I'm especially grateful of the nurturing support you gave me when it came time to take a medical leave from my studies, despite my kicking and screaming.”

Phew, I am almost near the end of my speech. Before I conclude, I have to take a minute for the finale as I sip back the last drops of my Baileys, wiping the tears rolling down my face. I kneel down to my niece and nephew; they've been standing right beside me the whole time. I clear my throat and turn to them and say,

“And finally, to my two favourite little humans to whom I dedicate my thesis: Tessa and Julian! I love you to the moon and back. I hope that one day you will read my work and be proud of your Zia. I hope this work will ignite the fuel in you, as it has in me, to

believe in yourselves, and to believe that you can accomplish anything you want in life, with the right supports in place. School is tough, but life is not easy. School never came easily to me, but I had the drive and passion, and I hope that you will remember how much work it took for me to get here and know that you can do it too. I will always be here for you two, in the same way that you've been here for me. Tessa and Julian, you truly inspire me to keep fighting. I love you for the strength you give me each day." I kiss them each both on their cheeks and foreheads before getting up and raising my glass one last time.

"This is it, I promise. This doctorate wouldn't have been possible without Dakota, Sam, Rowan, Morgan, Drew, Amy and of course, Jules. Thank you from the bottom of my heart."

I got this!

With love,
Nanc

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Tips for the Reader

- All participants came from two different Ontario Universities. They have included experiences in other universities in their conversations with me as well. So as not to compromise their anonymity by referring specifically to any university, I use the term “a university” or “the university” throughout.
- Data from co-participants and key informants were collected with online methods through blogging (co-participants) and e-mail interviews (key informants). I purposely use gender-neutral pseudonyms for all characters except one co-participant whose experience as a nursing mother was germane to the study. I use my own name for myself. I also use plural pronouns” to further protect the identities of those in this small sample of co-participants and key informants. For more information, see Jacob Tobia’s (May 16, 2016) “Everything you ever wanted to know about gender-neutral pronouns” (<http://motto.time.com/4327915/gender-neutral-pronouns/>).
- When a pseudonym appears in bold, capital letters, this indicates that the material is taken directly from the collaborative blog used to collect data.
- All transcripts from co-participants and key informants are presented verbatim with no editing for grammar or spelling, nor are errors indicated by (sic). My intention was to allow all participants, including myself, to express our stories without having to worry about grammar and spelling.
- I use asterisks to denote a shift in time, place, and tone, which allows me to weave considerations from the literatures of emotional geography and critical disability studies throughout the narrative (Ronai, 1995).
- Italicized text is used to represent the author’s internal dialogue, titles of books, and occasionally for emphasis.
- I use footnotes rather than the in-text author/date system of APA style so that in-text citations do not disrupt the narrative. Within the footnotes, however, citations follow APA style, as does the Reference List. Deviations from APA style are intended to conform to the dissertation requirements of McMaster University.

Prologue: Setting the Stage: Graduate Students' Disability Accommodation

*Grad accommodations are a joke!*²

No, I can't start my thesis with that statement, although I'm not denying the fact that I certainly feel the same way Jules did when we spoke for the first time about my project.

How should I begin, then? I need a beginning, right? OK, how about starting with a bit of background? That seems like a logical place to start. Maybe I'll save "*Grad accommodations are a joke!*" for the end. It's certainly powerful and I know it has a place in this thesis.

A place will come.

It always does.

² Before I continue to tell this story, I must acknowledge the use of style and language in this study and in my work. Regarding style, I use italics to indicate my inner voice. Regarding language, I use a critical disability studies perspective, employing the term "impairment" as Neville does "to draw attention to the bodily struggles involved in participation in everyday activities" (Neville-Jan, 2004, p. 115). I concur with Pothier and Devlin (2006) that "[a] primary concern of critical disability theory is an interrogation of the language used in the context of disability" (p. 3) in recognition of the concept that disability stems from social structures and attitudinal barriers that locate the problem of disability an individual's problem to be fixed (Oliver, 1996, pp. 32-33). I use the term "disabled people" instead of person-first language (see Barnes, Mercer, & Shakespeare, 1999) because, as Barnes and colleagues explain, people with disability "implies that the impairment defines the identity of the individual, blurs the crucial conceptual distinction between impairment and disability and avoids the question of causality" (p. 7). Using the phrase "disabled students and/or persons" demonstrates that students are disabled by society, not by their individual impairment (see Barnes, Mercer, & Shakespeare, 1999; Oliver, 1996; Morris, 2001; Wendell, 2001). As Pothier and Devlin (2006) explain, "we do not speak of 'persons with a gender' or 'persons with a race'" (p. 4). Finally, for the purposes of this paper, I use "impairment" and "disability" interchangeably as "embodied disability" to encompass all aspects of the person's emotional, mental, learning, and physical disabilities (impairment) as well as the geographical and social spaces and places in relationship to contexts of disability (disability). Impairment and disability cannot be separated from one another because they shape the experiences of individuals, groups and communities. Even if social or physical barriers are removed, there are still individual barriers and limitations, which I refer to the ways in which people "embody disability."

OK that settles it then, I'll start with the legislation landscape of disability accommodations. I'll write about how anti-discrimination legislation has increased the number of disabled persons pursuing degrees in places of higher learning.³ That sounds good. But I have to mention that we can't ignore that disabling barriers continue to limit access to accommodations that are intended to enable students' full inclusion.^{4, 5} Of course, I explain how non-visible impairments, such as learning disabilities, mental health disabilities, and chronic illness⁶ are the most prevalent disabilities documented among university students in academic spaces.⁷ And how learning disabilities and mental health disabilities continue to be highly stigmatized and frequently misunderstood by others (such as peers and professors) as excuses used to take advantage of the system.⁸

What remains unclear is how disabled students pursuing graduate degree programs experience spaces of academia as inclusionary, exclusionary, or both. From my

³ See Organisation for Economic Co-operation and Development (OECD), 2003; Rose, 2009.

⁴ Olkin, 2002.

⁵ Ontario's initiative to identify barriers to disabled people in our province, defines "barriers" in the Accessibility for Ontarians with Disabilities Act, 2005 (AODA) as follows:

"Barrier" means anything that prevents a person with a disability from fully participating in all aspects of society because of his or her disability, including a physical barrier, an architectural barrier, an information or communication barrier, an attitudinal barrier, a technological barrier, a policy or a practice; ("obstacle") (S.O. 2005, Chapter 11, 2).

For disabled students, *The Opportunity to Succeed* concluded that barriers to equal opportunity to higher education include, but are not limited to: (academic) accommodations that are "based on budgetary considerations rather than on an assessment of the actual needs of students with disabilities"; "delays in accessing accommodations" due to inaccurate or untimely information sharing; negative perceptions surrounding disability that create systemic barriers of accessing equal education that is available to their non-disabled peers, etc. (Ontario Human Rights Commission, 2003).

⁶ McCloy and DeClou (2013) explain, "The prevalence and needs of students with disabilities vary greatly. Provincially reported data from disability service offices in Ontario PSE [Post Secondary Education] institutions indicate that the three most common disabilities are learning disabilities, followed by psychiatric disabilities and chronic illness" (p.14). These figures do not include students who do not register with disability; as such, do not represent all disabled students.

⁷ OECD, 2003.

⁸ Damiani & Harbour, 2015; Denhart, 2008; Devaney, 2008; Farrar, 2004; Farrar, 2006; Low, 2009; Titchkosky, 2003; Titchkosky & Michalko, 2009.

own research, few studies highlight the frequency and various types of lived experiences non-visibly disabled graduate students in Canada negotiate when they try to receive accommodations. This missing information suggests that the voices of disabled students continue to be absent from the literature.⁹ As we know, research on disabled post-secondary students has tended to focus on undergraduate students.¹⁰ If these voices are not present, how can they be heard?

Little attention has been given to the complexity of the lived experiences of graduate students as they play both the roles of student and paid academic employee.¹¹ Because graduate students are often also employees of the university as they fulfill their academic requirements and are provided funding in the form of teaching and research assistantships, the issue of the dual role is critical. The research on disabled graduate students indicates that support and accommodations such as “reduced teaching loads while studying, valuing doctoral research as fulfillment of research workload, reduced or eliminated committee responsibilities during critical times in doctoral studies...”¹² are pivotal for academic success.¹³

What counts as “reasonable accommodations” has been, and continues to be, a contested issue between disabled students and academia. In several pieces of legislation, the use of the term “reasonable accommodations” refers to anything that intends to balance “the duty to accommodate” and “the duty to protect the academic integrity of the

⁹ Denhart, 2008; Duquette, 2000; Farrar, 2004; Farrar, 2006; Fuller, Healey, Bradley, & Hall, 2004; Hutcheon & Wolbring, 2012.

¹⁰ Denhart, 2008; Duquette, 2000; Fuller, Healey, Bradley, & Hall, 2004; Low, 2009.

¹¹ Damiani & Harbour, 2015; Dunn, Haines, Hardie, Leslie, & MacDonald, 2008; Olkin, 2002; Rose, 2009.

¹² Dunn, Haines, Hardie, Leslie, & MacDonald, 2008; “Employment Equity and Supports” para. 4.

¹³ See also Farrar, 2004; Olkin, 2002; Ontario Ministry of Education and Training, 1998; Rose, 2009.

institution.” Indeed, this balance is most often subject to the interpretation of the educational service providers.

No matter the interpretation, though, Canadians legally have rights to obtain an equal opportunity to higher education: “Section 1 of the Ontario Human Rights Code guarantees the right to equal treatment in education, without discrimination on the grounds of disability, as part of the protection for equal treatment in services.”¹⁴ Under provincial jurisdiction, the Ontario Human Rights Code (*Code*) stipulates that educational service providers have a “duty to accommodate” —short of undue hardship¹⁵—the educational needs of disabled students by providing “reasonable accommodations.” The *Code* urges that “accessibility goes beyond physical accessibility, to include accessible curricula, and delivery and evaluation methodology, as well as the provision of the necessary supports and accommodations to ensure that students with disabilities have equal opportunity to their education”¹⁶ Indeed, the fundamental right to access higher education is contingent on academic accommodations and individualized support. Disabled students pursuing graduate studies are neither strangers nor exceptions to this legal mandate.

In her work, Rhonda Olkin highlights that “Students with disabilities often have additional requirements to be successful in graduate school, and they frequently face

¹⁴ OHRC, (n.d.) para 3.

¹⁵ Stephenson, Tiffin, Nichols, Harrison, McCloskey, & Weintraub (1992) explain that, Undue hardship may be claimed on the grounds of excessive costs, as defined in the Guidelines and/or endangering the safety of individuals or groups. In an educational setting, undue hardship may be claimed on the grounds of maintaining the integrity of the programme or the institution. However, it is important to note that the traditionally cited issue of “academic freedom” for faculty is not enough to claim undue hardship and deny accommodations to students with disabilities. (p. 12).

¹⁶ OHRC, 2003, p. 46. See also Farrar, 2004.

barriers in their pursuit of a degree.”¹⁷

Other research similarly indicates that for non-visibly disabled students to succeed in their academic careers, they must be well informed about how their impairments and disabilities can affect their learning and about how the university can help them.¹⁸ I was well informed about my disabilities and knew exactly what I needed, but I was met with resistance and, consequently, a lot of added, extra work when I made my needs known to a university. My research is intended to fill the gap in our knowledge about the experiences of non-visibly disabled graduate students by exploring how these students negotiate both academic and workplace accommodations.¹⁹ Specifically, my research focuses on aspects of the ‘extra work’ that non-visibly disabled graduate students undertake in negotiating accommodations.²⁰

I consider extra work as tasks and additional responsibilities that disabled students undertake to ensure their full participation in university, which requires added effort, time and consideration. Moreover, these responsibilities are conceptualized as ‘hidden’ insofar as they are not formally recognized as “supplementary work” by various social actors at university such as professors, counsellors and peers.²¹

¹⁷ Olkin, 2002, p. 68.

¹⁸ Trammell, 2003.

¹⁹ From here on forward, unless otherwise indicated, I will refer to “accommodations” to include both academic accommodations, by which I mean accommodations to facilitate the grad student’s learning (e.g., extra time to write exams) and workplace accommodations, by which I mean accommodations associated with teaching, research and graduate assistantships (e.g., reduced teaching workloads).

²⁰ Olkin, 2002.

²¹ Jung, 2003.

Performing the role of a student involves work, defined as “...the application of mental or physical effort to a purpose; the use of energy”.²² In the case of the additional work that disabled grad students perform, this effort is often not understood as work, but rather as a set of responsibilities necessary for achieving the end result to earn their degree. For disabled students, performing the student role involves extra, hidden work “that might not ordinarily be observable or reportable as work”²³ but rather as their added responsibilities if they want to achieve their education in the academy.

I focused my study on non-visible disabilities, such as learning disabilities and mental health disabilities, because these disabilities continue to be highly stigmatized and frequently misunderstood by others (such as peers and professors) who regard students so labelled as taking advantage of the system.^{24, 25} They are also among the most prevalent disabilities documented among university students.²⁶

For the purposes of this study, non-visible disabilities include, but are not limited to, mental health disability (such as attention deficit hyperactivity disorder [ADHD], depression, anxiety), acquired brain injury (such as a concussion), and learning disabilities (such as dyslexia). Such impairments might affect one’s perceived academic abilities, which might impact academic performance, workplace performance, or both (regarding reading, writing, processing speeds, memory, time-management, and organization) as compared with students who do not have these disabilities.

²² Barber & Pontisso, 2005, p. 1354.

²³ Jung, 2003, p. 95.

²⁴ Denhart, 2008; Duquette, 2000; OHRC, 2003; Titchkosky, 2003.

²⁵ As Maureen Reed, Tanya Lewis and Eunice Lund-Lucas (2006) point out, disabled students feel that their professors did not fully understand their educational needs and “did not respect or help with their accommodations” (under “Difficulties related to learning disabilities”).

²⁶ OECD, 2003.

In this study, non-visibly disabled graduates students are defined as students pursuing graduate degree programs who embody impairments that are not visible to an observer unless otherwise specified or declared. Participants could include non-visibly disabled graduate students working as teaching assistants (TAs), research assistants (RAs), or course instructors during their graduate degree and students who did not hold teaching or research assistantships.

I focus on non-visibly disabled graduates students, because of my own lived experiences of disablement in the academy.

The I in “Dissertation”

This study explores the processes of disablement²⁷ in academic spaces with the assertion that non-visibly disabled students’ participation involves extra work, for example, in the form of educating others on their right to accommodations and the tasks associated with seeking accommodations on their own.

My position in relation to my research is an integral aspect of the research itself.²⁸ My research explicitly includes my personal and professional experience as a non-visibly disabled graduate student TA, RA, and course instructor at a local community college. As such, I am both a researcher and co-participant in my project.

²⁷ Borrowing from Crooks and Chouinard (2006, p. 346, as cited in Chouinard, Hall, & Wilton, p. 55), I use the concept of processes of disablement to include: “embodied processes of becoming and being ill in place(s) and over time in ways that they have disabling outcomes for individuals” but also to include how disabled persons re-negotiate their place. For example, in the context of academia, Low’s (2009) findings indicate that disabled students negotiate three types of identities when negotiating the physical environment on the university campus. These include processes of “negotiating environments”, “negotiating disabled identities” and “negotiating non-disabled identities” (p. 236). The processes of negotiating the physical environment is useful in understanding how exploring experiences of both non-visibly disabled and visibly disabled students offer insights that are applicable to ensure the physical environment does not only address removing structural barriers, but to also recognize the social aspects of disabling society.

²⁸ Ellis & Bochner, 2000. See also Rose, 1997; Seear & McLean, n.d.

My personal experience with disability is included in my project as epistemology, along with that of the co-participants. I have epistemic privilege having lived with the very kinds of disabilities I examine in the context of accessing academia. Having further regard to my location as a non-visibly disabled person, I consider myself to be both privileged and disadvantaged. I am privileged as a white, cis-gender female with access to higher education. I am also privileged not being visibly disabled by markers on my body or by assistive devices, (though there is nothing invisible about my disability to myself). I am disadvantaged for a number of different reasons, among them the extra work I must do to navigate academia in ways that non-disabled students do not.

As for methodology, I have chosen autoethnography.

Just as I'm about to finish typing the next line, I slam my hands on the table, raising my voice, "I wanna throw out my laptop."

"Yeah, whatever Nanc! We both know you wouldn't do that. What's going on?"

Jules pulls out the chair in front of me, about to take a seat, before noticing that I've already covered the chair with more books. I seemed to have hijacked not only two tables at Francie's Coffee Shop,²⁹ covering one with textbooks and the other half with manila folders filled with notes and transcripts, but also a number of chairs as well.

"I just can't get this to work. I'm trying to write the introduction to my thesis. But it's sounding too damn formal. I don't like it. I have to start writing about autoethnography, and I'm not quite sure what the problem is. I've got autoethnography under my belt, or so I thought. But this type of formal, traditional, academic writing is not

²⁹ Francie's Coffee Shop is a fictional name.

what I envisioned for my dissertation. I'm not sure I can pull off writing 300 pages like this. What the hell am I doing here? What was I thinking when I applied for a doctorate? I should have just applied for Teacher's College like I originally planned."

"Just calm down. You're freaking out! You're so close to the finish line that you're letting your anxiety get the best of you. Close the computer."

"Close the computer?! Seriously, do you ever listen to me? I can't write and you want me to close my computer? I have a thesis to finish."

Jules's laughter quietly turns into a stern look. "Are you done with your pity party now?"

Without saying a word, I move my cursor to the Apple icon, put my computer to sleep, and push it aside.

"Good, now that I have your attention I want you to think about this: In an ideal world, if you could write your dissertation in another way, how would you do it?"

"Oh that's easy! I'd write it the way Carolyn Ellis writes her novel *The Methodological I*. She says, how did put it? Something like using autoethnography to "merge ethnography and fiction."³⁰ I'd start by re-creating the scene of when we met at Francie's Coffee Shop—remember that time when I borrowed a pen from that couple beside us?"

"Yeah. They looked pretty annoyed with us."

"Still, it was funny. I mean we did hog two tables and chairs and covered them with stacks of books and our laptops, much like we are doing now. It didn't help that neither of

³⁰ Ellis, 2004, p. 332.

us had a pen. You were like, ‘what the hell is auto-ethno-what?’ And I was like, ‘do you have a pen?’”

“Yeah, I remember that. Really what’s up with you and pens anyway?” Jules laughs.

“I’m not sure.”

“OK, take me through that conversation again. How did you explain autoethnography to me then?”

“You got a pen on you?” I laugh.

“Seriously?”

“OK, I remember I had pulled out Ellis’s novel, *The Methodological I*, as I thought back to how she described ethnography to her students in Class Two. I reached for a couple of brown napkins from the empty table beside us and scribbled the words ‘ethno’ on one, and ‘graphy’ on the other, just like this. You know I’m a visual learner, so bear with me here as I re-create this scene.³¹

“No worries. Take your time.”

I pause.

“Yeah, that’s it! I remember I read you a line from her book—I use it in almost all my work. Ellis writes,

Ethno means people or culture; *graphy* means writing or describing. *Ethnography* means writing about or describing people and culture, using firsthand observation and participation in a setting or situation. The term refers both to the process of

³¹ Ellis calls this “emotional recall,” which will be further explained in Chapter Five: Methods (Re)Considered, p. 173.

doing a study and to the written product.³²

Then, I wrote the word *auto* on a third napkin. *Auto* means looking from the inside, through a reflective lens similar to the ways we'd write for autobiographies. So, when I put all three napkins next to each other, it reads *auto, ethno, graphy*.

Ann Neville-Jan recommends “using autoethnography as a method of understanding disability as embodied.”³³ She writes, “Autoethnography also situates me amid discussions in disability studies that argue for a ‘turn to impairment’ (Goodley, 2001, p. 208), a recognition that the personal experiences of impairment are just as significant as the structural dimensions of disability that are represented by the social model.”³⁴ The notion of embodied disability that I develop attempts to create an understanding of disability that is as complete as possible. Embodied disability does not deny that disability is a social construct, created by social barriers. Rather, the concept of embodied disability explores the fluid and malleable spaces where disabled people negotiate and navigate social barriers, medical realities, lived experiences—both emotional and physical, and identity. For the non-visibly disabled graduate student, for example, accommodations may remove one kind of barrier (time limitations), while creating another (such as stigma or self-doubt). Nancy Hansen and Chris Philo write about embodied disability like this,

Understanding the embodied reality of disability in everyday life is crucial, and we

³² Ellis, 2004, p. 26, (emphasis in original). See also Ellis, Adams, & Bochner, 2011 (emphasis in original, under “History”).

³³ Neville-Jan, 2004, p. 113.

³⁴ Neville-Jan, 2004, p. 114.

need to ask about how the people concerned ‘notice’ their impaired bodies when seeking to go about their daily business (going to work, attending classes, using shops, cinemas or parks, taking a child to the swings). Their embodied ‘art’ of managing the time, space and speed realities of ‘doing’ daily living demands more recognition than it usually receives, and Hansen’s research furnishes detailed accounts wherein the most microscopic planning (of the timing and spacing) of (the seemingly most banal) activities is highlighted by her respondents.³⁵

Borrowing from Ann Neville-Jan, working “as both a researcher and a research participant, requires self-reflexive texts, ones that examine my values and preconceptions.”³⁶ I use autoethnography to explore my own experiences of embodied disability to examine the complexity attached to being a disabled grad student negotiating academic and workplace accommodations. As Smith and Sparkes explain “the body is a storyteller, and it is partly through the tales it tells that we may interpret, give meaning to and understand bodies.”³⁷ This includes the emotional, added work that disabled students do that is not required of other students (with respect to disability issues) to participate fully in academia.

As such, emotion work and emotional labour³⁸ is an integral analytical tool in my study. My interest in this study is to “convey the *meanings* [I] attached to the experience”³⁹ of negotiating spaces in academia. As both a researcher and co-participant, I want to share my lived experiences. As Ellis and Bochner⁴⁰ explain, the idea is to “evoke my readers to feel and think about your life, and theirs in relation to [mine]. You’d want them to experience the experience you’re writing about....”

³⁵ Hansen & Philo, 2007, p. 497.

³⁶ Hansen & Philo, 2007.

³⁷ Smith & Sparkes, 2008, p. 19.

³⁸ The notion of emotion work and emotional labour will be further discussed in Chapter Two: Theorizing Over Coffee.

³⁹ Ellis & Bochner, 2000, p. 751, (emphasis in original).

⁴⁰ Ellis & Bochner, 2000, p. 751.

“Why don’t you write the scene in which you explained autoethnography to me as part of your chapter?” Jules asks.

“You mean narrate my process?”

“Yeah, why not?”

“Actually, it’s funny you say this. One of the things I told my committee from the beginning is that I don’t want my research to sit on a shelf unread, collecting dust. I don’t want to—and simply can’t—write this as some boring report. I want to be creative while writing for social change.”⁴¹

“I have to admit, that sounds like fun, but isn’t academic work supposed to be, you know, boring? I mean, who’s going to take this seriously if you write this in a fun, creative way?”

“But who says research has to be boring? I think I told you about Patricia Leavy. She does arts-informed research. She wrote *Fiction as Research Practice: Short Stories, Novellas, and Novels*. I’ll bring it the next time we meet. Patricia cites Caulley’s work. Caulley argues that qualitative research doesn’t need to be boring.⁴² So why does my dissertation need to be boring—for me or the reader—especially if I want to make it accessible? Adams, Holman Jones, & Ellis, write,

- 1) To critique, make contributions to, and/or extend existing research and theory;
- 2) To embrace vulnerability as a way to understand emotions and improve social life;
- 3) To disrupt taboos, break silences, and reclaim lost and disregarded voices;
- 4) To make research accessible to multiple audiences.⁴³

“I’m making these decisions deliberately while attending to the writing process, in

⁴¹ See Bochner, 1997, p. 433; Leavy, 2013.

⁴² Caulley, 2008.

⁴³ Adams, Holman Jones, & Ellis, 2015, p. 36.

addition to the actual process of research.”⁴⁴

“This sounds interesting. Flaky, but interesting,” Jules says.

“Let me grab us some more java. Sounds like we’re going to need a top up? Jules, can you check out what I’ve started writing so far?”

“Sure.”

Introducing (and Explaining) Jules

Throughout this thesis, I speak with “Jules.” Jules isn’t real—well, no, that’s not really true. Jules is a composite character made up of the various lived experiences and stories of the co-participants, including me as a co-participant, who took part in the research study. Jules is the single voice that exclaims their experiences in a way that would not identify them.⁴⁵ Jules is the vehicle that gives a voice where disability is often not paid attention. Having said that, the co-participants mostly speak for themselves on the blog.⁴⁶

In addition, Jules represents other “voices”— those of colleagues who have given me their written permission to fold their words and dialogue into the making of Jules as a character. Leavy⁴⁷ reminds us that,

In the academic world, researchers are storytellers, learning about others and sharing what they have learned. Whether we go into the field in an ethnographic study or conduct oral history interviews, we are charged with telling the stories of

⁴⁴ Coylar, 2003.

⁴⁵ As Chang, Wambura Ngunjiri, & Hernandez (2013) explain, “Use of fictionalized retelling of the collaborative autoethnographic experiences is a good strategy for protecting not only authors but also others implicated in such accounts” (p. 126).

⁴⁶ More on this in Chapter Three: Discovering Autoethnography.

⁴⁷ Leavy, 2013, p. 35.

others in creative, expressive, dynamic, and authentic way. We may also be relying on our own autoethnographic experiences as data explicitly informing the stories we craft. Bud Goodall termed this “the new ethnography” (2000, 2008). When we represent and share our research, our goal is not simply to expose others to it, but to affect those who read our work.

Story-telling in this regards is narrating and living through the process of doing this work. For this reason, I position myself as both a researcher and co-participant.

Jules represents all I have learned about this subject matter through this research process, from my own experience before and after data collection, from the co-participants, from other colleagues, and from reading the literature and institutional texts (such as policies). Some of what Jules says is taken verbatim from the co-participants. I use verbatim quotes without attribution so that Jules becomes their voice at various times. Although, I use verbatim quotes⁴⁸ from the research blog, I sometimes paraphrase or reconstruct the scenes and dialogues not only necessary to protect the co-participants’ identities, but also to help to align the narratives with the particular themes being discussed.

I use gender-neutral names as an attempt to employ another tactic to ensure anonymity of each of the co-participants of the study. I asked co-participants on the blog to choose their own gender-neutral names to represent their character (Dakota, Morgan, Drew, Sam, and Rowan). One of the co-participants chose the name “Amy” to represent her character, which is not gender-neutral, despite a partial loss of anonymity for that participant. This name proved beneficial for Amy and me because we were able to speak

⁴⁸I have obtained permission in my ethics protocols (2013-009 and MREB 2012 185) to use verbatim quotes without attribution.

candidly about her experiences as a mother and of breastfeeding.

I, the researcher, and researched, chose the name Jules for reasons I do not want to disclose. “Nancy” is my own name.

I purposely use gender-neutral and plural pronouns “they” to reflect the experiences of people of all genders and to protect identities.

I recognize that the choice to use gender-neutral names achieves certain things (as noted above), but also means that I run the risk of not addressing issues of gender that can intersect with the space of academia—a historically gendered and exclusionary space for women and other minorities. Equally as important, I have not collected demographics on participants, such as race, age, class, sexuality, and so on, unless it was revealed during our discussions on the research blog. I left it open for co-participants to share how and if these experiences impacted their access to the space of higher education. Disabled students who have multiple marginalized identities can experience more barriers to accessing their accommodations.⁴⁹ My intention was that the intersectionality of disability with race, age, gender, and sexuality would arise in the writings produced for the blog.⁵⁰

Avery, Riley, Leslie, and Jamie are key informants; people I have collected data from during e-mail interviews about academic and employment accommodations in a university. Most of the dialogue is direct verbatim from each of these e-mail interviews.⁵¹

These are not composite characters, but rather individuals whose names have been

⁴⁹ See for example, Damiani & Habour, 2015.

⁵⁰ Richardson, 2000.

⁵¹ As will be addressed more fully in this work, all participants came from two different Ontario Universities and may have included experiences in other universities in their conversations with me as well. Also, the sample size for this study is small. It remains important to me not to compromise their anonymity by referring specifically to any university. As such, I will use the term “a university” or “the university” throughout.

changed to protect their identities.

As both the researcher and a co-participant of this study, I am a storyteller: learning about how others embody spaces of academia when negotiating impairment, disability, or both, and sharing what I have learned in telling and being in this story. This shared dialogue is an attempt to understand and create spaces of knowledge whereby we can learn through each other about identity, politics, research, and self-awareness or self-discovery.

This story is not only mine to tell.

I tell many stories.

Chapter One: The Pen Stops⁵²

“The pen stops? What do you mean the pen stops?” Jules interrupts the story just as I start telling it.

Taken by surprise, my mind wanders. My anxiety heightens as it often does when I share my experiences of being a person who is non-visibly disabled by and in academia. I catch myself looking over my shoulder to make sure no one is lurking. I’m careful not to name names even though we’re meeting at least 60 kilometres away from a university.

I’m not sure why I am worried about other people. Perhaps it has something to do with the feeling of being under surveillance, which I’ve felt since I disclosed my disability to a few of administrators at a university a couple of months ago. One administrator said, “I hear everything.”

And so, I feel watched, judged, oppressed in this place.

It is from this place that the story, my story, our story begins.

I start doodling in my notebook and I say, “Yes. The counsellor just stopped writing.”

I feel Jules staring at me with curiosity, waiting for me to continue. A sudden chill comes in from a draft that seeps from the front doors of Francie’s Coffee Shop. I need to pause. I ignore the stare by focusing my attention on the busy parking lot. I pick up my grande pumpkin spice latté, savouring each sip because doing so gives me a moment to

⁵² A version of “The Pen Stops” has been accepted for publication in Patricia Leavy (ed.) *Status Characteristics and Privilege in Daily Life: A Text-Reader*, Sense Publishers.

collect myself. I need time to process my thoughts before I say more about my own—often very difficult—experiences in academia. I learned to cope in stressful situations by drinking gulps of water and coffee when I am speaking in public, to slow down my speech, so I apply this technique in many face-to-face encounters. I worry about how others perceive me, so I'm careful about what I say about these experiences, and how I say it. I don't want to be accused of sounding dramatic. This is especially true when I speak to people with whom I've shared my disability. Unless you've experienced what I have at a university, I'll worry about how you'll respond to my stories.

To: lamonican@gmail.com
Re: Request for Research Participants

[...] I wish I had time to participate in your project because I think it's a very worthwhile and politically important project that may hopefully change attitudes around accessibility and dis/ability at [a university] and maybe other universities. As I'm sure you know from your other participants, it's hard being crip in school. This is exactly why I don't have time or energy to participate.⁵³

I'm disheartened. But I can relate to this potential participant. This is why I started this project for my dissertation. There are way too many students out there experiencing the extra work of being disabled, and I'm one of them. My research explores the experiences of non-visibly disabled graduate students by examining how they negotiate both academic and workplace accommodations. I plan to illuminate the processes of disablement in academic spaces with the assertion that non-visibly disabled students' participation involves extra work. I argue that this extra work requires laborious efforts, both

⁵³ Any e-mails shared in this dissertation have been done so with permission.

physically and psychologically for disabled students, and can be detrimental to their academic progress. For instance, disabled students must engage in time-consuming tasks associated with getting accommodated in the classroom and in their workplace. Such work can have physical costs when this exacerbates their impairments and disability by causing fatigue, for example. The physical manifestations of this extra work can also be emotional, threatening the student's self-esteem. Undertaking this kind of emotion work can affect a student's academic performance and might lead to academic burnout, even cause some students to drop out of their programs.⁵⁴ I write back,

To: anonymous student
Re: Re: Request for Research Participants

No worries. Concentrate on your health and studies. Take good care and keep me posted. If there is anything I can do, please feel free to contact me.

“Hi Jules. It's Nancy. I just got your e-mail. I'm so sorry to read that you can't participate in the study, but I completely understand.”

“Actually, I just couldn't handle academia anymore. My body took a beating. My health was compromised, and I tried to get medical leave. Twice in fact, but they gave me the runaround, and I just couldn't do it anymore. It really messed up my head. My supervisory committee was supportive: they wrote letters on my behalf and checked in regularly with me. But there was nothing more they could do to help.

Long pause.

“My psychologist was surprised to learn of my decision to drop out. He knew how

⁵⁴ Goode, 2007, p. 43.

much I wanted to complete my doctorate. He wrote a few letters himself and gave a detailed summary about how this was affecting my overall health. I couldn't focus on my studies anymore. I also ended up lashing out at my family and friends over the smallest things. I didn't feel like myself. But after my last bout of depression and increased medication I didn't want to be on, I decided it was time to give up.”

“What you're going through is the same story I've heard from other non-visibly disabled students regarding all the extra work they have to do to keep up. Sadly, it doesn't surprise me. I wish things were different and that there was an alternative solution, but I completely respect the decision you made. Self-care is so important. I'm not sure what to say other than, 'I'm sorry'. Is there anything I can do to help?”

“Actually, there is. That's why I e-mailed you. I thought about it, and I don't want to feel like all this work was for nothing. I know your study already started, but I'd really like to continue to help with your research. I'd like to offer any support I can. Maybe I can be your sounding board? I know how isolating doing a thesis can be. I wish I had turned to others for support.”

“Wow, thanks! I think this is great and so wonderful of you to offer. I could use all the emotional and intellectual support I can get. I could definitely use a sounding board. I do hope that I can help get your voice heard. Your voice represents so many. It's vital to share your story.”

From that day forward, we became comrades. We made Francie's Coffee Shop, our second home, to meet and discuss my work. Part of Jules's supportive role has been to play devil's advocate and push me beyond my comfort zone in an effort to make my work

better and, at the same time, provide emotional support on this journey.

Focus Nancy. Get back to how the pen stops. I'm having a hard time holding much of any focus today. My mind keeps wandering elsewhere. These stories are painful to re-tell. Over the years, I've had to learn to mentally train myself to focus back on the conversation, but this isn't easy. This is especially true when I become frustrated with re-telling painful lived experiences.

Jules is aware of my focus issues; we share similar characteristics because we both have lived experiences with ADHD.⁵⁵ I'm told that this is all a part of my impairment, I recall telling Jules. Medically, I'm labeled as severely ADHD. My attention span is weak; I'm impulsive; my mind doesn't stop racing. I'm perceived as having a problem in my body and mind when, for example, I can't sit still. As if that wasn't enough to impact my academic performance at school, I also have a learning disability. *Of course, this is my problem, right? No, not really.* I'm awakened from what feels like a trance—typical of my overactive brain—by Jules's snapping fingers.

“Hey, where'd you go? What'd you mean the pen stopped at the counsellor's office? I'm still confused about the whole notion of disability accommodations at the graduate level as it is. I never visited the counselling office for accommodations. I was too ashamed. I mean, seriously, they have the same counsellors that my own students use.

⁵⁵ ADHD is often medicalized, “[as] a disorder of the central nervous system (CNS) characterized by disturbances in the areas of attention, impulsiveness and hyperactivity” (Kelly & Ramundo, 2006, p. 14). Disability scholars and others, however, reject this medical label, noting that the so-called symptoms of ADHD can be sources of creativity and energy. See for example, La Monica & Chouinard, 2013. See also Goodley, 2011, p. 147.

I didn't want to be seen at the counselling office especially when I wasn't even sure if I was eligible for accommodations. What if one of my students saw me? I just couldn't do it. I tried. Several times, actually. Each time, I made it a bit further: first, I reached the second floor; next, the third; and finally, I made it to the front door. But just as soon as I made it to the third floor of the front doors, I quickly turned back. That was it. I figured if I made it this far to reach grad school, I should be able to complete my studies without accommodations. If I couldn't get through grad school without them, I really shouldn't be there in the first place. Right?"

"I can relate to how you're feeling, Jules, but I respectfully have to disagree. Why shouldn't disabled grads get accommodations? Research shows that accommodations are essential for students, including disabled graduate students. Yes, they can do the work. They have the "intellectual smarts"—however you care to define that. Why shouldn't they be able to access grad school? If it takes a person twice as long to mark essays because of their processing speeds, they're actually working twice the hours as another student for the same pay! There are lots of ways we could make accommodations happen. I tried to explain this to the counsellor the first time I met at their office to register as a student with a disability and access my accommodations. Well, what I mean is when I tried to register."

"Tried to register? What do you mean? What happened?"

"It's funny, you know," I say, mentally placing myself back in the registrar's office, "I imagined this highly bureaucratic process would be relatively smooth because I'm familiar with it. Not to mention, I'm both a student and researcher of this process, too. I

mean, I have a ton of knowledge about accommodations in academia. I've been exploring disability issues throughout my university career: serving on accessibility committees, taking courses in disability studies—I did my master's degree in disability studies—mentoring other students, being a disability ally and advocate. Oh, yeah, and I am also disabled.

Still, I found myself apprehensive about meeting with the counsellor as a graduate student. During our consultation, I asked the counsellor about workplace accommodations for disabled graduates like myself. The counsellor seemed unsure of any accommodations provided for disabled grads and suggested that medical programs offer modified work placements for disabled students, but that was about as much as I could get in terms accessing information. It was like pulling teeth.”

This experience brought back feelings of complete frustration when I first acquired the knowledge of my disability and first requested accommodations from the university.

“The counsellor asked me what accommodations I'd need. How should I know? I was just identified as a disabled. ‘Don't you have a checklist of the accommodations you offer?’ I asked defensively. I was basically given some speech about how accommodations are individualized, that there was no such thing as a checklist of accommodation options, and that if the university provided one all disabled students would take advantage of accommodations that they might not otherwise need.

“Take advantage?! Is that how they saw us, as taking advantage?!” Jules exclaims.

I couldn't help but remember how angry and powerless I felt as an undergraduate student with little to no knowledge of my rights to accessible higher education. Only this

time was different. I knew my rights as a graduate student—sort of anyway—and I was prepared to fight for them. You bet your ass I did my research beforehand.

“Yeah, it’s frustrating that they treat us that way, especially when the research shows that disabled grads need institutions to offer things like reduced teaching loads, the recognition of doctoral research as fulfilling the research workload, fewer or no committee responsibilities, especially at critical times in doctoral work.⁵⁶

“And I did exactly what they ask of students in the policy: I consulted my counsellor about any concerns about meeting the ‘essential requirements’ of the academic program. I went to the disability services department before I registered. I talked to profs about any concerns they may have about my ability to meet the program requirements. And still, with all this under my belt, I felt the counsellor wasn’t able to address my concerns, let alone tell me whom I could speak to about these concerns—concerns that would impact my academic progress in the program.”

A quick Google search reveals that these are the typical guidelines for students to access accommodations. I had made sure I read and followed the policies pertaining to academic accommodations. So why, then, was I having a difficult time navigating information for disabled graduates in their role as academic workers? Turns out that, for the most part, the accommodation policy is predominately for academic work such as extensions for submitting assignments. What about workplace accommodations? I couldn’t find information about who disabled graduate students consult if this is, in fact, a different process from the student academic accommodation process. If information about

⁵⁶ Dunn, Haines, Hardie, Leslie, & MacDonald, 2008, “Employment Equity and Supports”, para. 4.

access to accommodations wasn't "easily" available to me when I accepted entrance to my academic program, how was I to know how to navigate this process?

Like many graduate students, I was offered a stipend and scholarship through the university that required me to work as a teaching assistant.⁵⁷ While this is typical for "many" graduate students, it might differ from one department to the next. By accepting this offer, I'd be considered an employee of the university, protected by a collective agreement. Consequently, I had anticipated the counsellor's role would include helping me understand the processes for both academic and workplace accommodations. This wasn't actually the case because the counsellor knew very little about workplace accommodations. Surely, I couldn't be the only disabled graduate student who needed this kind of information. If my counsellor had no knowledge of workplace accommodations, how was I to find out if not by this office? Who then would be my institutional advocate? Did such an advocate even exist? I found myself becoming more and more frustrated about this subject with the counsellor.

Early into the intake process, the counsellor literally stopped writing. I became aware of my own anxiety. I shifted in and out of my seat, the heat of my breath quickening my statements, matching my quickening pulse. The chatter that occupies my mind daily is what got me into trouble that day: just before the counsellor's pen stopped, I blurted out, in an offhand way, that I had met with a new psychologist last month: 'His

⁵⁷ To the best of my knowledge, it is typical for graduate students to be offered stipends or scholarships in their academic programs. However, the amount of funding can differ significantly in how much a student might be funded (e.g., from a few thousand dollars to tens of thousands of dollars).

report will be ready for me to pick up in a few weeks—so I'll get this to your office soon,' I told the counsellor.

That was it.

The pen just stopped.

Abruptly closing the yellow manila folder where notes were handwritten, the counsellor stared blankly at me and stopped writing altogether with no explanation. I stared back wondering what just happened. *Did I say something wrong?* I felt my heart sink. The room was spinning. I temporarily blanked out for a few seconds while I watched the counsellor's lips move. The counsellor explained that the university requires the most recent psychological medical documentation before any student can be registered as a student with a disability.⁵⁸

Wait. What? I'm puzzled. Clearly, this is just a misunderstanding. I provided all the necessary medical documentation in addition to a pile of accommodation letters from my previous institution when only one was required. I might have provided too much. I had studied the university's policy before I made the appointment so that I knew I'd be prepared.

What's wrong with the medical documentation I provided you with? That documentation is within the 5-year validation period. I remember that my chest felt hot and I was sure it was visibly beaming red from my modest V-neck t-shirt.

That documentation is a part of my embodied disability—a constant reminder of

⁵⁸ Since the time of this writing, there has been a significant change to the accommodation process for disabled students in Ontario. Please see http://www.ohrc.on.ca/en/news_centre/new-documentation-guidelines-accommodating-students-mental-health-disabilities.

being labelled—a constant reminder of the emotional and physical fatigue I experienced after fighting with the university for 6 months straight, knocking on university administrators’ doors to help me get a provincial bursary to pay for the \$1850.00 psycho-educational assessment.⁵⁹ Do you know how many disabled students cannot access their accommodations because they cannot financially afford, much less emotionally afford, this assessment that the university requires?

For an assessment, that, I should add, demoralized me by making me answer questions about American history at the age of 27; a subject I had no recollection of. I recall throwing unanswered math equations back to the assessor because I can’t do math without a calculator. I completed timed writing and reading exercises, and played with building blocks feeling like a 7-year-old, over the course of 20 hours.

For an assessment that allows medical professionals like this psychologist to pathologize me—reproducing the notion of normalcy⁶⁰—when he advised me to not pursue a career in teaching because of my “lack of organizational skills” and apparent “severe ADHD” —his carefully chosen words. Adding to the insult, his assistant probed me as to why I wanted to continue into my grad studies, asking whether I was trying to prove something to someone or myself, offering advice I never solicited, telling me I have

⁵⁹ The cost of full-psycho-educational assessment varies depending on province. At some universities, assessments are completed internally, but students could find themselves on a minimum of a 6-month waiting list for an initial appointment. Depending on their available funding opportunities, some students endure the financial costs to take this (required) medical testing in order to establish a need for accommodations (Hibbs & Pothier, 2003, p. 203). Students must provide proof of disability to obtain any type of formal disability-related accommodation request. This requires a student to accept and disclose their impairment and/or disability to a university because “self-identifying as disabled, sets the disability policy in motion” (Jung, 2003, p. 102). In 2007, at the time of my assessment, the cost for such an assessment was \$1,850 in Ontario.

⁶⁰ Davis, 1995; Titchkosky & Michalko, 2009.

nothing to prove and should choose another career path.

Another career path.

I remember wanting to leave that office right away, feeling shame, fear, and regret. Why did I put myself through this crap anyway? Maybe they're right, I thought to myself. Maybe teaching wasn't something I should or even could do.

“You're telling me the assessment I handed you when I came in is not enough to register me today as a disabled student?” I asked the counsellor.

The counsellor appeared empathetic to my situation, even apologetic, reiterating that there was nothing that could be done to proceed until the office received my most recent documentation.

I am angry with myself because I couldn't stop myself from talking impulsively; I shouldn't have mentioned the recent report in the first place. If I didn't open my chatty mouth about this new doctor, the counsellor wouldn't have known and I'd be registered as a “student with a disability” and on my way home instead of feeling completely anxious.

I'm outraged.

Deep breathe in; slow breath out.

Silence.

I work hard to slow my breath down. I can't show my anger; I don't want to be perceived as someone with emotional or anger issues. I clear my voice, gather my papers back into my manila folder and tell the counsellor it was nice to meet them.

I quietly leave the office and immediately call my friend to vent my disbelief about what just happened.

Jules is soaking up this story like a sponge. Re-telling my story recalls emotions of frustration, failure, anger, and pain. I'm sure this story conjures memories for Jules as well. I was right.

“I'd like to say ‘That’s unbelievable,’ but I am not that surprised by any of this. When I first read about your study, I was taken aback because I didn’t think there were that many people in grad studies with disabilities. At least not, you know, disabilities that aren’t obvious. Disabilities like yours and mine. I mean, I know there are things in place for wheelchair users, like accessible washrooms. If you’re really lucky! I’ve heard it’s possible to ask for accessible classrooms. But accommodations for LDs and mental health? Really?”

“Well, actually,” I pause. “The number of students like us, and students with other kinds of disabilities, is on the rise. I read an OECD⁶¹ report published in 2003 that said anti-discrimination legislation is part of the reason for disabled persons pursuing degrees in post-secondary education.⁶² I assume that part of the reason there are more disabled students is that accommodations are understood to be a human right now. But we have such a long way to go before we break through the barriers that still exist and prevent full inclusionary spaces.⁶³ This is especially true for disabled grad students. As we both know,

⁶¹ OECD, 2003.

⁶² Rose, 2009.

⁶³ Damiani & Harbour, 2015; Olkin, 2002.

there's just not enough research out there.”

“Yeah, you can say that again!”

“And that's because research tends to focus on undergrads.⁶⁴ And even then their voices continue to be absent from the literature.⁶⁵ That's not to say undergrads aren't important. I'm just saying we need to get a better picture of how disabled grads experience academia as inclusionary and, or as exclusionary.⁶⁶ This is important for so many reasons!”

“Yeah, and without the proper supports in place, well, we've both heard about colleagues who couldn't progress in their studies and chose to drop out as a result of poor accommodations.”⁶⁷

“I use Marilyn Rose's work a lot. It's called *Accommodating Graduate Students with Disabilities* and she presented to the Council of Ontario Universities. She talks about the high cost of failing to accommodate disabled students like ‘the loss of talent to

⁶⁴ Denhart, 2008; Duquette, 2000; Fuller, Healey, Bradley, & Hall, 2004; Low, 2009, OMET, 1998; Rose, 2009.

⁶⁵ Denhart, 2008; Duquette, 2000; Farrar, 2004; Fuller, Healey, Bradley, & Hall, 2004.

⁶⁶ Farrar, 2004. See also Dunn, Haines, Hardie, Leslie, & MacDonald, 2008; Olkin, 2002; Rose, 2009.

⁶⁷ With the inception of anti-discrimination legislation, there has been a significant increase in the numbers of learning disabled persons enrolling in academia (see Harrison & MacKay, 2008; OECD, 2003; Tinklin & Hall, 1999). Higher education is important in the lives of disabled persons as those without degrees tend to be marginalized into lower paying jobs (Barnes & Mercer, 2003; Denhart, 2008). Despite efforts to ensure access to places in academia, institutional and social barriers continue to prevent these students from accessing equitable spaces (Hibbs & Pothier, 2006; Jung, 2003; OHRC, 2003), leading them to be more likely to drop out of educational institutions (as cited in Gregg, 2009. See also Roer-Strier, 2002). As Harrison and MacKay (2008) explain, “These students are capable of being successful... if they have the supports and services they require to level the playing field and demonstrate what they know” (para. 1). In Canada, educational service providers have a “duty to accommodate”—short of undue hardship—the educational support needs of disabled students by providing “reasonable accommodations.” The *Ontario Human Rights Code* defines access to education as moving

...beyond physical accessibility, to include accessible curricula, and delivery and the evaluation methodology, as well as the provision of the necessary supports and accommodations to ensure that students with disabilities have equal opportunity to their education (OHRC, 2003, p. 46). Indeed, the fundamental right to access higher education is contingent on academic accommodations and individualized support.

society’ when disabled students don’t graduate. And then, my personal favourite, she talks about ‘the loss of self-esteem and potential income’ for disabled students who can’t ‘keep up’—whatever that means!”⁶⁸

“Not to mention that grad students are often also employees of the university while they are doing their doctorates. If they can’t manage the full load of teaching and research assistantships, they might lose out on the scholarship money that is attached to those positions with the university.”

“Yeah. I know. That’s exactly what motivated this project in the first place, Jules. I have been so involved listening to students’ stories about access to accommodations. I’m so passionate about this topic because it’s not just personal; it’s also political. I don’t want to point fingers, but I do want to learn from these experiences even if they are hard to hear. No one wants to think that they’ve been a part of someone’s oppressive experience, of course. But if we don’t get the students’ voices out and heard, how will anything change for the better? And, seriously, I want to hear about the positive experiences too.

“We already know that LDs and mental health disabilities are one of the most prevalent disabilities documented among university students,⁶⁹ but they are still very much stigmatized and misunderstood. I hear from many disabled students they think we’re ‘taking advantage of the system,’⁷⁰ as if accommodations are some sort of special treatment. Of course, we know that accommodations are not special treatment; it’s an entitlement to barrier-free learning. I mean, the bottom line is, access to higher learning

⁶⁸ Parks, Antonoff, Drake, Skiba, & Soberman as cited in Rose, 2009, pp. 5-6.

⁶⁹ OECD, 2003.

⁷⁰ Denhart, 2008; Hibbs & Pothier, 2006; Jung, 2003; Ryan, 2007; Titchkosky, 2003.

shouldn't be laborious work as it currently can be. Why do disabled students need to do work to get accommodated? Sorry that was a mouthful.”

“No worries. I get it. Passion is what is going to get you through your doctorate.”

My pen stops. I smile.

Chapter Two: Theorizing Over Coffee

Perhaps it would be better to say that geography, like many of its disciplinary siblings, has often had trouble expressing feelings.⁷¹

It's 8 p.m. on a chilly Friday night. Jules and I have been hammering away at my work. After four hours of occupying what we call our academic equivalent of a bar, otherwise known as Francie's Coffee Shop, we decide to try out a new café to continue the work. This new place is nice. It's warm and inviting, and big enough for us to occupy a lot of space with our computers and all my manila folders.

Seconds after connecting with the Wi-Fi, I receive an e-mail for a conference call on Emotional Geographies being held in Rome next year. I'm hardly able to contain my excitement as I tell Jules about the conference call.⁷²

"Emotional geographies'? What kind of flaky shit are you into now?" Jules laughs.

"Well, it's interesting that you ask since we were just discussing how different this place is from our usual working space at Francie's Coffee Shop. Essentially, we changed geographies." I begin reading the call for papers out loud:⁷³

"Rome University, June 19–21, 2016.

Stretching itself beyond traditional physical geographic concerns, human and social geography have long recognized the role of space and spatial patterns in the social constructions of power relations and inequalities. Following in this vein, the

⁷¹ Bondi, Davidson, & Smith, 2005, p. 1.

⁷² This narrative of a conference call is rooted in a real call for papers; however, the purpose here is to introduce emotional geographies in a way that bridges creativity and academia. This scene actually happened, but with some modifications. This was a deliberate decision to make it consistent within the creative non-fiction writing genre I am attempting to achieve to make this work more accessible.

⁷³ This chapter uses a conversation that might seem unrealistic to some, but that I have actually had many encounters like this.

discipline took an ‘emotional turn’ in the early 21st century,⁷⁴ to consider the emotional landscape that underlies various manifestations of social inequality and exclusion, including issues of sexuality, disability, and aging among its key concerns (Chouinard, Hall, & Wilton, 2010; Longhurst, 2010; Reeve, 2004).

Emotional geographies continue the geographer’s study of our surroundings, arguing that ‘space is turned into place’ when people attach meaning to particular places (Cresswell, 2004, p. 2). As such, space can be considered ‘...an active constituent of social relations [and is] socially produced...’ (Kitchin, 1998, p. 345). The manner in which this space is socially produced has implications for understanding and addressing social exclusion or inclusion.

Chouinard, Hall, and Wilton’s (2010) edited collection, *Towards Enabling Geographies: ‘Disabled’ Bodies and Minds in Society and Space* respond to Parr and Butler’s (1990) call for a broadening of the scope of disability geography to encompass the embodied experiences of ‘all sorts of different people, with all sorts of different mind and body characteristics’ (p. 4). Robyn Longhurst (2010) “argues that mainstream spaces are often disabling, in emotional as well as material ways, for women who identify as ‘fat’, in the confinement and restriction of movement, and the soci-cultural non-acceptability of larger bodies” (p. 4, emphasis in original). Her participants discuss disabling spaces of, for example, going to the movie theatre. In this space, women are made to feel like they do not belong when chairs are not designed for their ‘larger’ body types. Not being able to ‘fit’ in the ‘normal’ theatre chair thereby excludes them from socially participating in going to the movie theatre in the same way as ‘normal’ bodies.

This conference will bring together scholars from diverse disciplinary backgrounds, third sector partners, and creative practitioners to explore and discuss emotional geography in spaces and society.

Participants are invited to submit individual papers and proposals for sessions that creatively explore the role of emotion in shaping the experiences of space and society. Topics may include emotional geographies in spaces and places of paid and unpaid work, in the arts and other creative activities, in voluntary organizations and social services, in public and private education, in formal and informal politics, to name a few. Creative and innovative approaches that draw from a range of theoretical and methodological engagements with emotion as a social and spatial phenomenon are strongly encouraged. Additionally, proposals for discussion panels are welcomed. Please send abstracts of 500 words to teconference@rome.eu by March 28, 2016.”

⁷⁴ Chouinard, Hall, & Wilton, 2010; Pain, Barke, Fuller, Gough, MacFarlane, & Mowl, 2001.

I finish reading the call for papers and take a sip of my coffee watching for Jules's reaction.

“Oh yeah, that clears it up! So what the heck is emotional geography?”

“Good question. I'm still trying to conceptualize this for the theoretical foundation of my thesis. Basically, in dealing with social issues, literatures from geographies of disability and disability studies haven't paid enough attention to how disabled people feel emotions, as embodied, and how these can shape how disabled people negotiate their everyday lives.

Reading the skepticism written all over Jules's face, I continue, “We are increasingly seeing how understanding disability and impairment as embodied emphasizes how emotions are produced through the body.⁷⁵ For example, it's humiliating to constantly ask for extra time, as I had to in one of my classes, which, by the way, I had to verify through disability services.⁷⁶ This constant request for accommodation was physically draining, because I had to use my energy to validate my needs by going back to disability services or my doctor. This also takes an emotional toll⁷⁷ on me when I begin to question my belonging in grad school. So you see, it's an important contribution that geographers have begun to make to include how we live through our emotions that help

⁷⁵ Bijoux & Myers, 2006; Butler & Parr, 1999; Chouinard, Hall & Wilton, 2010; Davidson & Milligan, 2004.

⁷⁶ Fuller, Healey, Bradley, & Hall, 2004.

⁷⁷ Goodley (2011) concurs that “maintaining this emotional labour can be psychologically testing” (p. 92).

to shape our experiences of feeling included, excluded, and sometimes both in certain places.”⁷⁸

I reach for what I call my “purple bible on emotional geographies” (referring to Davidson, Bondi, and Smith’s⁷⁹ edited volume of *Emotional Geographies*) and read.

“Phil Hubbard explains, ‘After all, emotions are embodied, in the sense that they are felt and experienced, and it might be suggested that language cannot adequately capture the way emotions are felt (e.g., the flush of embarrassment, the rise of anger, the pang of disappointment).’⁸⁰ I often say that emotional geographies refers to the ways in which emotions are lived and managed, sort of ‘negotiated’, in social interactions with others in different spaces of everyday life.⁸¹

“Obviously, the focus for my research is on the academic and work spaces of grad school. Davidson also wrote with Christine Milligan⁸² to highlight how social geographers are beginning to explore how ‘emotions matter’ in the geographies of illness, impairment, and disability.”

“Wait? Emotions matter? In *geography*?”

“Well, yeah. Davidson and Milligan remind us that ‘our first and foremost, most immediate and intimately *felt* geography is the body, the site of emotional experience and expression *par excellence*. Emotions, to be sure, *take place* within and around this closest

⁷⁸ Bondi, Davidson, & Smith, 2005.

⁷⁹ Bondi, Davidson, & Smith, 2005.

⁸⁰ Hubbard, 2005, p. 122.

⁸¹ Bondi, Davidson & Smith, 2005, p. 3.

⁸² Davidson & Milligan, 2004, p. 524.

of spatial scales'.⁸³ Just think about this.” I pause. “Do you remember how I told you that students from my research blog said that they felt resistance when they tried to negotiate their academic and workplace accommodations for their disabilities?”

“Yeah. Haven’t we all?”

“Well, I frame the social relations that students have with professors as a space of exclusion for students who struggle to access their accommodations—accommodations that they are entitled to by law, I should add. These spaces, presumably accessible to all, become a hostile environment where disabled students avoid requesting accommodations altogether because of bad memories of being placed in a space where they don’t feel like they belong.⁸⁴ This makes it difficult for students to fully participate in the classroom.”

“OK,” Jules says. “But if we get caught up in all this ‘emotions’ stuff, don’t we start to blame the disabled people themselves for what happens to them? That’s why I like the social model of disability. It’s more objective and puts the cause of disability squarely in

⁸³ Davidson & Milligan, 2004, p. 523, (emphasis in original).

⁸⁴ Price’s (2011) study highlights non-visibly disabled students negotiating mental health in the classroom and demonstrates how classroom spaces are disabling when students approach their instructors for support, only to be confronted with attitudinal barriers. She explains how for one student, instead of confronting the professor and disability services for support she needed, after being challenged on the legitimacy of her depression, the student negotiated her space by passing and showing her academic knowledge in other ways. Price notes how this student demonstrated strong grades on her exams and essays in comparison to her minimal “active” participation in the classroom. Ableism that structures spaces of the higher learning classroom with expectations that all students are evaluated for participation that include being vocal in class does not allow space for this student to demonstrate her knowledge in the same ways as her non-disabled peers. As such, this student negotiated her space without accommodations that made her work harder to prove that she “belonged” in academic spaces by showing and demonstrating her laborious efforts in engaging with the material in producing strong essays and exams. Her efforts are not typically acknowledged as “full participation” where the expected norms include “active participation” that require academic performances that this student could not participate in. Like the student in this example, it can also be understood how non-visibly disabled students can become visible in academic spaces when students resist asking for accommodations and jeopardize their academic performance. Teresa Tinklin and John Hall (1999) explain that, “disabled students face difficulties because they are operating in an academic environment which functions largely without regard for their differences” (p. 189). See also Titchkosky & Michalko, 2009, p. 228.

society's lap, not mine. Isn't that why Oliver promoted the social model of disability in the first place?" Jules probes.

"Yes, Oliver has argued that disability should be understood not as the limitations of body or mind functions, but as a result of societal processes that creates disability, for example, stigma and attitudes about disability in our society. Disability is a function of the disabling structures and institutions that continue to segregate, discriminate against, and oppress disabled people for failing to conform to the societal norms and expectations of able-bodied individuals. He argues for a clear distinction between impairment and disability—arguing that we shouldn't conflate the two separate entities. Oliver has done well to remind us that an impairment doesn't disable a person; rather it is the social structures (such as academic or medical spaces) that require negotiation that do.

"But, it goes beyond the physical environment, like a lack of ramps for wheelchairs users that disable a person from actively participating in spaces and society. Take, for instance, spaces that don't take 'different' bodies and minds into consideration, like ableist educational evaluations. An example in the academic context: the structure of exams. Why do exams need to be written in one sitting? In some cases, why are take-home exams not an option? Even with an accommodation, I remember I had to fight in both my undergrad courses and then my PhD comprehensive exams to be able to write a take-home exam."

"But, don't you risk going back to the 'individual model' of disability that Oliver refers to? You said that he explains that the individual model sees disability as the result of an individual's impairment—viewed as an individual problem, needing fixing or

something to ‘overcome’. God I hate that word! You know, by external remedies like medical rehabilitation so that we can, quote on quote ‘normalize’ the body and mind.⁸⁵ Hasn’t the individual model been critiqued for taking little account of the ways in which society is structured to keep disabled persons with impairments socially oppressed and spatially marginalized—to use your geography terms? So much focus has been on the individual that their social contexts and the environments they attempt to access are never fully being addressed, as if it’s the individual’s fault. Yeah, that’s how disability becomes medicalized.”⁸⁶

“Yes, this is all true. But, the social model has been critiqued for not considering impairment and the individual’s needs. Maybe, medical treatment or rehabilitation could be helpful for the impairment, but that doesn’t mean we should define our disability in medical terms. The point is that we don’t have to deny the body’s experience when we argue that disability is caused socially.

“I really like how Jenny Morris says it here:

...there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social barriers are a crucial part of our experience of disability—and do indeed disable us—to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying.⁸⁷

⁸⁵ Oliver, 1990.

⁸⁶ Chouinard, Hall, & Wilton, 2010; Gleeson, 1996; Hall, 2000; Morris, 1991; Oliver, 1990; Reeve, 2004; Thomas, 1999.

⁸⁷ Morris, 1991, pp. 11-12.

“So, when the social model of disability limits disability issues to only social processes and structures of the environment, it also limits our understanding of disability as an embodied experience.⁸⁸

“Just like Morris and some other feminist disability theorists,⁸⁹ some geographers suggest that the social model of disability should include the embodied experiences of disability such as illness, pain, and impairment. Scholars like Gleeson⁹⁰ and Hall⁹¹ challenge Oliver’s conception. Gleeson cautions Oliver and the social model because he thinks it should not

...abandon the body and neglect the critical fact that it plays a foundational, if historically spatially specific, role in the constitution of human society. Each body provides a unique set of pathological capabilities and limitations that informs the social experiences of the individual—the point is that geographical and historical differences mean that these *corporealities* correspond to unique *social* realities, i.e., distinct embodiments at different points in time and space.⁹²

“In my comps exam, I used Hall⁹³ to talk about how including the ‘embodied notion of disability’ strengthens geographies of disability. He explains that the body is a contested notion that has been resisted by both disability studies and geographies of disability literature.”

“But won’t bringing in all this emotional stuff water down the political fight for the equality of disabled people?”

⁸⁸ Dyke, 2010; Gleeson, 1999; Hall, 2000.

⁸⁹ Chouinard, 2010; Dyke, 2010; Kafer, 2013; Parr & Butler, 1999; Reeve, 2004; Thomas, 1999.

⁹⁰ Gleeson, 1999.

⁹¹ Hall, 2000.

⁹² Gleeson, 1999, p. 20, (emphasis in original).

⁹³ Hall, 2000.

“No one is saying that the social model isn’t important for rejecting bio-medical approaches to disability.⁹⁴ As Gleeson⁹⁵ argues, spatial structures, as well as social structures, play a critical role in examining and understanding the social oppression of disabled people in society and space.”

“Fair enough. But I’m still not getting where emotions come into all of this,” Jules interrupts me again.

With a stern look, I say, “Can you let me finish?”

“OK, OK. Sorry.”

“Crap, now where was I...?”

I take this opportunity to pause for a minute and quickly read through the draft of my theory chapter I have open on my laptop that I am about to submit to my committee for review and feedback.

“Donna Reeve⁹⁶ and Carol Thomas⁹⁷ have also made similar criticisms.”

“I’ve read some of Reeve’s work. I thought it was pretty good,” Jules says enthusiastically. “But Reeve still focuses on environmental barriers, doesn’t she?”

“Well, she talks about structural disability, but she brings emotions into the discussion. She points out that the difference between the experience of disabled people and those from other oppressed groups can be found in physical things like separate entrances that result in psycho-emotional disablism; you know, that makes disabled

⁹⁴ Hall, 2000; Shakespeare, 2006.

⁹⁵ Gleeson, 1999.

⁹⁶ Reeve, 2004.

⁹⁷ Thomas, 1999.

people feel like second-class citizens. But friends, family, professionals can also be ‘agents of psycho-emotional disablism.’”⁹⁸

“OK, go on.”

“In my work, I am acknowledging the emotional, psychological, and physical pain associated with the work of disabled grad students seeking accommodations as vital to my contribution to disability studies in its current state. It’s something professors—and I’ll add, the university as a whole, including administrators, and counsellors—don’t consider when facilitating accommodations. Some have no idea how to approach it. A friend of mine, who spoke from their experience, reminded me that even the most motivated students find it impossible to do their academic work if they are in intense pain.

“But again, doesn’t Oliver⁹⁹ acknowledge these critiques of the social model. He admits they exclude the embodied experience of impairments?”

“He certainly does. Here, I have it right in front of me. Oliver explains, ‘The point that I am making is that the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability.’¹⁰⁰ He goes on to write,

We must not assume that models in general and the social model in particular can do everything; that it can explain disability in totality. It is not a social theory of disability and it cannot do the work of social theory. Secondly, because it cannot explain everything, we should neither seek to expose inadequacies, which are more a product of the way we use it, nor abandon it before its usefulness has been fully exploited.¹⁰¹

⁹⁸ Reeve, 2004, para under “The extended social relational model of disability.”

⁹⁹ Oliver, 2009.

¹⁰⁰ Oliver, 2009, p. 25.

¹⁰¹ Oliver, 2009, p. 27.

He contends that we should instead develop a social model of impairment to include experiences such as illness, pain, and impairment, which appears to be closer to Gleeson's notion of 'an embodied social model of disability.'"¹⁰²

"OK, let me see if I have this right. You're not denying that addressing disability requires removing institutional and physical barriers, right?"

"Yes, exactly. I'm not denying the advantages of the social model, such as its political agenda for social change. I'm saying that we also have to consider how these barriers make us *feel* as part of what we are calling 'disability' in the social model. Reeve, for example, says 'internalized oppression is one the most important manifestations of psycho-emotional disablism'.¹⁰³ This is how 'space gets turned into place.'"¹⁰⁴

"Well, I certainly understand internalized oppression. I live with it all the time. But what is this 'space turned into place' stuff?"

"Well, that's the contribution that geography makes to understanding how we experience disability. In the call I just read to you, Rob Kitchin describes space as, 'an active constituent of social relations'.¹⁰⁵ He says 'space is socially produced to exclude people in two main ways: spaces are currently organized to keep disabled people 'in their place'; spaces are social texts that convey to disabled people that they are 'out of place'.¹⁰⁶ When we think of space like this, we can see how non-visibly disabled students'

¹⁰² See Gleeson, 1999; Hall, 2000.

¹⁰³ Reeve, 2004, para under "Internalised oppression".

¹⁰⁴ Cresswell, 2004, p. 2.

¹⁰⁵ Kitchin, 1998, p. 345.

¹⁰⁶ Kitchin, 1998, p. 345.

fundamental right to access spaces of the academy is undermined, despite the fact that anti-discrimination legislation is supposed to ensure equal opportunity for all students.

“With an understanding of the emotional geography of disability, like the emotional geographies of negotiating accommodations that we’ve been talking about, we can better understand how emotions shape academic spaces as enabling.”

“Or disabling,” Jules add.

“Yes. It’s complicated! For example, advocating can be empowering for oneself, and at the same time, it can be time-consuming and disempowering. On the other hand, some students use their frustration to fuel social change by advocating not only for their own rights, but also for others.¹⁰⁷ They become informed of their legal rights, which in turn, have been found to empower disabled students. Personally, I have learned how to be an informed advocate of my human rights, in addition to learning networking and professional skills that formal teaching of university programs do not instill. Unfortunately, this work takes time and effort and it’s not valued as other academic skills might be—raising hell about human rights is not exactly a skill that you want to add to your CV, for example.¹⁰⁸

“For my understanding of place and space, I like using Tim Cresswell’s and Rob Kitchin’s work. For Cresswell,¹⁰⁹ ‘space is turned into place’ when people attach meaning to particular places. For disabled students like you and me, we attach a meaning of

¹⁰⁷ Chouinard, 1997a; Damiani & Harbour, 2015, p. 407; Goode, 2007.

¹⁰⁸ This type of academic experience will be discussed in more detail in Chapter Five: Hitting the Brakes. See also Mountz, Bonds, Mansfield, Loyd, Hyndman, Walton-Roberts, Basu, Whitson, Hawkins, Hamilton, & Curran, 2015, p. 9.

¹⁰⁹ Cresswell, 2004, p. 2.

frustration, among other things, to spaces of academic life when we are stigmatized for supposedly using our impairments as an excuse to get out of work, for example. We've discussed situations where professors construe a disability accommodation request as 'special treatment or unfair advantage'.¹¹⁰ And not just in completing assignments, but also when we try to get workplace accommodations. This transforms academic spaces into places of struggle for inclusion. This is not how we are supposed to experience higher-learning environments. It's supposed to be a place that fosters inclusivity in intellectual learning, a space that enables opportunities for people to gain credentials needed for meaningful employment, build new friendships, and establish professional working networks.¹¹¹ As we both know too well, not all students experience social spaces of academia as places that give everyone an equal opportunity for social experiences of friendship building or for meaningful work. Space is socially produced because when space becomes place, there are implications for social exclusion or inclusion in society. How can we be really inclusive if we don't address this? How can we address stigma disabled people experience if we don't understand how we attach meaning to spaces through our emotions?"¹¹²

¹¹⁰ Denhart, 2008; Marshak, Wieren, Ferrell, Swiss, & Dugan, 2010.

¹¹¹ Dunn, Hanes, Hardie, Leslie, & MacDonald, 2008.

¹¹² Likewise, in terms of meaningful employment, not all students are afforded the privilege of higher education. Patton (2009) explains that persons embodying ADHD do not benefit from meaningful employment in the same ways as their non-disabled counterparts. His findings suggest that in spite of their high intellectual abilities, they find themselves working in low status occupational positions (as cited in Patton, 2009, p. 333). See also Arndt, 2008; Barnes & Mercer, 2003, p. 47; Gleeson, 1999, p. 132. Patton suggests that education plays a key role in this outcome, since many individuals with ADHD face various institutional and social barriers in places of academia, especially when they are not supported with resources. He argues that low status occupational jobs "only exacerbate their condition" (p. 333), noting that these individuals "are very productive in fast-paced management positions that involve a busy and hectic environment" (p. 334), making many 'blue-collar' jobs inappropriate for them.

“Wait a minute,” Jules interrupts. “That makes me think of that famous book. Yes, didn’t Erving Goffman write about this in his book, *Stigma*? Are you using him in your work?”¹¹³

“Yes, I am. This relates back to geography and the way place and space contribute, exacerbate, or cause these tensions to occur. Goffman’s work on stigma is a great example that fits well with geography’s ideas of how we attach meaning to space. I have to type this out before I forget, but wait, I know I wrote about this in one of my papers. Let me find it. Just one second...” “Ha, I got it!” I start reading aloud:

Goffman’s (1963) concept of stigma is of particular interest to explore how disabled persons both manage and resist discrimination in the academic environment with respect to disclosure. He describes how stigmatized individuals, in particular those described as “discreditable” live under scrutiny for being “found out” when they try to pass as able-bodied. Discreditable persons are able to conceal their stigmatizing effects by passing and concealing their identities.¹¹⁴

“I love how Goffman puts it here: ‘To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not lie; and in each case, to whom, and how, when, and where.’”¹¹⁵

In this sense, disabled students undertake emotion work to resist and offset negative stereotypes and perceptions, in a similar way to the way Goffman describes resisting the perceptions of others.”

Jules interjects, “That makes me think of how Chouinard puts it. What did she say? It was something like having a disability is to be ‘negatively different.’”

¹¹³ Goffman, 1963.

¹¹⁴ Sierra-Zarella, 2005 as cited in La Monica, Ph.D. Comprehensive Exam, Unpublished, 2012.

¹¹⁵ Goffman, 1963, p. 42.

“Yes! She talks about how ‘[t]he term ‘dis-abled’ conveys the message that these bodies are negatively different from the able-bodied ideal: less able to take part in normal activities and, more importantly, to succeed in socially valued ways.’¹¹⁶

“So let’s use the example of my dual role as a student and academic worker when I’m a teaching assistant. Well, let’s say that after a few weeks into a semester, I decide to disclose my impairment to my students. These students might react as if this means that I might not be capable of teaching, or grading assignments, or both. I react to them by not only feeling viscerally fearful of disclosing my disability to others, but also by feeling emotional pain when these students who never questioned my capability before might react negatively and now question me as their instructor. It is only after I disclose my disability to the students that their perception of me as a credible instructor is changed.

“My work really resonated with my colleague and friend, Stacey Coffman Rosen. She reviewed an earlier chapter on my theoretical foundation. She said it so well that I keep it handy. Here it is:

Student’s reactions, even if they don’t intend to view you as ‘less than’ often happen anyway. Another thing that makes it difficult is that they often don’t make a direct comment, but there is often an internalized shift within them that makes them view the instructor as ‘less than’ from their prior internalized experience. I just got a harrowing response paper from one of my students that said their ‘life would be over’ if they were suddenly paralyzed from the waist down and it wouldn’t be worth living. I felt like everything I had taught up to that point was invalidated and that the student wasn’t getting it. Thanks so much “Million Dollar Baby”. Yes things will change, but that doesn’t mean that the joy of life has been sucked out or that there aren’t alternative ways of approaching life activities (especially sexuality).¹¹⁷

“OK, so you want to add all this to the social model of disability...” Jules begins.

¹¹⁶ Chouinard, 1999, p. 269.

¹¹⁷ S. Rosen Coffman, September 04, 2014, personal communication.

“Well, I’m not adding to the social model of disability. I’m saying that the social production of space is part of the society that the social model points to as the source of disability (as opposed to impairment).

“What I am doing is considering how emotions shape our lived geographies of disability much like Reeve does. Reeve’s¹¹⁸ work in disability studies builds on Carol Thomas’ notion that the social model needs to recognize the importance of emotions in the lived experiences of disabled persons—what Reeve calls the ‘psycho-emotional disablism’ that we were just talking about. In her model, ‘disability is seen as a form of social oppression that operates at both the public and personal levels, affecting what people *do* as well as who they can *be*.’¹¹⁹ She thinks that, ‘the inclusion of these oppressive relationships with the self [for example, internalized oppression] and others within a social model of disability is innovative’.¹²⁰ And so do I. I want to add to what she is doing when she tries to ‘raise the profile of the psycho-emotional dimensions of disability within disability studies and the disabled people’s movement.’¹²¹ But I want to do this by contributing to the discipline of geographies of disabilities and emotional geography.”

I continue, “To put it another way, disabled students who’ve been met with resistance might not ask for accommodations to avoid re-living painful emotions such as humiliation and embarrassment—you know, that ugly embarrassment of handing your

¹¹⁸ Reeve, 2004, para under “Introduction”.

¹¹⁹ Reeve, 2004, para under “Introduction”, (emphasis in original).

¹²⁰ Reeve, 2004, para under “The relevance of the psycho-emotional dimensions of disability for a contemporary social model of disability”.

¹²¹ Reeve, 2004, para under “Introduction”.

professor that accommodation letter only to be met with a look of skepticism, as if you're looking for 'special treatment.'¹²² It's not uncommon for disabled students to be accused of or perceived as using their disability as an excuse to get out of academic work."¹²³

"Been there more times than I care to recall. It's devastating especially as a non-visibly disabled grad student—as if I enjoy being stigmatized so much that I want to keep the stigmatizing experiences coming.¹²⁴ Because you know, being penalized for not being able to submit on time isn't hard enough to deal with as is."

"Exactly. How many times have you heard of disabled students being blamed for not making their needs known to their professors or criticized for not disclosing—as if it's such an easy and comfortable conversation? That's how and why emotions matter. At least, this is what I argue in my work.

"And I'm not alone. Davidson and Milligan point out that experiences of such emotional geographies provoke these negative feelings that have...how did they put it again, oh yeah, right, 'have tangible effects on our surroundings and can shape the very nature and experience of...being-in-the-world'.¹²⁵ Phil Hubbard says something similar.

¹²² Students in D. Roer-Strier's study (2002) refer to instructors who lack an understanding of the importance of basic disability accommodations. The combination of hostile professors, coupled with unknowledgeable peers leaves many disabled students emotionally exhausted and socio-spatially marginalized by feeling misunderstood when accommodations are perceived as seeking out special treatment. See also Denhart, 2008; Hibbs & Pothier, 2006; Low, 2009; Price, 2011; Ryan, 2007; Sierra-Zarella, 2005.

¹²³ Denhart, 2008; Devaney, 2008; Farrar, 2004; Low, 2009; Ryan, 2007; Titchkosky, 2003.

¹²⁴ In Sierra-Zarella's (2005) experiential account, she explains that students who are not afforded accommodations for their academic work are also less likely to seek accommodations for paid work (p. 141).

¹²⁵ Davidson & Milligan, 2004, p. 524.

Ah, it's right here: 'This embodied ontology stresses that individuals can express themselves in space only through their bodies....'"¹²⁶

Jules groans. "No kidding. How else could you represent yourself in the world except through your body? I've never understood this debate about 'embodiment.'"

"That's why I want to elaborate on the emotion work and emotional labour for the conference in Rome. I have a draft of my abstract written right here—I've been working on this for a few months, because I knew this call would be coming soon," I say, pointing to my laptop, "Do you wanna read it?"

"Do I have a choice?"

"Good point!" I laugh and turn my laptop around to face Jules. "I'll grab us another round of coffee."

Abstract Title: Doing "Emotional Work" in Academia
Presenter Name: Nancy La Monica

Abstract: (Max 500 words)

In this social geographic study, I use a conceptual framework that recognizes the social model of disability, but includes not only the embodied experiences of impairment and disability, but also emotions, as part of the social barriers that turn an impairment into a disability. Within this approach, I move "beyond geography's more traditional concerns such as the physical and built environment to more contemporary concerns, such as how *processes* of social exclusion are embodied."¹²⁷ This includes how emotions shape the lived geographies of disabled people, that is, how their emotions and feelings shape their sense of being included and/or excluded in certain places.¹²⁸ I explore the embodied experiences of non-visibly disabled graduate students as they negotiate academic and workplace accommodations in places of academia in their dual roles as student and academic worker. I examine how non-visibly disabled graduate students' everyday embodied

¹²⁶ Hubbard, 2005, p. 121.

¹²⁷ Chouinard, Hall, & Wilton, 2010; Longhurst, 2010; Reeve, 2004.

¹²⁸ Bondi, Davidson, & Smith, 2005.

experience of academia consists of a place of academic learning, research, and paid work.

An integral part of this work includes exploring the emotion work and emotional labour that students do as they contend with processes of disablement in the academy, for instance, by considering how these students are made to feel by the bureaucratic and administrative systems of power in institutions of higher education.

This research will add to the existing work in this interdisciplinary area of inquiry by drawing on, and adding to, the study of emotional geographies of places, space, and society,¹²⁹ the emotional geography of places of education,¹³⁰ and current insights into emotion work and disability.¹³¹ In doing so, I offer ways of making places of the academy more enabling for students, which can also be extended and applied to other stakeholders within academia, such as disabled faculty and staff. My work contributes to “making space” and calling attention to emotional geographies of disability in the emerging field of geographies of disability.¹³²

I make it back just in time; Jules is wrapping up reading my abstract. I’m feeling apprehensive of the feedback I’ll receive. Theory has always been a struggle for me.

“OK,” Jules says. “I think I get this. So how these spaces become places is basically the geography of a particular person’s disability.”

“Exactly.”

“And the person’s emotional experience is a big part of the nature of ‘place’ that the ‘space’ becomes.”

¹²⁹ Davidson & Milligan, 2004; Longhurst, 2010.

¹³⁰ Louise Holt (2010) is amongst the few geographers to have examined how youth who embody socio-emotional differences experience the United Kingdom’s primary educational system (see also Hall, 2005; Hall, T., Healey & Harrison, 2004). Holt argues that emotional and behavioural differences need to be re-conceptualized as a form of labeling arising from being disabling by institutionalized attitudes and practices that re-produces spaces of exclusion. See also Imrie & Edwards, 2007.

¹³¹ Scully, 2010; Wilton, 2008.

¹³² Imrie & Edwards, 2007.

“Yes! You could say that emotions are an important factor in creating the terrain of that geography. I want to show how experiencing emotion work and emotional labour can contribute to the literature of disability studies and geographies of disability. To simplify this, I’m making the connection between emotional geography and the body by including emotions to show how emotions manifest physically and mentally.”

Jules stares silently at me as I continue. “OK. So that’s the ‘embodiment’ part?”

“Yes. And it’s important to point out that when I talk about embodiment, I do not separate mind and body.”

“Well, that makes sense, considering that you’re arguing that it is important to acknowledge the emotional costs of all the extra work disabled students have to do survive in the academy.”

“Yes. What better place to look at the psycho-emotional aspects of disability than in all the emotions associated with the extra work that disabled students have to do?”

“Come to think of it, Nancy, I do recall you mentioning this in a paper you presented at the CDSA Congress in Victoria.¹³³ I remember one professor who approached you after your panel presentation to thank you for calling attention to the extra work and emotion work disabled students do. If I remember correctly, she shared that, as a professor, she wasn’t aware of how much work is attached to being a disabled student. In fact, didn’t she comment that there needs to be more recognition in this area, especially for faculty? Even the good ones who understand disability and accessibility, like she does?”

¹³³ Canadian Disability Studies Association Congress in 2013.

“Yup! I was surprised by this encounter myself. I keep thinking that my work is obvious. It was validating to say the least, and I thanked her for that. I’ve always felt intimidated, thinking that my contribution to the field is apparent, when in reality, much more work is needed to explore these lived experiences in academia and how they might, at worst, hinder or, at best, support a student’s access to accommodations.”

“But you didn’t explicitly talk about emotion work in that paper presentation, did you?”

“Well, I didn’t draw it out enough, no, that’s for sure. I was so nervous about presenting my work in front of my disability studies colleagues for some reason, and I was afraid that I just couldn’t iron out my theoretical foundation enough to make it stick.”

“Yeah, but you know this literature. Maybe it will help if you talk it through. Tell me, what’s the difference between emotion work and emotional labour, and where does it fit in your work? How did you get here in the first place?”

“Well, I began research in emotion work and emotional labour during my undergraduate thesis work. My friend Sheryl Peters not only introduced me to autoethnography, but she also introduced me to the work of sociologist Arlie Hochschild. It all started in a paper I was working on outlining all the extra work disabled students do just *by being disabled*. I looked at the processes of disablement in academic spaces. I argued that to really participate, non-visibly disabled students must do extra work, such as by having to educate others on the right to accommodations. I argued that this extra work requires laborious efforts by disabled students and can be detrimental to their academic progress. Things like educating others about student rights to access inclusionary learning

spaces, such as accommodations, means that they have to engage in time-consuming tasks associated with getting accommodated instead of focusing on their own academic work. This can lead to higher dropout rates¹³⁴ and feelings of guilt and shame for not being able to keep up in their academic programs.”

“OK. But what about the difference between emotion work and emotional labour?”

“For that I have to look at Arlie Hochschild. Let’s see. . . . She introduced the concept of ‘emotional labor’ to look at how employees have to manage their emotions in particular settings where they have face-to-face interactions with customers. She describes ‘emotional labor’ as the work involved ‘to induce or suppress feelings in others to sustain the outward countenance that produces the proper state of mind in others.’¹³⁵ So ‘emotional labor is sold for a wage and therefore has *exchange value*.’¹³⁶

“Disabled workers, such as myself, who are employed by the university as teaching assistants, research assistants, or both, are protected by the *Code* and, like disabled students in dual roles of student and employee might also require workplace accommodations. In addition to the emotion work we undertake in our student role—which is unpaid work—we have the added work of doing emotional labour in paid spaces, such as by demonstrating that we are knowledgeable in our subject area to instill confidence in students about our teaching abilities.¹³⁷

¹³⁴ Barnard-Brak, Lechtenberger, & Lan, 2010; Dunn, Hanes, Hardie, Leslie, & MacDonald, 2008; Duquette, 2000; OECD, 2003, p. 41.

¹³⁵ Hochschild, 1983, p. 6.

¹³⁶ Hochschild, 1983, p. 7, (emphasis in original).

¹³⁷ Holly Ann Larson (2008) discusses the role of college professors as requiring emotional labour in the classroom, as unpaid and unacknowledged, which will be discussed in greater length throughout this work. See also Bellas, 1999; Bondi, 2005; Damiani & Harbour, 2015; Goodley, 2011; Hochschild, 1983; Price, 2011.

“Yeah and while this might be true for all students, this is distinct for disabled grads because of the social oppression we’ve internalized,”¹³⁸ Jules adds.

“Exactly. I’m not saying that many grad students don’t experience a lot of stress.¹³⁹ I’m arguing that not all students experience the particular stress that disabled students do. And a good way to understand this added work is in terms of emotion work and emotional labour.”

“But you really haven’t told me the difference between emotion work and emotional labour.”

“In the private realm, such as spaces in the home, ‘emotion work’ or ‘emotion management’ ‘refer to these same acts done in a private context where they have ‘use value’¹⁴⁰ but are unpaid so they don’t have exchange value.

“In my work, I use the concept of emotion work to refer to the unpaid work (distinct from emotional labour) that disabled students undertake to manage their own feelings and the emotions of those they interact with in spaces of academia. For example, I am constantly managing my feelings when I must offset perceived stereotypes attached to the label of disability and accessing accommodations. At the same time, I’m afraid I’ll be denied accommodations when others simply don’t believe that I am disabled, or I’m feeling embarrassed when I am perceived as being lazy when I can’t get my work in on time.

¹³⁸ Damiani & Harbour, 2015.

¹³⁹ See Soorenian’s (2013) work on the experiences of disabled international students and the academy.

¹⁴⁰ Hochschild, 1984, p. 7, (emphasis in original).

“There’s not a lot of scholarly work on disability on emotional labour¹⁴¹ and emotional geographies. Robert Wilton¹⁴² suggests that disabled workers perform various types of labour to manage their own emotions and those of their co-workers, supervisors, and customers, because they are trying to resist ableist stereotypes and legitimize their non-visible impairments. Some workers conceal their impairment by ‘passing’ as non-disabled to avoid the emotional work involved in legitimizing their ‘belonging’ in the workplace. In both situations, managing emotions involves strategies of what Wilton calls ‘feeling out’¹⁴³ to describe the efforts of workers with non-evident disabilities as they are constantly trying to figure out supervisors’ likely reactions to disclosure and/or a request for accommodations.¹⁴⁴

“The implication of not feeling comfortable to disclose means disabled persons may not access accommodations that might help them in their workplace. In the same way, accessing academic accommodations is emotionally charged, invisible work, which non-visibly disabled students do to negotiate ableist geographies of the academy.¹⁴⁵ So, looking at the added work faced by non-visibly disabled students is important.¹⁴⁶ It contributes to furthering ‘interest in shaping policy and agendas and the *place* of disabled people in contemporary society.’¹⁴⁷

“Jackie Leach Scully has done some great work on ‘hidden labor’ of disabled persons in social interactions with non-disabled persons. She describes how disabled

¹⁴¹ Goodley, 2011; Scully, 2009; Wilton, 2006; Wilton, 2008.

¹⁴² Wilton, 2008.

¹⁴³ Wilton, 2008, p. 368.

¹⁴⁴ Wilton, 2008, p. 368.

¹⁴⁵ Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010.

¹⁴⁶ Imrie & Edwards, 2007.

¹⁴⁷ Chouinard, Hall, & Wilton, 2010, p. 4, (emphasis in original). See also Dyke, 2010.

people use certain emotion tactics, such as displaying ‘gratitude for access or aid [even though disabled people] are entitled to such support by law.’¹⁴⁸ On several occasions during my grad school experience, I’ve felt grateful to the academy, even though I am entitled to these rights to academic accommodations and workplace accommodations. As I became more knowledgeable of my human rights to accommodations, no one told me about the challenges I would face, about the pain of being denied accommodations, or the extra work involved in educating the educators such as the ombudsperson office and even the disability services office. My emotional struggles are not acknowledged as an additional component to the work that non-visibly disabled grad students must do to access certain spaces. It is this gap of unrecognized work that I hope my research will contribute to, an area I hope to change. Does that make sense?”

“I’m following, yes.”¹⁴⁹

“This is why I want to elaborate on the emotion work and emotion labour for the conference in Rome. I want to acknowledge the lived experience of impairment and disability as embodied in spaces and society.¹⁵⁰ We’ve already talked about how discrimination and marginalization are embedded within public space, and how people live in those spaces in their bodies; well, I argue that emotions are part of embodiment. And the emotional experience can either enable or hinder how disabled people participate in these spaces and places.

¹⁴⁸ Scully, 2010, p. 30.

¹⁴⁹ Goodley (2011) explains, that “Disabled people learn to respond to the expectations of non-disabled culture – the demanding public – in ways that range from acting as a passive disabled bystander, the grateful recipient of others’ support, the non-problematic receiver of others’ disabling attitudes” (p. 92). See also Aguirre & Duncan, 2013; p. 540.

¹⁵⁰ Chouinard, Hall, & Wilton, 2010; Dyke, 1999; Hall, 2000; Gleeson, 1999; Parr & Butler, 1999.

“Nanc, it’s interesting that emotions have not been explored much from the study of geography¹⁵¹ of disability, considering the social relations we have to people and place?”

“Right? As geographers have noted, this is beginning to change. Getting back to my work, I show how our emotions shape our lived geographies. In my conceptualization so far, I work from the understanding that disabled students are unable to access learning when their educational support needs are not met by accommodations, such as flexible time lines, multiple teaching pedagogies, and collaborative decision-making that may take place between an educator and a student. In short, when educational support needs are unmet, disabled students face the prospect of negotiating ableist spaces. The same is applied to students in their dual roles as an academic worker, of course. I want to draw attention to the gaps in the literature about how these ableist geographies, as Chouinard puts it, are lived.”

“Ableist geographies? What’s that?”

“Chouinard has a good definition of ableist geographies: ‘the lived environments which incorporate and perpetuate physical and social barriers to the participation of disabled persons in everyday life.’¹⁵² Building on this idea, I suggest that we use emotional geographies to help us further understand how the stigma attached to being ‘disabled’ helps perpetuate ableism, you know, the presumption that every body is able-bodied and abled-minded, but also, how it’s lived in embodied ways and how it shapes their geographies as exclusionary spaces in academia.”

¹⁵¹ Bondi, Davidson, & Smith, 2005; Davidson & Milligan, 2004.

¹⁵² Chouinard, 1997, p. 380.

“OK. So when we met for the first time, I remember telling you about my issues with disclosure in the university—how I feared, and quite frankly, still do, disclosing to the school because of the stigmatizing effects associated with it. Is this an example of how space is socially produced and has implications for social exclusion or inclusion?”

“YES! Hang on; I have to type this out before I forget. I begin typing and speaking the words out loud: ‘Passing as able-bodied is a social response to the ways in which disabled people are not included in spaces and society.’¹⁵³ We pass to avoid the painful reactions of others, to fit in, and for all sorts of valid reasons. This is a particularly pressing issue for non-visibly disabled students, who may have more potential to pass as able-bodied, because their impairments are not always readily apparent. Goffman¹⁵⁴ refers to passing as an embodied way of concealing identifying social information that would reveal their social identity as a disabled person. As a result, non-visibly disabled students negotiate university spaces by passing, no pun intended, on entitled accommodations that are only accessible to us via disclosure.¹⁵⁵ Thus, academic spaces continue to reproduce environments that normalize students into passing as able-bodied instead of understanding that differences exist in the ways students learn and that these differences are part of the human condition.’ How does that sound?”

“Bang on, actually!”

I continue typing. “It’s not simply to suggest that there is a structural barrier; I am not denying that. What I am suggesting is that we need to take into consideration how

¹⁵³ Damiani & Harbour, 2015; Goffman, 1963; Goode, 2007; Titchkosky, 2001; Sierra-Zarella, 2005.

¹⁵⁴ Goffman, 1963.

¹⁵⁵ Aubrecht & La Monica, 2016 (forthcoming) to Canadian Journal of Higher Education; Damiani & Harbour, 2015; Farrar, 2004; Rose, 2009; Sierra-Zarella, 2005.

spaces make disabled students feel, how they embody spaces of academia as ‘ableist’, or rather, how spaces of disability are (re)produced.”

Jules is looking more intrigued. I think I finally got through.

“OK, go on,” Jules says.

“So as I mentioned, geographers are beginning to explore how emotions matter in the geographies of illness, impairment, and disability.¹⁵⁶ Disabled academics and disability rights advocates such as Vera Chouinard,¹⁵⁷ Isabel Dyke,¹⁵⁸ and Pamela Moss¹⁵⁹ bring emotions to the forefront of disabled women’s geographies and the ‘struggle to re-negotiate a changing embodied relationship with a restrictive social and built environment’.¹⁶⁰ For example, Chouinard, who identifies as a disabled scholar with a chronic illness, writes about her personal struggles for accommodations and inclusion in academic workplaces. By acknowledging that experiences of impairments and disability are embodied, Chouinard and others¹⁶¹ share in the social model’s political agenda of improving the lives of disabled persons¹⁶² by creating more inclusionary spaces in places of the academy. But they also take into account the emotions associated with space turned into place—or as Gleeson argues—working towards enabling geographies. While feelings of pain, frustration, and humiliation might be highlighted as ‘emotional highs and lows’ in accessing spaces to inclusion, Davidson and Milligan remind us that emotions ‘may

¹⁵⁶ Davidson & Milligan, 2004, p. 524.

¹⁵⁷ Chouinard, 1995/1996; Chouinard, 2010. See also Chouinard & Grant, 1999.

¹⁵⁸ Dyke, 1999.

¹⁵⁹ Moss, 1999.

¹⁶⁰ Davidson & Milligan, 2004, p. 524.

¹⁶¹ Butler & Parr, 1999.

¹⁶² See also Shakespeare, 2006.

nevertheless work as an incentive toward activism and perhaps enable a different sense of achievement.”¹⁶³

I pause, waiting for Jules to say something.

“Moving right along, then,” Jules says, “Hang on, I have this written in bullet points.” With a short pause, Jules turns to the computer and continues, “Yes, right, here it is. You want to include that emotions can help us in the following ways: by identifying barriers that remain invisible to others who may not understand the actual work processes of attaining accommodations; by scrutinizing the ways in which non-visibly disabled students are stigmatized; and by identifying successful accommodation strategies and recommending changes or additions to enhance existing practices and policies. You’re advocating that recognizing the extra emotion work and emotional labour involved in these graduate students’ academic spaces will help us to make these more inclusive for everyone.”

Before I have a chance to respond, Jules exclaims, “and that’s why emotions matter!”

We stare at each other before bursting out in laughter.

¹⁶³ Davidson & Milligan, 2004, p. 525. See also Goodley, 2011, p. 93.

Chapter Three: Discovering Autoethnography

“What is autoethnography?” you might ask. My brief answer: research, writing, story, and method that connect the autobiographical and personal to the cultural, social, and political. Autoethnographic forms feature concrete action, emotion, embodiment, self-consciousness, and an introspection portrayed in dialogue, scenes, characterization, and plot. Thus, autoethnography claims the conventions of literary writing.¹⁶⁴

I begin writing at page 758.

I was at the gym earlier today. I had set out for a cardio session: running on the treadmill with intervals of 5 minutes running and 5 minutes of walking. Instead, I got sidetracked after preparing for my first interval of running. My research and dissertation work is on my mind—surprise, surprise—I am too immersed with Carolyn Ellis and Art Bochner’s¹⁶⁵ chapter, “Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject.” I simply can’t put it down so I can run. I want so desperately to hit page 768, the last page of the chapter, but I find myself re-reading page 758. This page would literally mark (my pages are all marked up with different coloured highlighters) my understanding of my methods and methodology section for my dissertation work.

I’ve been stuck here for a while.

But, I am thrilled.

I became consumed in the field of autoethnography when my tutor, Sheryl Peters introduced me to it during my undergraduate thesis research. But today I feel like I am

¹⁶⁴ Ellis, 2004, p. xix.

¹⁶⁵ Ellis & Bochner, 2000.

reading this for the first time and falling in love all over again.

“Google autoethnography,” I can still hear her softly say to me like it was yesterday.

“*Auto-what*”? I replied.

“Au-to-eth-nog-ra-phy” she slowly sounded it out for me. “Yes. I think it’s just the qualitative methodology you are looking for. But don’t take my word for it. You should start by looking up ‘Carolyn Ellis’. She’s the guru of autoethnography. I think you’ll love it!”

Indeed, I did.

It was love at first read.

It didn’t take long for me to plug “autoethnography” into a Google search engine. I can’t remember how many times I misspelled it. Quickly, I learned that autoethnography is a narrative approach that a researcher uses to critically analyze the lived experiences of a particular phenomenon. Shortly after, I did another Google search by typing in “Carolyn Ellis”. My search legitimized that Ellis is considered one of the most eminent autoethnographic researchers. She describes autoethnography as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural.”¹⁶⁶ As Ellis notes, authors “use their own experience in culture reflexively to bend back the self and look more deeply at self–other interactions.”¹⁶⁷ Autoethnography is a form of qualitative research in which the researcher

¹⁶⁶ Ellis & Bochner, 2000, p. 739.

¹⁶⁷ Ellis & Bochner, 2000, p. 740.

is also *researched*.¹⁶⁸

Yes, this was just what I'm looking for!

Initially, I didn't fully understand what "autoethnography" was. But, it didn't take long for me to establish what I believe will be a lifelong relationship with this methodological approach—one that would follow me into my graduate work. I gathered as much scholarly material as I could to understand what exactly it was, and more importantly, *how to do it*. With no manual or guide for me to follow on how to do autoethnography, I soon felt defeated. I was getting confused about whether autoethnography was a methodological approach or method. I started thinking, once again, that maybe academia was not the place for me—these thoughts take me as far back as elementary school, where I never felt "smart" enough as I struggled with comprehending the curriculum being taught. Now, the only certainty I had was my passion to tell a story. I wanted to share what my experiences of being disabled in and by academia felt like. More importantly, I wanted to share my story in relation to other students like me.

I had read and re-read the Ellis and Bochner chapter several times over when I was first introduced to this method and methodology. It never *fully* made sense.

Today is different.

Today brings new meaning.

I feel like I've been awakened by an epiphany. I wonder if it was Ellis's responses to "Sylvia's" questions (coincidentally, also a doctoral student) that helped me realize this

¹⁶⁸ Chase, 2011, p. 423; Ellis & Bochner, 2000; Ellis, Adams, & Bochner, 2011.

moment when the chapter *finally* resonated with me, so that I could move forward with my work non-traditionally.¹⁶⁹ At this point in the chapter, Ellis writes, “But just because we decide to do analysis doesn’t mean we have to do it traditionally.”¹⁷⁰ She explains to Sylvia that there are multiple ways of doing this work, rhyming off alternative ways that others have used autoethnography in their work. Ellis suggests that Sylvia might think about using “snippets” of her participants’ stories in each of her dissertation chapters.¹⁷¹ This conversation really strikes me. I felt like I was right there. I realize that I want to do autoethnography.

It has taken me months to get here. I can beat myself up for not arriving in this place sooner, but I don’t.

The point is, I’m finally ready to write.

I figured out that autoethnography is both a methodology and a method. As methodology, autoethnography is a type of ethnographic research that values the researcher’s own personal experience as data.¹⁷² Ellis, Adams, and Bochner write, “A researcher uses tenets of *autobiography* and *ethnography* to *do* and *write* autoethnography. Thus, as a method, autoethnography is both process and product.”¹⁷³ Through this autoethnographic approach, I aim to gain a better understanding of how non-visibly disabled graduate students—like myself—negotiate everyday embodied

¹⁶⁹ Ellis & Bochner, 2000.

¹⁷⁰ Ellis & Bochner, 2000, p. 758.

¹⁷¹ Ellis & Bochner, 2000, p. 758.

¹⁷² See for example, Adams, Holman Jones, & Ellis, 2015 (chapters 1-2).

¹⁷³ Ellis, Adams, & Bochner, 2011, (emphasis in original, under “History”).

experiences of being disabled in academia. I critically analyze the lived experiences of this particular phenomenon as both a researcher and a co-participant of my own study.

Art Bochner explains,

Autoethnography is inquiry; something we can call experience is being inquired into, interpreted, made sense of, and judged. Facts are important to an autoethnographic storyteller; they can and should be verified. But facts don't tell you what they mean or how they make you feel. The burden of the autoethnographer is to make meaning of all the stuff of memory and experience—how it felt then and how it feels now.¹⁷⁴

This is it. I know what I am doing.

My committee knew I was doing autoethnography.

But they didn't know I was going to write it up like this!

An agonizing week goes by. I'm preoccupied about my meeting with my supervisor. I've been having dreams about it in anticipation. While I'm a bit anxious about it, I'm also excited about sharing my creative approach with her. I have a committee meeting coming up, so the timing is perfect; but I need to run this by my supervisor first, before sharing it with the whole committee. While I anticipate she'll be supportive, I'm not sure how she'll respond to writing the dissertation as a story using elements of creative non-fiction writing¹⁷⁵ and interpretive narrative.¹⁷⁶

Ellis further writes,

Usually written in first-person voice, autoethnographic texts appears in a variety of

¹⁷⁴ Bochner, 2013, p. 54.

¹⁷⁵ Anita Sinner (2013) explains that "Creative nonfiction begins with transdisciplinary perspectives on the constructs and practices of expressing self in a broader social community..." (p. 2). See also Ellis & Bochner, 2000; Leavy, 2013.

¹⁷⁶ See for example Adams, 2011; Tillman-Healy, 2001; Goodall, 2008; Leavy, 2013; Richardson, 2000; Sinner, 2013.

forms—short stories, poetry, fiction, novels, photographic essays, scripts, personal essays, journals, fragmented and layered writing, and social prose. They showcase concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness. These features appear as relational and institutional stories affected by history and social structure, which themselves are dialectally revealed through actions, feelings, thoughts, and language.¹⁷⁷

I'm nervous. I've given this a lot of attention and have read a lot. But, I'm not sure if I'll be able to articulate what I want to convey, as I'm still working this out in my head. To represent and write this dissertation, I want to use a layered account approach¹⁷⁸ to weave in the literature in the same way many autoethnographers do.¹⁷⁹ Ellis, Adams, and Bochner explain that,

... unlike grounded theory, layered accounts use vignettes, reflexivity, multiple voices, and introspection (Ellis, 1991) to "invoke" readers to enter into the "emergent experience" of doing and writing research (Ronai, 1992, p. 123), conceive of identity as an "emergent process" (Rambo, 2005, p. 583), and consider evocative, concrete texts to be as important as abstract analyses (Ronai, 1995, 1996).¹⁸⁰

Skype call rings in.

OK, this is it. I don't immediately answer, as I need a chance to take in some breaths. I also need another sip of coffee. I let the call ring a few times before I pick it up. We are both on a video call. After a brief greeting and my giving her a progress report, the nerves rapidly set in as I feel her question coming.

"Have you given much thought about how you plan to write your dissertation and represent the data?" my supervisor asks.

¹⁷⁷ Ellis, 2004, p. 38.

¹⁷⁸ Ronai, 1992, p. 123. See also Goodall, 2008, p. 70.

¹⁷⁹ T. Adams, personal communication, April 01, 2014. See also Adams, 2006; Ronai, 1992; Tillman-Healy, 2001.

¹⁸⁰ Ellis, Adams & Bochner, 2011.

There it is.

Crap! I knew I couldn't stall her much longer. I should have had a clear response ready, but I don't. I can see my face turn beet red through the camera on my computer as my supervisor waits for a response. Here is a moment of internalized ableism,¹⁸¹ where people like me, with lived experience of ADHD and other disabilities, embody internalized ableism. This is an important aspect of my research. As a graduate student, I have this overwhelming belief that you can and need to instantly respond to tough and complicated questions as they are posed to you. This is not something this girl can do—and it's not something that should be a prerequisite of being a graduate student. My supervisor has never made me feel this way either. My self-doubt was alive and well in this moment. Whenever something goes wrong—especially in an academic setting—I am constantly battling the internalized ableist devil that tells me that this is a result of my disability. That, when I cannot respond right away, it must be due to my disability, rather than ableist practices that do not support my needing more time to respond, or the fact that I am just not supported as a disabled student who needs extra time without feeling stigmatized.¹⁸² I feel like my mind is playing head games with me.

OK. I'm ready. I smile back at her and say, "I'm not quite sure yet!"

Oh crap. Did I just blurt that out? Here is another moment of internalized ableism at its best. I ask myself: what do you mean you're not quite sure yet? How is it that I could articulate all of this to Jules with no trouble, but face-to-face with my supervisor,

¹⁸¹ Campbell Kumari, 2008; Hutcheon & Wolbring, 2012.

¹⁸² Mullins & Preyde (2013) reflect on disabled students' experience notion of the imposter phenomenon. See also Damiani & Harbour, 2015; Shessel & Reiff, 1999.

all I can muster is, “I’m not quite sure yet”? Of course, I’m sure. I’ve never been surer of anything before. What is holding me back? Why am I so petrified of explaining that I want to challenge traditional ways of writing dissertations? And that I’m not the first? There are many before me who have embarked on similar challenges. There are those who’ve written their dissertations as a graphic novel, or as a blog, or in indigenous languages and even languages such as ASL.¹⁸³ There are others who include poetry and art. I am following in this non-traditional genre of writing as a way of both breaking the mold on traditional dissertations and allowing more people into these spaces, and more importantly, as a way for me—with my disability—to communicate my ideas and thoughts about this matter. I want to write my work so it’s accessible.¹⁸⁴ As Leavy writes, “Researchers across the academy, but particularly in the qualitative community, are seeking new ways of making their work more accessible.”¹⁸⁵

As I wrote in my comprehensive comps, the process (how I collected data) and product (how I wrote this) autoethnographic dissertation is my self-accommodation.¹⁸⁶ I used online methods as a way to avoid having to transcribe text that I knew I wouldn’t be able to do in a timely matter.

I’m trying to articulate that this way of doing, and writing my thesis, is also a way to self-accommodate in an academic context that continues to privilege only certain ways of being “capable”. Being restricted to writing in a traditional social science genre

¹⁸³ Francis, 2015.

¹⁸⁴ Smith & Sparkes, 2008, p. 25.

¹⁸⁵ Leavy, 2013, p. 22. See also Richardson, 2000.

¹⁸⁶ Damiani & Harbour, 2015; Grundy, Pollon, & McGinn, 2003. See also Aguirre & Duncan, 2013.

would mean that I would never finish this dissertation within the timeline given—because I just can't easily write like that.

Susan Chase summarizes my feelings about autoethnography so eloquently, noting,

The goal of autoethnography... is to show rather than to tell (Denzin, 2003, p. 203; Saldaiia, 2008, p. 201) and thus to disrupt the politics of traditional research relationships, traditional forms of representation, and traditional social science orientations to audiences (Langellier & Peterson, 2006; Miller & Taylor, 2006).¹⁸⁷

I know this is why I want to do autoethnography. Yet, all I can do is draw a blank and mutter the words "I'm not quite sure yet."

I'm so damn frustrated with myself.

Getting Started in Creative Non-Fiction Writing

Holy shit!

That's Tony Adams!

I first met Tony at the “Doing Autoethnography” conference in San Angelo, Texas in February 2013. Tony was the one of the keynotes listed on the call for papers. His name looked familiar, but I couldn't piece it together at the time. Not too long after I submitted my abstract, I recognized his name—and who he was in the field of autoethnography.

I am beside myself.

I am going to meet that guy.

I was so excited that he was going to be at the conference that I made Jules change

¹⁸⁷ Chase, 2011, p. 423.

our travel plans to leave from Dallas early so we could make it in time for Adam’s book launch of *Narrating the Closet*.¹⁸⁸ Despite rental car issues that had us delayed by an hour, in addition to getting pulled over by the Texas police for speeding, we made it just on time.

Prior to the book reading, I had made arrangements to meet with the conference organizer, Derek Bolen, whom I had been e-mailing for several months leading up to the conference. He had graciously offered some time to chat about my work and some concerns I had with doing autoethnography.

“I need some advice about how to write my findings of the research without implicating others, including myself.” I told Derek. We met over coffee to discuss some strategies—from disguising identities to constructing scenes in my writing—before Derek suggested that I speak with Tony Adams. Derek characterized Tony as being approachable and shared his sense that Tony would be more than happy to discuss this with me over the course of the conference weekend.

He was right!

Thanks Derek.

It’s 7 p.m. We’re gathered in the university lecture hall waiting for the book launch to start. There are rows of other students and scholars filling the seats. It’s a full house. Jules and I find two empty seats in the front row. Neither one of us knows what to expect. I’m thrilled to be in the audience with autoethnographers including Tami Spry and Stacy

¹⁸⁸ Adams, 2011.

Holman Jones. I have read their autoethnographic work, so it's exciting to be a part of a weekend where I'd be attending their workshops and meeting them in person.

Tony's up!

He begins.

Within minutes, I find myself squirming into my seat, carefully hiding tears and wiping them away with hand gestures, hoping Jules and others won't see me. It didn't take long to realize that I wasn't in isolation. You could hear the sniffing of numerous audience members and as I watched, tissues were passed around one row to the next. My long sleeve shirt was drenched in my own tears as Tony continues reading.

No one told me to bring Kleenex.

In his talk, Tony discussed lived experiences of same-sex attraction, passing, and disclosure amongst other important and sensitive topics. His talk is coming to an end.

No, no. Don't stop! I have so many questions. I want more.

Jules and I turn and stare at each other. But we say nothing. It was as if we both knew what the other was thinking. And were both aware of the importance of this moment, for we rarely shared silent moments. At the end, Tony opens the floor to questions from the audience. I'm too shy to ask whether Tony explores aspects of disability and passing in his work, at least not in front of a full lecture hall with all of these academics.

The power of autoethnography was clear that night: the cracks in his voice, the pitch of his voice, the movement of his body from one end of the stage to another. It was different to have the person who *lived the experience* read their experience to us. Having

Tony share his thoughts, written down, edited and still full of his voice and passion, it was the most profound book launch I've ever been to.

After the book reading and Q&A, the conference attendees were invited for a book signing. I immediately line up to purchase his book and asked him to sign my copy.

I'm next.

As I stand across the table from Tony, I express my excitement about his work and congratulate him on his work. I tell him how much of his work relates to the work I am doing on disability and passing in the academy. I have no trouble disclosing to him that I'm a non-visibly disabled grad student. The process of deciding where and to whom to disclose doesn't naturally come this easily and quickly to me. But something about this space just felt safe. Tony smiles at me and thanks me for sharing this with him. It didn't take long for me to forge a collegial friendship with him after he signed my book: "To Nancy—To making life better—and to continuing the autoethnographic tradition! Warmly, Tony."

"Would it be OK if we continued to chat by e-mail Tony?" I nervously ask.

"Yes, of course. I'll write my e-mail here inside the cover of my book. Feel free to touch base. I'll see you around this weekend."

Jules is right beside me, and I can hear them sighing under their breath, "Tony, you have no idea. She will (academically) stalk you!"

I will.

I have.

Jules knows me all too well.

After a full day of attending conference presentations, Tony and I arrange to meet. We find a wooden bench to sit on outside the hallways of the university to talk. The bench is uncomfortable, like the ones you find in hospital rest rooms, but this doesn't seem to bother me. Almost immediately, I can feel my eyes welling up—trying hard to hold back tears as I share my story with Tony.

“I have ethical dilemmas,” I say as he smiles back at me. “I worry about implicating others in my storytelling, and about protecting my own identity. I know that you and Carolyn have written about this.”

I continue to share my fears about disclosure in the academy and the struggles attached to being non-visibly disabled in a graduate program. “How can I share my story without revealing details that might bite me in the ass later? I want to survive this PhD in one piece. I don't want to feel like I have to self-censor what I write. I have heard from some disabled professors who don't disclose to their university or who have only written about it after being tenured, while still others wrote and spoke publicly about having been psychiatric patients before being hired or tenured.¹⁸⁹ They share similar fears of not being able to gain or keep employment in the academy, fears of being treated differently, and more.”¹⁹⁰

¹⁸⁹ For example, Professor Geoffrey Reaume publicly disclosed his psychiatric history in print and in public talks during the 1990s long before he was hired at York University in 2004 and tenured in 2007 (G. Reaume, personal communication, June 07, 2016).

¹⁹⁰ Numerous scholars (Chouinard, 1995/1996; Chouinard, 2010; Jago, 2002; Moss, 1999; Price, 2011; Rose, 2008; Titchkosky, 2003) have written about their accounts of disability in the academy.

Tony suggests I review *The Ethnographic I* where Ellis¹⁹¹ uses composite characters to tell stories in an attempt to protect identities. In her methodological novel, she reconstructs a graduate classroom as a way to teach about autoethnography.¹⁹²

“Yes, I have her book, but I haven’t read it from start to finish. I have also been in contact with Ellis since my undergraduate studies. She’s wonderful—such a blessing!”

Tony continues to explain that maybe one way I could conceal identities is to use fictional characters and construct fictional scenes, in the same way Ellis did in that novel.¹⁹³ I’d still be speaking the truth, but blurring the lines so that I don’t risk implicating others and/or myself in the research.¹⁹⁴

Constructing composite characters is a method that might just work. Tony made me realize I just might be able to survive my doctorate after all.

Thank you, Tony.

It takes me at least another six months before I finally get back to reading Ellis’ research novel closely again. But it’s all there on page 758 of the chapter she wrote with Bochner, where I had my methods epiphany. She explains “...you could fictionalize a detail in a way that camouflages the actual event but still conveys the meaning you want to get across. Or use pseudonyms or composite characters, if that helps.”¹⁹⁵ When I return to her novel, I turn straight to her preface, where she explains the structure of her novel

¹⁹¹ Ellis, 2001.

¹⁹² See also Hernandez & Ngunjiri, 2013.

¹⁹³ Geographers Moss and Dyke (2002) also employ this method. See also Chang, Wambura Ngunjiri, & Hernandez, 2013, p. 126.

¹⁹⁴ Adams & Ellis, 2014 (unpublished manuscript); Adams & Ellis, 2012; Chang, 2008; Holt, 2003.

¹⁹⁵ Ellis & Bochner, 2000, p. 758.

and story, and it all comes together now. Ellis writes,

In this work, I intentionally combine fictional and ethnographic scenes. I never actually taught the class I describe, two of the characters are made up, and many of the scenes did not take place. What *has* taken place is that I've watched (and felt) myself learn, write and teach autoethnography for the past eighteen years... This book is based on ethnographic details, making it possible to construct the ethnographic scenes that happened and the fictional scenes that didn't—but could have.¹⁹⁶

I turn back to Tony's book. Processing all of this information seems easier to me now. Despite how much I'm absorbed in the story and the literature alongside of it, it takes me a long time to process, let alone, finish readings—it can be a real pain to be honest, especially when trying to make it in the academy.

But I am proud that I made it through.

Six Months Later: An Outline is Born

“I still don't have an outline for my dissertation Jules. I told my supervisor I'd have an outline ready ASAP. That was six months ago! What the hell was I thinking? I'm freaking out! Why can't I get started on the writing? I know the methodology. I know autoethnography. I know how I arrived at my methods. I can write my thesis using creative non-fiction elements to narrate my work including the process of actually *getting here*.”

I feel my eyes about to flood with tears of frustration. I'm trying desperately to hold these emotions back as I blurt this out to Jules upon being greeted at the door. I barely give Jules a chance to even say “hello.” Fortunately, my anxious behaviour is nothing new to Jules.

¹⁹⁶ Ellis, 2004, p. xx.

I've been here before.

“Nanc, calm down.” Jules says with a nurturing laugh, trying to assure me that it'll be fine. “What's that line you always tell me: 'You've got this.' You know you do. Why don't we pull up the current drafts you've written so far and work from these to map out an outline together? I can't imagine working without an outline. I have no idea how you get anything done without one. Come in, I'll make some coffee.”

“I really don't know what it is about outlines. I just hate them. I've tried working with them, but I end up focusing all my time and attention on the damn thing I end up getting nothing written for my actual work. It's frustrating.”

“Don't worry. We'll figure this out. Just take me through the process of the research. The great thing about writing a scientific paper is that there are rules for where stuff goes. So in some ways that makes it easier, but if you don't like working that way, we have figure out how to make sure you have all the components of a scientific paper, even if you call them something different.”

“That's just it. How do I articulate this to the committee?”

“Is that supposed to be rhetorical question?”

I stare at Jules blankly.

“That's the whole point of an outline, Nanc.”

“Yes, of course. Sorry. I told you I'm nervous.”

“Typically, for a thesis in social science as you're writing, you'll need an introduction, a theoretical framework, methods section, results or analysis section, discussion and finally a conclusion. But you objected to the notion of a traditional thesis

right? Ideally, as long as you're meeting all the requirements of a typical thesis, you'll be fine. You'll just be creative about how you meet those requirements."

"Are you sure?"

"Yes, I'm sure. OK. Take me through your process. Let's start with how you collected your data since your methodology and methods chapter seems to be an area you're most nervous about right now? Sit down. Take me through it again while I turn the coffee on. Tell me what you did. Remind me how you collected the data. From here, we'll record your process, and I'll help you put this into chart form...."

"I hate charts as much as I hate outlines!"

"Well, I need a chart. Besides it will help clearly show you're meeting all the components of a traditional thesis in a non-traditional manner. This will make more sense in no time, you'll see. I'll take notes. You just talk as you usually do," Jules chuckles.

"And for goodness sake! Stop worrying."

I take out my laptop, open my thesis proposal document, and create a document entitled "Methods".

"Oh yeah, here it is." I take a minute to catch my breath. Reading from my proposal, I say, "I draw from two Canadian universities. I can't name them as I promised anonymity in my ethics application and to all the informants of this study. I'll have to figure out what to call them without making them known. I also used multiple methods of data collection. I wanted to collect data on accommodation policies as they are experienced by disabled students, perceived by the people who facilitate them, and what the policies actually say."

“Wait. Wait. I thought you were doing autoethnography? Isn’t that just telling your story?”

“Well, yeah, that was the initial plan. But after reading and re-reading, I realized it’s important to capture other perspectives, at least for my dissertation. I felt it was imperative that I work in solidarity with other disabled graduate students, a population that receives little attention. This story, after all, doesn’t just belong to me.

“Heewang Chang says, and I’m quoting here, ‘multiple sources of data can provide bases for triangulation that will help enhance the content accuracy and validity of the autoethnographic writing.’¹⁹⁷ Studies say that the voices of disabled students themselves continue to be absent from the literature,¹⁹⁸ so I wanted to get multiple perspectives of experiences. Besides, this is an important way to ensure that I am not privileging my own story, a common critique against autoethnography.”¹⁹⁹

Jules can’t resist. “So there you are: you’re talking about the limitations of your methods. That usually goes at the discussion section. But first tell me how you collected your data.”

“So, in essence, I had planned to rely on four kinds of data: my own experience;

¹⁹⁷ Chang, 2008, p. 55.

¹⁹⁸ Denhart, 2008; Duquette, 2000; Farrar, 2004; Fuller, Healey, Bradley, & Hall, 2004.

¹⁹⁹ Chang Heewang (2013) explains,

...individual autoethnography is at risk of privileging one perspective. Researcher subjectivity in qualitative research is a long standing topic of debate; to this debate autoethnography adds one more dimension—mixing the researcher role with the participant role. The concern with the privileged perspective of the author-researcher-participant, raised by Anderson (2006) and defended by other autoethnographers (Denzin, 2006; Ellis & Bochner, 2006), should be carefully considered as researchers undertake individual autoethnography. The researchers may either maximize the full benefit of individual autoethnography—delving deeply into the researcher’s experiences with the recognition of their limited perspectives—or incorporate perspectives of others in their individual autoethnographies (p. 111). See also Holt, 2003.

interactive interviews via blog interviews with six other non-visibly disabled graduate students; e-mail interviews with key informants from both universities; and discourse analysis of institutional texts that inform disability accommodations from both of the universities. With the discourse analysis, I wanted to compare what the institutional policy says with the actual experiences of the non-visibly disabled students, as they negotiated inclusion and exclusion within the academy. So I looked at accommodation policies, employment policies, and human rights legislation that was applicable to disabled grad students. But this didn't work out the way I had planned."

"Well, yeah. That's never happened to a researcher before! Just tell me what you did."

I roll my eyes at Jules. "First, I used innovative methodological approaches including virtual (online) data collection following Annette Markham's, Ellis', and others' work.²⁰⁰ I used this method to collect data from all co-participants. I did this simultaneously while using e-mail interviews to collect data from key informants. But that didn't work out."

"What do you mean? What happened?" Jules probes.

"It's not like my plan for this study changed; however, the plan didn't work out as I had set out. I felt it was critical to incorporate multiple perspectives to better understand students' experiences. I mean, these perspectives are crucial in understanding the barriers and enablers of fostering inclusive academic spaces. I had no intention of taking away

²⁰⁰ Ellis, 2004; Markham, 1998. See Robyn Boylorn (2013) who uses blogging as a method of autoethnography.

from the disabled student voices—it was quite the opposite. I use premises of inclusive research approaches to ensure the co-participants’ voices are part of the research process,” I try to reassure Jules.

“I’m not following. What happened? Why didn’t it work out?”

I continue, “Well, the key informant aspect didn’t work as I thought would. And I didn’t do a full discourse analysis on the written policies...”

Jules interrupts, “One thing at a time. Why didn’t the key informant interviews work out as you’d hope?”

“Well, it’s linked. For starters, there wasn’t much ‘discourse’ to analyze in the policies, and they were supposed to be the basis for my key informant interviews. I did review key policy documents to inform the key informant e-mail interviews—but the key informants are people at the universities who could speak to how these policies play out in practice. However, I never wanted to interview key informants. I wanted this work to be strictly about disabled grads. I had to remain open to the advice I was given from my committee, and I was. I tried. But it just didn’t work the way I wanted it to. It felt to me that if I was going to remain true to the perspective of “nothing about us without us”,²⁰¹ I couldn’t do this because many of the co-participants didn’t actually speak to the policies during our blog discussions. In truth, I am finding the key informants data aren’t getting used that much. As much as I tried to gain this perspective, the co-participants didn’t explicitly speak about the ways in which the policies informed their lived experience. I mean, this came out when we shared experiences of not wanting to go through the

²⁰¹ Charlton, 1998; Fudge Schormans, 2011; Kitchin, 2000; Oliver, 1990.

accommodation process as both a student and an academic worker. But these experiences were quite limited, and I made the decision to focus solely on where the blogs took me. Rather than completing a full discourse analysis of the formal written policies about accommodations, I ended up instead looking at how the processes made co-participants feel—capturing what they wanted revealed as most important in sharing their voices.”

“OK, slow down. I think you’re conflating what happened with what you set out to do. So you planned to do a discourse analysis, key informant interviews, gather the perceptions of your co-participants—all with the purpose of examining whether there were discrepancies between the written policy and the experiences of students. Is that right?

“Yes, but it didn’t work out because....”

Jules interrupts, “Because the policies did not figure into the whole thing as much as you thought they might. The policies weren’t a big part of how your co-participants experienced the process of getting accommodations. So you focused more on what the co-participants had to say, and less on what the universities had to say, either in writing or through the key informants. Is that fair to say?”

“Yes, and I worried about that because my committee wanted me to....”

Jules waves me off. “Never mind that for now. So in a traditional outline, you would say what you plan to do under in the methods section, and what actually happened in the results section, and then talk about why it didn’t work out as planned in the discussion section. See why I like outlines? You may want to breathe by the way.”

I realize I have been holding my breath. I start to breathe again. ‘No, I don’t see

why you like outlines, but whatever it takes to get this done,” I mutter, sipping the coffee Jules has handed me.

“So now,” Jules says, “All we have to do is figure out how you want to talk about your methods, results, and discussion in a way that works for you, but convinces your committee that you’ve covered everything. OK?”

“OK.”

“Before we move on, remind me of your research questions again.”

“Hang on. I have to scroll through my proposal. Ah, here we are. I’m using an interdisciplinary approach to address the following four overarching research questions: First, what are the formal written accommodation policies and procedures at each University? Next, what are non-visibly disabled graduate students’ experiences of seeking accommodation of their needs? How do these students’ experiences compare to policies and procedures laid out in institutional documents? How does university staff (e.g., those counselling disabled graduate students) in practice try to assist these students in securing accommodations? For example, what factors enable and/or constrain their capacity to ensure that student needs are accommodated?”

“OK, I got it.”

“Great!” My excitement is quickly followed with a sense of self-doubt, “But where do I start?”

“From the beginning. Where else would we start?”

“Very funny, smartass.”

“You’ve told me what you planned. Now tell me what you did—start from data collection.”

“Calling all Disabled Graduate Students (Including Me)”

Hi Nancy,

I saw your recruitment poster at my university and would like more information about your project. I’m a second year PhD candidate with a non-visible disability. I’m also a TA. More importantly, I have experienced issues of stigma in relation to feeling pressured to disclose in order to receive academic accommodations. But it wasn’t until I saw your recruitment poster that I realized that as a disabled graduate, I am entitled to workplace accommodations. I was not aware of this information.

Do I meet your inclusion criteria?

Jules

Hi Jules,

Thanks for your interest in this study. To participate in this study, you must be a student pursuing or have pursued a Master’s degree or PhD at [names of universities], who identifies as having a non-visible disability such as ADHD, LD, or mental health disability. You must have either worked or are currently working as a teaching assistant, research assistant, or course instructor during your graduate degree at your respective institution. Note: You do not currently need to be in these dual roles as both paid worker and student to be in the study. Finally, you must agree to the terms of participation (e.g., you might be identifiable due to the small numbers of participants in this study).

And yes, you most certainly do fit the inclusion criteria!

As a participant,²⁰² you’ll be asked to blog via a private secure webspace with me and five other non-visibly disabled graduate students about your experiences of being disabled by the academy. We will explore issues around disclosure and what

²⁰² I didn’t decide to call them “co-participants” until we worked through the study.

that means and feels like for disabled grads and the extra work students do in managing stigma in the workplace and learning space. For example, students may find themselves managing the perceptions of professors, peers, or admin staff who may not understand disability as a systematic barrier located within the structures of the academia.

If this is of interest to you, I'd be happy to e-mail you a letter of consent form.

Warm regards,
Nancy

Hi Nancy,

I have a story to tell!
I want my voice heard.
When can we start?

Sincerely,
Jules

“Next, let’s chat about recruitment. I remember reaching out to you via e-mail. But take me through this.”

“Yes, I remember our e-mail conversation too—mostly because recruitment for this study was a challenge, and you were one of the first to reach out to me. The first thing I did was to send out the recruitment e-mails to listservs and disability counselling offices. I also put posters around both campuses. But I wasn’t receiving as many e-mails as I had hoped for. So I decided to do purposive sampling²⁰³ recruitment. Plus, I wanted to include students that don’t necessarily identify as disabled, so I had to be creative. So, I used my

²⁰³ McGuirk and O’Neill (2010) explain that

purposive sampling ... is commonly used where sample selection for questionnaire respondents is made according to some known common characteristic, be it a social category..., or an experience.... There are no specific rules for this type of sampling. Rather, the determinants of the appropriate sample and sample size are related to the scope, nature, and intent of the research and to the expectations of your research communities (p. 205, emphasis in original).

networks both for the snowball sampling²⁰⁴ and to reach out to those who might not identify as disabled. I have always worked hard to establish collegial networks with relevant graduate organizations at each of the two research sites. So, the snowball sampling allowed me to access graduate students who self-identify as non-visibly disabled, but who don't register with disability services. I provided contact information for interested students should they wish to discuss the study further.

“How many co-participants did you include again? Six, right? That was enough?” Jules curiously probes.

I pause before I respond. I know what Jules is getting at, but this is a qualitative study. I am not trying to generalize my findings to the entire population of non-visibly disabled grad students. My head is filling up with the nightmares I had with the ethics review process, as I recollect that this very question was posed to me by one of the reviewers. I turn my attention back to my research journal that I have been keeping in a file on my computer. Without even realizing it, I start reading out loud to Jules:

November 16

Today marks the day of my ethics nightmare. I had been preparing the ethics protocol application for about six months prior to the first submission. I had feared this process, as I knew that autoethnography would be hard to get ethics approval for—even harder to get passed with the type of research I wanted to do with disabled people.²⁰⁵ With the amount of preparation I did on the ethics protocol (e.g., meeting with the ethics office adviser multiple times, reviewing my application with my committee, re-reading the tri-council ethics protocol), one would only assume this would go smoothly. Of course, I was wrong!

²⁰⁴ Bradshaw and Stratford (2010) explain that “**snowball** (or *chain*) **sampling** identifies cases of interest reported by people who know other people involved in similar cases (Kirby & Hay 1997; Stratford 2008, p. 75, emphasis in original).

²⁰⁵ Kitchin, 2000; Oliver 1990.

One of the reviewers asked me if six other subjects would be sufficient given the wide range in disabilities fitting within the inclusion criteria. This was marked by the ethics committee as a minor concern.

Good question I think to myself.

This is a qualitative study. This study does not purport to be a representative sample of all non-visibly disabled graduate students in each of the two universities. I included that too. I'm certainly not trying to represent all graduates' experience of non-visible disabilities. I'll justify this to the ethics committee by citing Ellis and Bochner's "Methods of Collecting and Analyzing Empirical Materials"²⁰⁶ where Ellis discusses how only "five or six" participants including the researcher are needed for a study. She writes, "You'll want to interview each woman a number of times to build trust in a relationship, and also so they can read and respond to each transcript before you follow up with the next interview."²⁰⁷ I also came across Mike Hayler's *Autoethnography, Self-Narrative and Teacher Education*,²⁰⁸ in which he too uses a small sample for his autoethnographic work. I reiterated to the ethics board that seven participants is indeed sufficient as this is a qualitative study in which I am seeking rich data; it does not purport to be a representative sample of non-visibly disabled graduate students in Ontario. I concluded my comments to them by citing Patricia Leavy²⁰⁹ who argues, "Narrative inquiry often relies on small sample sizes but produces rich case studies."²¹⁰ Since autoethnography and narrative inquiry are the methods I use in this study, yes, six participants would be enough—in fact, one voice, my own, would be enough.

I finish reading this to Jules.

"In the end, it took me almost a year to finally get ethics approved," I say. "I ended up with six co-participants selected from two southern Ontarian universities; three from each site. I wanted to maintain a balance between master's and PhD students, and, though this was tricky, I did end up with three PhD students and three master's students. All co-participants had current status in their program, with the exception of one co-participant who had to drop out of their PhD program prior to the research due to medical and

²⁰⁶ Ellis & Bochner, 2000.

²⁰⁷ Ellis & Bochner, 2000, p. 756.

²⁰⁸ Hayler, 2011. See also Leavy, 2009, p. 28.

²⁰⁹ Leavy, 2009, p. 28.

²¹⁰ Leavy, 2009, p. 28.

personal reasons. It was important that my study did not exclude part-time students or students who are not working for a university at the time of the study.

“All of the student co-participants self-identified as being non-visibly disabled, experiencing for example, ADHD, mental health disabilities, and learning disabilities.”

“Yikes. That’s intense. I remember you telling me about some of your ethics delays. This sounds like a great paper to write in the future.”

“Yeah, that’s for sure. But it’ll have to wait until I defend this first.”

“Yes, of course.”

Narrating Access

“OK. What happened next? Take me through the phases of the study.”

“Because I wanted to use online methods, I first had to set up the blog website.”

“Wait. What? A blog? Why a blog? Online methods? How do you come up with these ideas?” Jules laughs.

“Yeah. I first got the idea for a blog from my interest in social media sites like Facebook and Twitter. Since I use social media platforms for therapeutic purposes—you know, when I need to vent about how disabling academia can be—I began hearing from other marginalized students (and faculty) that shared in my anger and frustration. I found that social media platforms offer an outlet and source of support to connect with others. It wasn’t long ago that I learned how to use Twitter just so I could follow the hashtag #AcademicAbleism. Here disabled grad students share stories of ableism in the academy from all over the world. It’s really interesting. One of my friends posted it on Facebook

and that was it, I was hooked. I was also relieved to follow the tweets about other students facing the same sorts of issues I do.”

Nodding, Jules says, “Yeah, I follow that hashtag myself. It’s great,” and, following a pause, “I can certainly relate. Social media, in many ways, has become my ally in fighting against ableism in academia. I share in your need of wanting to break this silence about the institutional violence we constantly encounter. I’m terrified of saying anything though; so like you, I censor myself with what details I share on any social media site. I fear the kinds of institutional reprisal we discussed earlier.²¹¹ I find solace in networking with so many others who understand what I am going through. In fact, just today I posted something about my meeting with the admins I had.”

“Oh yeah. How did that go?”

“Are you sure you want know? I don’t want to distract you from the thesis outline.”

“Actually, this would be a welcomed distraction,” I laugh. “I think I’m ready for a short break anyway. My head is sort of spinning from all of this work.”

“OK then. You asked for it. This is what I posted on my Facebook page headline status just before you got here, ‘I think I need to take a course in anger management and ableism! I fantasize about smacking ablest grins off people's faces—this can't be ‘normal’ and more important, productive! Though it does ignite the fuel of activism in me.²¹² It's a catch-22.’”

²¹¹ Because disability in the academy is stigmatized, many disabled graduate students do not disclose for fear of stigma and consequent discrimination and/or discomfort sharing their lived experiences negotiating spaces of the academy. See Aguirre & Duncan, 2013; Damiani & Habour, 2015; Devaney, 2008; Farrar, 2006; Hibbs & Pothier, 2006; Rose, 2009; Sierra-Zarella, 2005.

²¹² Askins, 2009; Goode, 2007.

“Ouch”, I wince. “I take it your meeting with the advocates office didn’t go well?”

“That’s an understatement.”

“What happened?” I probe.

“I met with the administrators this morning to discuss workplace accommodations again. I was so frustrated and bursting with anger. Do these people understand what an accommodation is? I walked out of the meeting feeling so defeated. This feeling of being watched has not left me since I started this program. I was warned by one of the administrators of the department, shortly after I entered the program: ‘I know everything that goes on here. I hear everything’. How am I not supposed to take this as some sort of institutionalized surveillance? I’ve said it once, and I’ll say it again, this school is a ‘toxic and hostile environment’ for me. My family doctor consistently asks me when I’m going to leave this place—as if it’s that easy to just transfer to another school and program. In all the years I’ve known her, she’s never witnessed me crying at her office, that is, until she asks me about my studies. At one point, I actually had to take anti-depressant medication for anxiety from all of this. It was awful.”

Jules continues without allowing me to respond, “They suggested this and that, but with no definite outcomes. I’ve contemplated going to the Ontario Human Rights Tribunal one day but to date, no disabled grad student has challenged an Ontario university before.²¹³ As you know, I don’t like discussing this with many people because I just don’t think they understand. There’s still so much stigma attached to being disabled

²¹³ Since the time period I am writing about, there have been students who have challenged Ontario Universities that I am aware of.

in the academy. I don't want to seem like I am looking for special treatment. It makes for an isolating experience as a disabled graduate student.”

“You got that right. I'm sorry you had such a crappy experience in trying to negotiate your accommodations.”

“Negotiating with these people is like brushing your teeth with bricks.”²¹⁴

I tried so hard not to laugh, but I couldn't help myself.

“Brilliant, and yet disheartening all at once,” I add.

“OK, let's get back to your looming outline,” Jules says trying to lighten up the tense atmosphere we just created.

“Great. So, I knew I wanted to do some sort of online methods but I wasn't entirely sure how to do it. So I did what I do best.”

“What's that?”

“I reached out for help and e-mailed Carolyn Ellis.”

“Dear Carolyn...Not sure if you remember me? I'd like to start... a research blog, where I share my battles of struggling for accommodations as a grad student with disability. This blog would be set to private, with access only granted to the about six participants. I wouldn't necessarily formally interview students; rather I'd like for them to read my story and share their perspectives where [the other participants] can share and dialogue. Do you have suggestions of where I could look to for advice on what this method [of data] collection might be “called”?...Thanks in advance, Nancy”

“Nancy, Well it's really ‘online interactive interviewing’. I know of folks who

²¹⁴ Anonymous, personal communication, November 10, 2012.

thought of doing this but nobody who has. You can read our article on interactive interviewing and then add ‘online’ and/or you can check for more online autoethnography... Good luck, Carolyn.”²¹⁵

“So then blogging is a method used to collect data to complement autoethnography in your study?” Jules asks.

“Yes, that’s right. As I continued reading the literature, I discovered that when people engage in reflexive writing in virtual spaces of blogging websites, this can be described as autoethnography.”²¹⁶ However, as Ellis told me in her e-mail, “The literature that addresses autoethnography and blogging methods is minimal to date.”²¹⁷

Autoethnography and blogging provide a space for both co-participants and researcher (myself) to participate and share ideas and meanings attached to places of higher learning and paid work. My aim in using a private blog as a space to collaborate is to provide participants with a safe environment to reflect on their own experiences, as well as on mine, to understand and give meaning to our experiences in oppressive spaces of the academy. This type of data collection is considerate of the needs of disabled graduate students who already have to work harder to keep up in their graduate degree programs.

As such, autoethnography can be used as a methodological tool to advance social change. Brett Smith and Andrew Sparkes note that,

²¹⁵ C. Ellis, personal communication, December 04, 2012.

²¹⁶ Ellis, 2004.

²¹⁷ See Boylorn, 2013; Ellis, 2004, pp. 212-213.

...well-crafted autoethnographies can be a call to witness and open up possibilities to get research across in a thought-provoking and accessible manner to a variety of diverse audiences and not just to “expert” readers of academic journals. This further enhances the potential of the research to initiate individual and institutional change and make a difference in the “everyday” world.²¹⁸

Similar to the ways that autoethnography can challenge traditional ways of writing in academia,²¹⁹ I’m challenging how we collect data by using online methods that are typically normalized as appropriate to reach participants who are spatially inaccessible.²²⁰ My purpose in using online data collection, however, is also address the emotional “inaccessibility” of data collection pertaining to sensitive topics (e.g., stigmatization, disablism). I aim to make this work accessible.²²¹

My research topic is an area of sensitivity for not only myself, but also for other disabled graduate students.

Online research methods are a “valuable tool” in qualitative research.²²² Dunn suggests that there are several advantages to using online research methods including “expanded samples”, “reduced interview effects”, “enhanced convenience” for participants, and “more reflective informant responses.”²²³ This is an important consideration for these participants, because not only are they graduate students (with a heavy academic workload), they also have disabilities that need to be accommodated. Online methods also offer a kind of confidentiality that is harder to achieve in other

²¹⁸ Smith & Sparkes, 2008, p. 25.

²¹⁹ Holman Jones, Adams, & Ellis, 2013, p. 32. See also Bochner, 2014.

²²⁰ Dunn, 2010; See also O'Connor & Madge, 2001.

²²¹ Holman Jones, Adams, & Ellis, 2013, p. 32.

²²² Hookway, 2008; O'Connor & Madge, 2001.

²²³ Dunn, 2010, p. 129.

methods.²²⁴ I wanted to ensure that these methods provided inclusive spaces to share lived experiences, ensured confidentiality (a significant consideration for informants who have concerns regarding social stigma), and to allow for more self-reflexive responses.²²⁵

Online methods are also a way to draw attention to the needs for accommodation of disabled grad researchers. For example, for this project, I chose to use online methods to self-accommodate my own needs as a disabled grad researcher, so that I wouldn't have to transcribe the data. It also supported my access needs for flexibility of time to complete and process this work.²²⁶

Research has shown that e-mail interviewing can be empowering to participants by giving them access, flexibility, and control over how and when they will respond.²²⁷ For instance, participants can take their time to reflect on their responses. It allows for ongoing dialogue between the researcher and participants. For someone experiencing mental health disability, e-mailing responses with flexibility and control can relieve pressure of having to answer as quickly as one would in traditional interviewing strategies like face-to-face interviews.²²⁸

The advantages of using autoethnography and blogging for social change are that they provide me, as a disabled researcher, with an accommodation that addresses my need

²²⁴ See for example, Hookway, 2008, p. 93.

²²⁵ Worth, 2008.

²²⁶ For other examples of creative approaches to creating inclusive research practices, see Aguirre & Duncan, 2013; Grundy & McGinn, 2008; and Grundy, Pollon, & McGinn, 2003.

²²⁷ Meho's (2006) findings suggest that, "Overall, e-mail interviewing offers an opportunity to access, in an interactive manner, participants' thoughts, ideas, and memories in their own words. It allows the recording of many anecdotes that participants share to enhance the accounts of their experiences. It also allows participants to construct their own experiences with their own dialogue and interaction with the researcher (p. 1291).

²²⁸ Smith's (2005) work also notes how e-mail can allow for rich responses for participants who experience speech "differences" (p. 72).

for doing things differently, thus challenging ableist practices.²²⁹ Unlike other accommodations that exclude or single out disabled researchers, for example, when the use of technological aids such as speech-to-text software is needed, I would not have to struggle to get an accommodation to receive support with transcribing interviews because blogging eliminates the need for transcription.²³⁰ This is an important element to consider as a disabled researcher who would require a substantial amount of time to accomplish this task.

“So far, we talked about your use of autoethnography and why blogging works with this methodology. I’ve got that. We also discussed the importance of how this method is accessible to disabled graduate student researchers. I imagine that this is also applicable to disabled faculty members too, but I guess you can save that for future work.”

“Yeah, I’m actually thinking about doing that for a post-doc. But let’s focus on me getting through the PhD first. You know how ahead of myself I will get,” I laugh.

“Good point. OK. So after recruitment, you started with an open-ended question to generate student narratives. Explain that part.”

“Yup. All co-participants—including me—were asked to write an individual narrative describing their experiences of negotiating accommodations in their dual role as a disabled student and academic worker. I asked them to share whatever they felt was important about their lived experience. An important aspect of this process is to ensure that participants only tell me—us—what they want to tell without feeling pressured. I

²²⁹ Grundy & McGinn, 2008.

²³⁰ Meho, 2006.

offered some guiding questions to prompt the writing and subsequent dialogue: ‘How were you first informed of accommodations at the graduate level?’ ‘Did you disclose your disability prior to applying to your program of study?’ ‘If you didn’t disclose your disability, can you describe why not?’

“I made it clear that in writing their narratives they could share as much or as little as they were comfortable with, reminding them that these narratives would become part of a shared dialogue among all seven of us on the private blog. I told co-participants that they could use images if they’d like (but to ensure that any images posted did not identify them). I stressed throughout the research process that grammar was not a concern.”²³¹

“How long did they have to complete their narratives?”

“I asked that they return the narratives to me in four weeks. I also asked them to assign themselves a user name to protect their anonymity. Then I asked them to e-mail them to me in a Microsoft Word document. Once all narratives were e-mailed to me, I edited out any identifiers (e.g., names, program names). All narratives, including my own, were posted on the private research blog and co-participants were informed by e-mail when the narratives were posted. To accommodate all co-participants, I was initially going to upload all seven narratives in an audio file, but decided that this might change the aspect of the research (e.g., reading and listening are two different ways of knowing).²³² While this option was made available, no one requested it. In hindsight, I should’ve just done it to keep with making this as accessible as possible without people having to request these as accommodations. Why not just make it universal, instead of

²³¹ Meho, 2006.

²³² Aguirre & Duncan, 2013; Grundy & McGinn, 2003.

making it about an individual's disability accommodation needs?²³³ This universality also has me thinking about how I accommodate myself as a researcher, while ensuring the needs of the participants are met.

“In many instances, co-participants also engaged with me through e-mail first, and then after this e-mail contact provided permission for me to share their dialogue on the blog and/or in the final writing of this thesis.

“The next stage was for co-participants to read and reflect on each other's narratives that were then posted to the blog. I didn't allow any commentary for two weeks. I wanted to allow time for each of us to reflect on the readings of the narratives before opening the dialogue and allowing posts. This also allowed me time to analyze the initial narratives.”

“So you coded the initial narratives first?” Jules queries.

“Yeah, well, I prefer to say that I used thematic analysis to capture dominant themes that emerged in the initial narratives. I decided to focus on three themes so as to not overwhelm the co-participants and myself. I identified three significant themes that emerged from the initial narratives, which I characterized as information issues, (mis)perceptions, and extra work. I wasn't surprised that these were the themes that the co-participants talked about the most, because these issues are frequently discussed in the literature, too. These three themes structured each of the blog discussions, essentially the focus of our conversations, over the course of the study.”

“Wait,” Jules interrupts. “Back up. The themes were information issues, (mis)perceptions, and extra work.”

²³³ Dolmage (Unpublished manuscript).

“Yes. The blog creates the virtual space to discuss specific issues that co-participants faced as non-visibly disabled graduate students and employees in their respective universities. We started with the first theme of information issues. I allowed for a minimum of six to eight weeks of dialogue on the blog. Given the nature of our busy schedules, we did need to extend our time on each theme.

“Before I introduced each theme, I wrote an introduction to how I arrived at that theme, which I shared with the co-participants before opening the discussion. I allowed for a minimum of six weeks for co-participants to read how I arrived at each theme. This also allowed time for each co-participant to read each other’s responses before adding their own commentary to further dialogue. If I noticed that no one was responding, I sent out e-mails to ask if more time was needed to respond. I used a variety of tactics to encourage participation.”

“Like what?”

“Oh lines like, ‘this is just a gentle and friendly reminder that comments are due for the blog’. I also mentioned that it was important for me to get everyone’s perspectives acknowledged for each theme. Of course, I always thanked co-participants for their contributions. Instead of sending out an e-mail to the group, I tried to do this individually to prompt them so I could try and build more rapport.²³⁴ I did this for the first and the second theme, with the intention of also doing this for the final theme. But this changed.”

“What do you mean? The blog discussion didn’t work out?”

²³⁴ See for example, Markham, 1998; O’Conner & Madge, 2001.

“Well, my main objective for using online methods was to be inclusive.”²³⁵ I also wanted to remain true to the accessibility component of the blog by providing flexibility for students to respond with the extra time they might need. I went over my notes and took a look at how long each blog discussion was actually taking us. As it turns out, we needed more than just eight weeks to complete each discussion. But this is pretty common to inclusive research and knowledge co-production; many researchers have written about the extra time these methods take.²³⁶

“I also needed more time as the researcher to try to pull this all together, and I noted that I was nagging for some responses by the time we concluded with theme two. I hated feeling like this. Because I was using inclusive research methods, I decided to turn to the co-participants to ask them how to move forward with the next phase. Noting my time constraints to conclude the blog, I reached out to the co-participants to see whether they felt the same way that I did. I wrote to them as a group,

As with all research, it’s a messy process. I think I’ve said that more than once now and I enjoy having each of you as fellow grads who understand. So, I need to ask you for your feedback as you’ve all been fantastic, but I am working with a stricter deadline as this blog has gone on for longer than I initially anticipated. I am working with some modified changes now for your review. I need your help.

I’m not giving up on the methods used here in blogging but due to time constraints, I need to place some firmer deadlines. I know we are all busy—life happens—and we are all negotiating some type of added work with disability...for theme three, I am hoping I can get some consensus on doing this a bit differently.

I have never done a focus group and while I feel this won’t fit our flexibility in accommodating each other, I wonder if you might think about this and let me know.

²³⁵ This is consistent with the social model’s political agenda of improving the lives of disabled persons and geographies of disabilities literature that call for more “inclusive research designs” (Chouinard, 2000, p. 73). See also Grundy, Pollon & McGinn, 2003.

²³⁶ Fudge Schormans, 2011.

I'd like to get us all on-line at the same time, on one particular date in the same manner we would meet in person for a face-to-face interview. I could send out a list of dates and times that work for me and coordinate everyone. I will post the third theme shortly and will still allow you to submit via the blog if you wish, but I wonder if you might consider this as an option just to speed up the process if you will. I will continue to leave the blog up so there will be ample opportunity to reflect and respond further. Can you let me know if this might work? Alternatively, I am happy to speak with each of you by phone to allow for other methods of getting this done. I really do value your feedback.

I am thinking if we could set aside 1.5 hours for a focus group blog, we could wrap up the blog. But I need your thoughts...

Apologies for this rather long e-mail.

Can you please respond by this Wednesday November 13 either by e-mail, blog, or my cell: 416.560.9166?

"I was pleased to hear back from all of the co-participants when they agreed, so we negotiated that we would devote ninety minutes or so on one day to the final theme of extra work."

By this point, I feel like I'm defending my dissertation proposal all over again. The truth is I really don't mind the probing at all. It's actually helping me conceptualize my thoughts in being reflexive in my work. I feel like it's also preparing me for questions that my supervisory committee may have for me at our next meeting. So I am actually grateful for working with Jules, a fellow graduate student who is knowledgeable about the processes of doing research work.

This reminds me of another benefit of being in a culture: "working from insider knowledge."²³⁷ My co-participants are aware of how my disabilities might impact the

²³⁷ Holman Jones, Adams, & Ellis, 2013, p. 33.

research process when I am late with deadlines (many times due to a lack of grad support), and how this might shape decisions with respect to revisions to the research process, for example, by providing extended deadlines for the blog contributions.

“One of the advantages of autoethnography, for me at least, is that it encourages self-reflexivity.”²³⁸ I say. “As a non-visibly disabled graduate student, my positionality with respect to the research is an integral aspect of my study.”²³⁹ Chang explains that ‘close attention to personal feelings, thoughts, and emotions open up autoethnography to a deep well of self-reflexivity.’²⁴⁰ As both a researcher and co-participant of the study, these roles will shape the research process and interpretation of results.”²⁴¹

Jules looks puzzled, and asks, “Can you explain this a bit more?”

(re)Imagining Key Informant Contributions

“Sure thing. You know it was important for me to include the co-participants in the research process, so I also asked them to go over the key informant interview responses with me. Before I interviewed key informants, I initially proposed a full discourse analysis of the texts that inform accommodations. I did an abbreviated analysis of the accommodation policies—just enough to inform the key informant interview guide. But I didn’t use these data to the extent that perhaps that I thought they’d be used.”

“Yeah, I wanted to ask you about this phase actually. I was a bit curious about your decision to interview key informants. I mean, I thought this was a study, *about and for* disabled graduate students whose voices are missing from the literature?” Jules probes

²³⁸ See Berry, 2013; Chang, 2013.

²³⁹ See England, 1998; Frank, 2000; Rose, 1997.

²⁴⁰ Chang, 2013, p. 110.

²⁴¹ Seear & McLean, n.d. See also England, 1998.

with some confusion.

“Yes. You are right. And it is. This is why I asked the co-participants for their input on whom I should interview at the two sites. I asked for their input, but I made the final call on whom I could approach, because I needed to protect the identities of the key informants.”

“I guess that makes sense.”

“Yeah, but like I said, I didn’t use all the data for a variety of reasons. I was reflexive throughout the research process; I kept a lot of notes and re-read the literature. And while online methods allowed for accessibility needs to be met, this is not to say that online methods don’t come without their own challenges.”

Jules smiles as I continue.

“I actually addressed this in my comps exam. Like any method, there are contradictions in the challenges and benefits of online research methods. Researchers challenge the benefits of these methods by suggesting that blogging is more time-consuming, and participants have to have access to a computer.²⁴² While this may indeed be true, blogging is still beneficial for types of research that involve sensitive topics, and which require data collection that is more reflexive in nature—meaning that co-participants can answer at their own pace, revise their contribution, and spend time deciding in what they want to reveal. I didn’t reject such claims. In fact, part of the ‘screening’ for participants involved a detailed discussion about the potential challenges that might arise during the research process. I spoke to each participant individually about

²⁴² Dunn, 2010.

both the advantages and challenges of blogging in comparison to, for example, face-to-face interviews. I wanted to allow potential participants to make an informed decision on whether they would be able to participate.

“A missing component to this claim is the fact that all methods of data collection have the potential to be time-consuming depending on a participant’s life. For example, face-to-face interviews may be time consuming for a working disabled mother who might find blogging to be more accessible. I wanted to offer another opportunity to collect data so I moved our third theme discussion to a live discussion, similar to a focus group. Because I wanted to remain inclusive, this was a decision we made together. This didn’t mean that blogging didn’t work. I had choices to make to move the research forward. I also had an obligation to all the co-participants to check in and redesign the method collection where necessary. ‘Research is messy,’ as they say. I just never knew what that meant until I lived through it myself.”²⁴³

²⁴³ This will be further discussed in the Methods Re(Considered) section on page 172 of this thesis.

Chapter Four: Dialoguing Over Access

[Some] write evocatively with concrete detail, action, and dialogue. They tell a story. They help me to understand more about myself, society, the world... That's the stuff of autoethnography!²⁴⁴

After months of trying to figure out how to organize all the transcripts, collected via the research blog, I decide to pull out a stack of manila folders. Turning to my printer, I spend the next few hours organizing all the blog transcripts onto a Microsoft Word doc and print them off. I organize the transcripts into separate manila folders according to each phase of the research (e.g., initial narratives; each respective theme; the key informant transcripts; discussion; institutional policies).

Beginning with the initial narratives takes me a few hours. I repeat this process for each of the research phases. Before I know it, my floor is covered with open folders, multi-coloured sticky notes, and an array of paper coloured with highlighters. I have no particular order I follow.²⁴⁵

My overactive brain is no stranger to this sort of organization—others might refer to this as a tornado hitting my office. I'm finally ready to attack this.

The nerves begin to creep in again.

Deep breath in.

²⁴⁴ Ellis, 2004, p. 213.

²⁴⁵ Patricia Leavy (2013) writes in her book *Fiction and Research Practice: Short Stories, Novellas, and Novels* about writing fiction, "The data (or empirical bits) exist on a continuum, and data may be collected and analyzed using a traditional method and then fictionalized or the writing process itself may be viewed as the generative act" (p. 76).

With a pink highlighter in hand, I grab the first manila folder labelled “initial narratives.” I don’t have a particular reason for the pink highlighter; it just happens to be one of my favourite colours. It’s also the closest one to me.

These initial narratives are what guide the three themes of the blog.²⁴⁶

My latté is within close reach. I anticipated needing comfort food for what I was about to embark on. I imagined that reading other graduate student’s experiences of embodied disability in the academy would resonate with me.

I begin with the shortest narrative thinking it would be the easiest to begin with. How hard could reading two sentences be?

It turned out to be very hard, actually.

Dakota writes,

I have not requested any academic accommodations for my non-visible disability (i.e., ADHD). While doing my undergrad, I have heard of some undergraduate students requesting such accommodations, but I was actually not aware that they existed at the graduate level.

It doesn’t surprise me that Dakota wasn’t aware that accommodations existed at the grad level and, at first glance, I’m annoyed reading this. In fact, while I’m not at all surprised, I still find myself frustrated. I take a moment and read it again. I remind myself that I too wasn’t aware of accommodations at the grad level during my undergrad. This is likely due to the fact that I wasn’t even considering grad school at the time.

After a few moments of more reflection, I highlight the phrase “but I was actually

²⁴⁶ Co-participants were asked to write individual narratives describing their experiences of negotiating accommodations in their dual role as a disabled student and academic worker. See Chapter Three: Discovering Autoethnography (p. 104).

not aware that they existed at the graduate level.” I write a big question mark beside it. I smile because this is what drove me to this research project. I think about what bodies are missing from grad spaces. More importantly, I wonder why it has to be this way.

Unlike Dakota, I had registered with the disability services offices during my undergrad degree before transitioning into grad studies. I too had limited knowledge that accommodations existed at the grad level—I certainly did not speak about grad school with my counsellor as an option. It was only when I opened up to my mentors at the end of my undergrad studies that we started a dialogue about pursuing grad school and talked about *how* accommodations would enable me to succeed.

Even still, with this limited knowledge of my *right* to accommodations, I had trouble accessing accommodations. So it’s understandable that Dakota didn’t know about this. I try not to let this upset me too much and remember the purpose of this research.

I make some notes on my reflections on the printed transcripts as I move on to the next narrative. I want to establish my momentum. My aim in this phase is to read through each narrative over at least once, so I’m not concerned with making too many notes and offering my analysis. I know I’ll come back to them after I’ve had a chance to read them all. I already feel myself getting emotionally charged by Dakota’s narrative. It’s also hard for my overactive brain not to make the leaps I want to start making with the upcoming analysis work I will do.

I feel the blood rushing to my head. I conclude my notes in my research diary.²⁴⁷

²⁴⁷ I use the term ‘research diary’ loosely as I have made notes sporadically by starting new journals, continuing in old journal books, e-mailing individual committee members to discuss frustrations in person, and keeping relevant e-mails. Keeping a private research diary along the way throughout my research

Keep your emotions in check. Record them, but don't let them get in the way of being open to what you will find. Look for both the similarities and differences. Keep an open mind. Work through these emotions.

I reach for Morgan's four-page narrative. I take a few more sips of coffee as I begin reading.

I barely make it through the first few lines.

Morgan writes,

Unfortunately for me, I never had any guidance or assistance on this. When I got accepted to my MA program I was offered a TA ship and a scholarship. I didn't know what exactly would be involved in the TA ship and by the time I did it was too late to be able to work on accommodations. I ended up dropping one of my electives of my academic program in order to accommodate my work responsibilities because I just could not mentally balance both. As a result I will have to pay an extra semester of tuition and delay finishing my degree by at least one semester.

No guidance. Not sure what to expect regarding TA work. No time to work on accommodating yourself for your TA ship. I jot down these notes quickly, knowing if I don't, they'll be a faded memory. *Wait, it's not the student's responsibility to self-accommodate.* I can only imagine how this exacerbates Morgan's disability. This is

provides me with the space I need to disclose my emotions and diffuse any situation that I might confront as uncomfortable. In doing so, and keeping within an emotional geographical approach, I acknowledge that emotions are part of the research process and are as natural as any other embodied practice we experience daily (Bondi, 2005; Dickson-Swift et al., 2009; Hubbard, Backett-Milburn & Kemmer, 2001; Seear & McLean, n.d.). Having said this, I recognize a contradiction in this work. Initially I made the decision to conceal my feelings from the co-participants. I know now why I felt this is important—I wanted to ensure my work would be taken seriously; but on the other hand, I have come to recognize that emotions are part of research and are not frowned on the way they might have been in the past. A research diary also serves as a useful tool to achieve trustworthiness in my study by using the technique of maintaining an “audit trail” (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), the audit trail “may be the single most important trustworthiness technique available to the naturalist” (p. 283). My audit trail will consist of my researcher diary/blog, where I will keep detailed field notes, journal notes, pictures, and data reconstruction and synthesis (e.g., categorical structure: themes, definitions).

certainly not consistent with the written policies and the legislation that guides them at Ontario institutions. I make a note to cite the *Learning Opportunities Task Force*²⁴⁸ report and the *Code*.

My frustration gets worse when Morgan continues to explain how, as a result of all this work, they had to sacrifice academic work in their program and drop courses to keep up with their paid work. I find myself growing angrier.

I can't believe what I'm reading—wait, of course I can—this is no different from what I experienced.

I retrieve the notes I had written when I was analyzing a university's union documents that indicate that academic work is supposed to take precedence over paid work.

Breathe Nancy; just breathe. Keep reading.

Morgan writes,

By the second semester I new what to expect from the workload and when I asked for a reduced load I was advised (by the prof) that “this was not possible” as this would not be fair to the other TAs. We had to share the load as equally as possible. I didn't think to appeal further as I was afraid of losing the position and I couldn't afford to continue without the opportunity so again I took one less course to accommodate. In hindsight I should have been more proactive but I adapted by taking on the burden of my own. And it is ironic because as a result I will incur extra fees as a result, with no funding after April 30!

The prof actually suggested workplace accommodations wouldn't be fair to the other TAs.... Had to ensure the load as equal as possible. Are you kidding me? So being disabled justifies exclusion from meaningful employment?

²⁴⁸ Stephenson, Tiffin, Nichols, Harrison, McCloskey, & Weintraub, 1992.

I then turn my attention to Michelle Damiani and Wendy Harbour’s work, where I highlighted, “Not being in a position of power, graduate teaching assistants are limited in their ability to obtain necessary opportunities and to be viewed equally competent, capable, and productive in comparison to nondisabled peers.”²⁴⁹ This is certainly not equal treatment.

Morgan’s words express the experience of the social oppression embodied as a product of ableist assumptions (i.e., wherein the professor assumes that graduate students are able-bodied) that negate how some bodies require different ways of negotiating spaces of academia.²⁵⁰ These ableist ideologies presume that every “body” is able to perform in the same way without recognizing differences, for example, academic abilities, or in this case, performing expected duties of paid work.²⁵¹ While disabled grads may be included in such spaces of employment, they are, in cases such as Morgan’s, excluded from the accommodations that would enable them to both manage the paid work and complete their studies. And in Morgan’s case, this meant that they had to withdraw from some courses, extend the time taken to complete their degree, and deal with additional tuition costs. Not to mention the emotional consequences all of this would have on someone—I can only imagine how Morgan must feel.

I’m getting off track. I am not supposed to be writing up the analysis at this stage, but I am so engaged in Morgan’s story, I can’t help it. Morgan’s story resonates so much with my own lived experience that I have a hard time departing from it. I guess this is one

²⁴⁹ Damiani & Harbour, 2015, pp. 402-403. See also Farrar, 2004; OMET, 1998; Rose, 2009.

²⁵⁰ Morella-Pozzi, 2014

²⁵¹ Chouinard, 1995/1996; Chouinard, 2010; Damiani & Harbour, 2015; Farrar, 2004; Hansen & Philo, 2007; Olkin, 2002; Price, 2011; Rose, 2008.

of the complexities of being both the researcher and the subject that so many autoethnographers²⁵² talk about.

I think it's time for a break. But instead, I am so hyper-focused that I reach for my latté thinking back to my paper, "Accommodations in the Ivory Tower", which I wrote for Congress in Victoria. I search my laptop and re-read my paper out loud:

I argue that disabled students are entitled to accommodations in both academic spaces and in the workplace spaces. Here, I make the distinction that academic workers, like those employed as teaching assistants and/or research assistants, are indeed protected by the Ontario Human Rights Code.

This should be common knowledge. I mean, it's right there in a university's policies that are guided by the *Code*. All Ontario Universities must follow the *Code*. This is not specific to any particular university.²⁵³

Surely, Morgan is aware of this entitlement?

As I move along and continue to highlight and write notes, I fully understand why Morgan felt the need to take on the burden instead of fighting the prof for their accommodation. I continue highlighting in pink and yellow, underlining in pink pen, phrases like: "I didn't think to appeal further as I was afraid of losing the position" and "I couldn't afford to continue without the opportunity so again I took one less course to accommodate." I circle words like "afraid" and write "accommodated self—sacrificed academics for work opportunity" and write "FEAR" in caps.

By this point, all I want to do is reach out through my computer screen and shout, "MORGAN, THIS IS NOT YOUR FAULT. I KNOW YOU THINK YOU 'SHOULD

²⁵² Adams & Ellis, (unpublished manuscript); Chang, 2013; Ellis & Bochner, 2000; Ellis, Adams, & Bochner, 2011; Holt, 2003. See also Hubbard, Backett-Milburn & Kemmer, 2001.

²⁵³ Rose, 2009.

HAVE BEEN MORE PROACTIVE’ BUT OUR RIGHT TO EDUCATION IS NOT SOMETHING WE SHOULD HAVE TO FIGHT FOR ALONG THE WAY!”

I’m reminded of Dana Morella-Pozzi’s work that Tony had suggested I read. She writes, “Our relationships with culture and with one another inform how we react to, cope with, and internalize our thoughts and experiences.”²⁵⁴ There is a wealth of literature to support just how Morgan feels—this feeling of internalized ableism—blaming ourselves for not being able to meet ableist norms constructed by an ableist society.²⁵⁵ Much like Reeve’s notion of internal oppression, Fiona Campbell Kumari also explains that embodying,

Internalized ableism can mean the disabled subject is caught “between a rock and a hard place”; in order to attain the benefit of a “disabled identity” one must constantly participate in processes of disability disavowal, aspiring towards normativity, a state near ablebodiedness, or at very least to effect a state of “passing”.²⁵⁶

I scribble “passing” as a reminder that this theme has come up in my literature review.²⁵⁷ I anticipated that other co-participants would write about it too. This ableist understanding of accommodation being unfair to non-disabled students reflects underlying assumptions about disabled students. Non-visibly disabled students are stigmatized as being “weak” and “lazy”.²⁵⁸ Titchkosky²⁵⁹ and others²⁶⁰ have written about

²⁵⁴ Morella-Pozzi, 2014, p. 176.

²⁵⁵ Chouinard and Grant (1995) draw on examples of ableist practices in places of the academia for disabled professors that include “evaluating disabled workers by the same criteria used to evaluate able-bodied employees, holding events in physically inaccessible locations, and treating not being able-bodied as defining a disabled person” (p. 139). See also Rose, 2009.

²⁵⁶ Campbell Kumari, 2008, p. 156.

²⁵⁷ Campbell Kumari, 2008; Goffman, 1963; Goode, 2007; Olney & Brockelman, 2008; Sierra-Zarella, 2005; Titchkosky, 2001.

²⁵⁸ Denhart, 2008, p. 483.

²⁵⁹ Titchkosky 2003.

the suspicion of the legitimacy of non-visible disabilities. I like how Morella-Pozzi²⁶¹ explains this suspicion so well that I have marked it as “amazing!” I start to read this paragraph out loud to myself,

Non-visible disabilities are socially constructed, more so than visible disabilities. Unlike medical accommodations, there are no ICD-9 codes referenced by medical doctors needed to receive accommodations in the classrooms. The social construction dictates how we (educators, students, administrators, and witnesses) respond to moments of oppression. The suspicion of the non-visible disability, or more accurately, the person who is claiming to have a non-visible disability, lingers in the minds of all present. It is this suspicion, this piece of the social stigma and the social construction of disabilities, that needs to be eradicated. Why is the suspicion so prevalent? There are no good answers, but I can tell you that in my experiences, it is often because those without disabilities often think non-visible disabilities do not require any accommodations, especially in adulthood.

I’ve written extensively about passing and the invisibility of non-visible disabilities in my initial narrative and throughout my studies. This is not surprising to me at all, as I know the literature quite well too.

I leave my story for last.

Moving forward, I’m excited to read what Morgan has experienced with their academic accommodations and professors. Morgan refers to them as being “actually quite exceptional.”

Oh, thank God! Here’s an enabling practice I can discuss later for the recommendations section.

Morgan describes receiving extra time to complete work as per their accommodation letter. Morgan’s professors even accepted the disability counsellor’s late accommodation letters. Of course, my cynical self starts pondering why the counsellors

²⁶⁰ Morella-Pozzi, 2014, p. 181. See also Ryan, 2007; Sierra-Zarella, 2005; Tinklin & Hall, 1999.

²⁶¹ Morella-Pozzi, 2014, p. 181.

were late with the official letters in the first place. But I don't pay much attention to this detail. I take the good for what it is; Morgan was supported.

My excitement is short-lived. I'm disheartened within minutes after reading that Morgan's paid work responsibilities hindered their progress in completing their academic work. I continue reading Morgan's narrative,

Unfortunately one of my accommodations is extra time for papers and tests so the same issue would normally apply for my work but this was not possible due to the nature of the work and the dependence on other people (or the need to be finished my stuff within a reasonable time of theirs no matter what else I may be struggling with). By the time I had had my meeting with [disability services] and the requisite accommodation paper work had been signed and returned to the profs, the semester was nearly over. However the [disability] counsellor had e-mailed the two profs in question and did advise that the list of needs were coming. I ended up writing one paper and finishing it on Christmas Eve (I didn't want to go home before completing it). The second one didn't get finished until Dec 31. Both the papers were very late but I got a decent grade on both despite their relative lateness. Both profs said they'd rather have a late paper that was good than a hastily drafted one with no quality. My anxiety got in the way.

But your accommodation papers weren't ready until nearly the end of the semester—this is unacceptable. You had to work up to Christmas and New Year's Eve—thus not getting a study break. What is the trouble with handing in papers late? Why is a deadline so essential when we know that there is flexibility to these things? If these deadlines were so crucial for the TA ship, why couldn't the supervisor pitch in and take a load off of Morgan? I know I had a very supportive professor who did this for me in my last years of my TA work. In fact, earlier into my degree, a fellow TA, who had been a TA in the same course for the past three years, so was able to grade faster than me, also helped me out when she saw me struggling to balance my first year as a doctoral student and worker. She was non-disabled and had no issue supporting me. In fact, she was

surprised our supervising professor didn't accommodate me better.

By this point, I'm fuming. Clutching the pink highlighter, I think about how to make note of the complex interrelation between student and academic worker on this transcript. And how academia gives little attention to disabled students' need for accommodations within both of these spheres.²⁶² This is hard to swallow, but unfortunately, I don't have a lot of time to explore this topic yet, so I make a note of it to include it in my discussion chapter. I have to move on to the next narrative. In frustration with what's happened to Morgan, I just tossed the papers to the side watching as they scatter all over the floor.

I take note of how difficult the process of reading these narratives continues to be. I've read two, and I have four other co-participants' narratives left to read.

But don't forget your own narrative.

It's time to move on. Next up is Drew. *Here we go.*

Drew writes,

I developed my disability and was diagnosed while in my graduate studies. At that time, I requested a LOA [leave of absence] due to illness and was granted this. I was only formally advised of the right to request an accommodation when I was struggling to complete my thesis while under very strict deadlines and while a family member was critically ill. I was made aware of my rights many years after diagnosis.

I had also previously asked for leave of absences due to extreme situations due to family illness and was told by the assistant dean of my school that this was not an option, in retrospect. So situations that exacerbated my disability was not considered and my time in the program was identified as being beyond expected experiences. This made me feel that I was in a catch 22....

²⁶² Damiani & Harbour, 2015; OMET, 1998; Rose, 2009.

That's it. I've had it. Life happens—students get divorced, students have surgery, students are disabled; students need to take breaks—maybe even multiple breaks, students get hit by cars! Why is this a problem? Universities have policies in place like those for leaves of absence for a reason.

Disabled students have the right to a barrier-free education, yet we learn from Drew and Morgan that when you ask for an accommodation, you are perceived as unlikely to complete your work. How is one expected to pick between personal and/or family obligations and school commitments? I scribble these phrases all over Drew's narrative: "lack of understanding"; "duty to accommodate"; "advocacy"; and "lack of info." I highlight and circle, in bold blue, several parts of the narrative.

Drew's last line stands out when they write, "Messages were never direct but made me feel that if I couldn't manage this situation [family illness and graduate school], I did not belong in this environment."

I can relate to (both Morgan and) Drew about feeling that they do not belong in this space. This is rooted in the ways in which I'm perceived or treated, even penalized academically for not meeting the "expected" ableist ways of submitting my work on time when I request academic accommodations for extended timelines.²⁶³ And of course it's not only about academic consequences such as grades; it's also the psychological, emotional, and social ways of being made to feel like I don't belong. It's in these ways that emotions are evoked in my body when I am in these places. This is why emotions matter!

²⁶³ See for example, Chouinard, 1997; Holt, 2010; Tinklin & Hall, 1999.

To add to the stress of academic life, I was also heavily involved in the health care of my grandfather when he became terminally ill during my comps exam preparation. Compassion didn't seem to be a word that a university recognized. Even after disclosing this personal information, on top of disclosing my disability, I was required to do extra work to access my comprehensive exam disability accommodations—having to make one appointment after another, recruiting allies, digging my nose into the letter of law—all in an attempt to be accommodated. A straightforward process, at least on paper, seeing as I had all the necessary documentation, including the support from my supervisory committee, my counsellor, and a medical professional, in accordance with the institutional policies. I spent countless hours working on getting my accommodations—time and energy that should have been devoted to my family and to studying for my upcoming comps.

No one should have to navigate institutional ableism—let alone while dealing with the upcoming death of a loved one.

Navigating these disabling spaces made me feel similar to how Drew was feeling—if you can't manage the situation, you don't belong.

Over the course of my grad studies, I declined a term of paid work so that I could, just as Morgan did, “self-accommodate”. I spent hours, days, and countless amounts of energy fighting this ablest system, when I should have focused this energy on completing my studies. Such experiences set me back and prevented me from completing my work on time. Not only that, I also lost many opportunities to compete with my peers when I

had to pass on conference and publishing opportunities. All because—without accommodations and support—I couldn’t keep up.

So much for leaving my experiences until the end!

OK, enough about me. I have to move on.

I pick up Sam’s narrative next.

At the outset I should state that my accommodation experiences have all been with regards to academic work. (Indeed, it had never been brought to my attention that it would even be possible to receive a modified teaching assignment...perhaps its own problem worth reflecting on.)

“Yes Sam, it is definitely ‘its own problem worth reflecting on’”, I find myself saying out loud as I highlight that line in red pen and mark it with “already identified theme.” I continue reading:

My experiences of receiving accommodation have been similar to how I have found my dis/ability to be received in general. I’ve struggled with depression and anxiety (and a few other odds and sods) for as long as I can remember. However, it’s only been recently that I’ve had any luck receiving attention or treatment for them. When I was younger, my family and teachers seemed to subscribe to what I call the “coherent mind theory.” That is, a person’s mind can only be one way. Thus, if I wanted to be smart, I couldn’t really be depressed. So for a very long time, I found myself treated like a slacker, looking to exploit a system designed to help “people with real problems.” Though I never quite managed to internalize this view, it has (and continues) to sharply frame how I experience my own dis/ability. Indeed, one of the primary challenges I have seeking accommodations is that I can’t muster the energy and focus necessary to advocate on my own behalf while I am experiencing the issues which necessitate the accommodation in the first place. (This is mirrored by a second issue I have found, which is that you need to be confident and persistent to receive accommodations...but that administrators are often reluctant to believe someone possessed of confidence can suffer from depression or social anxieties...) But, I have wandered off track.

No worries about wandering off track Sam. I do it all the time!

I find it comical that I feel like I am speaking to the narratives, as if the co-

participants are right in front of me. I continue scribbling notes like: “perception of disability” and the “charity model.” *Disability accommodations are not something we should consider ourselves lucky for receiving. This is ridiculous.* I continue with scribbling “legitimate disability” and at the end of the paragraph, I write and underline my own words “advocacy as a form of work.” I reach for my coffee, take a sip and continue reading Sam’s narrative:

At my previous university, a student needed to clear the major barriers to accommodation only once, after which their file would reflect an entitlement to accommodation, streamlining the process in future instances. I was actually extremely fortunate in this matter, and was assisted in receiving this status by the (university affiliated) therapist I was seeing at the time. She attended to the necessary paperwork while completing my intake, which was extremely kind of her as I was in no position to attend to my own needs at the time.

This was “extremely kind” of your counsellor—for doing her job? Seriously?

I know this is just a way of speaking or writing, but this holds profound meaning for how we understand accommodations and accessibility in our society. This clarifies for me the charity model that I’ve witnessed so many times in the ableist geographies of disabled students. That I’m to be grateful for the accommodations I receive. I’m to be appreciative of the support from staff, and thankful for a university’s kindness. I’m to acknowledge these social interactions in this space, like Sam does, as something outside the norm for academia.

Reading this takes me back again to Dana Morella-Pozzi’s work where she discusses an exchange between herself (as a disabled grad student) and her disability service advisor. In this exchange, she was made to feel “guilty” when expressing to the advisor’s supervisor that her accessibility needs were not being met. The supervisor

ignored Dana's experience by suggesting that the advisor had "good intentions" in addressing those needs when the accommodations didn't work out.²⁶⁴

Like Morella-Pozzi, Sam brings up so many intriguing points to think through. I continue to log them into my research journal, scribbling all over the printed pages and adding this to the manila folder.

I have to admit, I've had trouble interpreting Sam's responses. I'm never sure if I was being criticized during the blog participation or applauded for my probing. In hindsight, I should have e-mailed Sam to ask for clarification in more depth than what I had responded to on the blog. But how would Sam interpret my asking for clarification? This is one of the limitations of not doing face-to-face interviews. Perhaps it would have been easier to ask this if we were doing interviews differently. Or maybe not. I may have had the same issues if I read Sam's body language too. And then my own internalized ableism takes over as I begin thinking that maybe I am not smart enough to be engaging in this level of education. Would I have been comfortable enough to ask Sam in person? I mean, the whole purpose of me doing online methods is that I have the safety and flexibility of processing the information I am working with, as much as I offer these advantages to the co-participants.

I think I need more coffee before I proceed to Rowan's narrative. With my orange highlighter in hand, I begin to read. I recall speaking with Rowan over the phone about participating in this study. One issue Rowan brought forth was the financial barrier of

²⁶⁴ Morella-Pozzi, 2014, p. 178. See also Goodley, 2011, p. 92.

being a disabled graduate student and not being able to access the available bursary.

Interestingly, none of the other co-participants has voiced any concerns about the Bursary for Students with Disabilities grant (BSWD) yet.^{265, 266} This strikes me.

Where's my pen?

Perhaps the others weren't aware such a bursary existed. If this is the case, there's another issue in itself. If they did not know about it, maybe the others didn't perceive this as a barrier they wanted to focus on. I don't know.

I was careful not to lead the co-participants. I wanted them to tell me about their lived experience and share what they feel is most important. Rowan writes:

In an attempt to get my accommodations I registered with disability services, including providing them with a full psycho-educational report. I then worked with my counsellor to identify the necessary supports needed (I am returning to school after a long absence and have never been accommodated before). She was going to apply for BSWD to get the materials I needed however I was turned down for OSAP (due to "bad credit check") as it turned out this made me ineligible for both the BSWD and the grant for students with disabilities that I would otherwise have been eligible for (as I have a disability and am on a low income). I went through a frustrating processes having multiple meetings including with the graduate students union, the faculty of graduate studies, my department student union, my union, my program advisor, my advisor, the human rights office, the human rights commission and my disability counsellor, to no avail. Each suggested one of the others might be able to help. Ultimately I was told there duty to accommodate was covered by providing the accessibility lab on campus and suggesting I ask my "friends in class" to take notes for me. The disability counsellors said she could put me in a 'draw' to

²⁶³ According to the Ontario Ministry of Advanced Education and Skills Development (2015) website, The Bursary for Students with Disabilities provides aid to students self-identifying as having either permanent or temporary disabilities. This bursary assists with the costs of disability-related services or equipment, such as tutors, note-takers, interpreters, brailers or technical aids that are required to participate in post-secondary studies. Retrieved from <https://osap.gov.on.ca/OSAPortal/en/A-ZListofAid/PRDR013041.html>

²⁶⁶ Furthermore, as noted on York University's website, "If you applied through the full-time OSAP program, but did not receive any assistance because the calculated resources were higher than the allowable expenses, you may still qualify for BSWD support. Please see your disability counselor to discuss further." This is applicable to all Ontario Universities. Retrieved from <http://sfs.yorku.ca/aid/scholarships/disabilities> (Under "Special Appeal for Full-time Students").

potentially win an award for a student with urgent accessibility needs... I didn't win. The only way it seemed possible to get the accessibility needs met was to make an appeal to OSAP which had to include a pity letter and up to 20 pages of documentation—which I was told would take 4-6 months. By this point I was so exhausted by going around in circles, being behind in class (because I didn't have the accommodations I needed) and having to look for work (because I was turned down for OSAP) that I had neither the mental energy or the time to complete the appeal (they also asked me to resubmit documents that they had lost that would cost me money I didn't have to get again).

I'm overwhelmed reading Rowan's story. Again, this resonates with me, as I think about the disabling processes I engaged with in order to secure bursaries in similar ways to Rowan. It was exhausting work—I had to do it myself, with every one of those organizations and offices. The time needed to just to obtain the proper documentation to access these programs was enough to make me call it quits.

I feel like I need to take a short break from this. I can't distinguish if my exhaustion is from the emotional toll of reading these narratives, or if I have just worked for too long without a break.

I take a short break before returning, trying to keep my momentum.

Despite legislation, financial barriers continue to affect disabled students in the academy. I have brought forth many of the issues Rowan raises at a few university committees that I have worked with. I, too, felt many times that these folks were just “passing the buck.” Like Rowan, I went through the “frustrating processes having multiple meetings...to no avail.” I highlight and underline this phrase as it jumps out at me. Yes, this is just how I felt. And I know of many others who have said this too. I make

a note of the “added work” that disabled students endure as they navigate the processes of securing accommodations. Rowan continues,

I have not secured the accommodations I need for the classroom. This process was extremely frustrating. I felt powerless alone and confused, sent from person to person and while most people were sympathetic no-one was helpful. I got very shut-down and overwhelmed and it took away valuable time from my now more difficult studies and work. I was exhausted and burned out. In the end I felt like I had to let go the idea of getting accommodated and focus the energy I left on finding work and studying.

Like Sam (and Morgan), Rowan expresses feeling “lucky” with respect to assistance in accessing accommodations. There it is again, this rhetoric that accompanies the charity model, that we are to feel grateful, instead of feeling like we have a legal right to be here. Why should we feel lucky about accommodations that are a legislated entitlement?

I’m empathetic to Rowan’s situation and its consequences for Rowan as a student. Without access to financial support, Rowan had a difficult time accessing much-needed supports such as a laptop.²⁶⁷ Rowan also brings up a good point that since grad students are not frequently on campus, access to supports available “on campus” is not always feasible.²⁶⁸

ROWAN: As for not being accommodated in the class... It turns out that all the money for accommodations are based on students being approved for OSAP... It took me months of anxiety and frustration to discover that if you are not funded by OSAP then you are not eligible for any money for supports or accommodations.

²⁶⁷ Dunn, Haines, Hardie, Leslie, and MacDonald (2008) note the high rates of poverty experienced by individuals with disabilities. Furthermore, without access to funding disabled students lose access to assistive devices.

²⁶⁸ Rose (2009) highlights distinct “kinds of academic work” between disabled undergraduate students’ and disabled graduate students (p. 2). She writes, “In comparison with undergraduate programs of study, for example, the essential requirements of graduate work, particularly in research-based graduate programs, will often include higher-level standards for original and highly independent academic work (p. 9).”

They fall back on the computer lab on campus and say that addresses my needs. But, since I am a grad student and not on campus very frequently it really didn't address my needs adequately at all. If I want to have accessible readings generally I need to go to campus (usually a special trip for this purpose) which takes me over an hour each way and sit in the computer lab converting documents into audio files in Kurzweil (some times scanning them first) which if you have used Kurzweil you will know takes quite a while. On many occasions it was taking me a whole day on campus a week trying to convert my readings for the week (and didn't necessarily get through them all). This was made more stressful with some profs only e-mailing the readings a day or two before the class making it practically impossible for me to get them converted and listen to them in time.

I also don't have a laptop (which was identified as one of my needs by [a university]) so have been going to the public library and borrowing friends computers trying to get papers written and files downloaded.

Rowan writes about the enabling spaces of the library below. This is good news and I'm excited to read,

The only place I feel I have had meaningful support is from the library accessibility services. They have been great with converting texts to PDF to save time on that part at least, and other than the beginning of the year overload they have been very timely and responsive.

In one of the many meetings I had trying to get classroom accommodations I was told about work place accommodations through the union. It sounded like a much simpler process and the union was friendly and encouraging of me to apply for what I needed but I didn't actually need any accommodations in my work. My workplace supervisor was supportive and said they'd be happy to sign off on anything we could but the reality is that position didn't require any significant reading/writing, which is what I need the support around so I couldn't justify applying for the supports in that position.

I am managing ok in my course work. I am not doing as well as I would if I had the accommodations and I have had to deal with a lot more anxiety and depression from the fall out of all of this, in addition to the additional financial stress of being turned down from OSAP. I have considered taking a term off to try and deal with the anxiety and to try and get things in a better position for returning but in the end wasn't sure that I would be in a better position on returning or if anything would change so I have so far just continued to push through (but it is still something I may take up next year if necessary). I was advised by my disability counselor to take a lower course load by that means I would have to stay for at least an extra term with no funding and I think if I did that I could end up in a position of not

being able to afford to complete the program and after all of this I REALLY want to finish!

I have decided to reapply for OSAP for the summer term in the hopes I will be approved this term and be able to get the supports in place for next year at least... We'll see what happens!

Phew. Well, that was a lot to digest.

I put the papers down and continue jotting some initial thoughts beginning with having a “supportive workplace supervisor.”

This is great! Here's an enabling practice I can work with. What does a supportive workplace supervisor entail?

I highlight in pink how Rowan said they were told about workplace accommodations, and that while the union was helpful, the Rowan felt that their workplace needs didn't require accommodations. I move on to write notes like “continued process of provoking anxiety and depression ‘from the fall out of all of this’” referring to the financial barrier of being rejected for OSAP; I know the pain of that bureaucratic process all too well.

I can also relate to Rowan's experiences of accessing support through accessible library services.

Why is it that only the folks at accessible library services seem to get this?

I recall several encounters with various librarian service providers who took the time to sit with me and listen to my needs. They never brushed me off.

I can barely read my own handwriting as I am trying to get everything down as fast as I can so I don't lose any of my thoughts as I often do when my mind is racing and

about to wander off. I find myself reflecting on all the ways the co-participants had self-accommodated.

I know it's time for a break.

OK, five down, one more to go. But how do I include my own story?

I like how I've been weaving it in and out of the analysis. For now, it'll stay like this.

Next up is Amy.

I recall speaking with Amy about this study for almost an hour by phone. Amy raised some concerns about her time commitment to the research blog. I reassured her that the blog was meant to allow for as much flexibility as possible to meet the needs of busy graduate school students, but in no way, would I be offended if any co-participants needed to drop out of the study at any time.

Amy writes:

The graduate process for negotiating accommodations was much more difficult due to the closer relationships with professors. There seems to be a skewed notion that if you were bright enough to get into graduate studies you should be able to complete your course work on time. I often felt that my struggles were minimised or forgotten. I am not sure if this is because my disability is hidden or considered "funny." I have narcolepsy, I fall asleep.

I was lucky that my programme did not have exams. I ended up modifying my own graduate assistant workload when I saw how little the other students were doing I followed their example. I think as a person with a disability there's a lot of pressure to do everything asked and then some. There was less official paperwork involved than at the undergraduate level and my professors would admit to not reading it. I always get a medical note, I hate being questioned. Sometimes I include a brief internet found medical article on narcolepsy as academics aren't doctors.

My experience was poorer as a graduate student in securing my accommodations. I felt really crappy about asking maybe because as an undergrad I was one in hundreds, most of my interactions were with ta's where as a grad student my profs

I'm one of a handful. They help with funding and other opportunities. There was more pressure to hide.

I found myself having to re-read this narrative a few times over. Amy addresses an important point about feeling like her “struggles were minimised or forgotten” and attributes this to the fact that her disability is “hidden” or interpreted as being “funny”. I scribble these notes in the margins about “passing” as she refers to the pressure to hide and the “coping” strategies she uses to self-accommodate. I pause and remember that there were others who spoke about self-accommodating and passing. But it's this line where she says, “I think as a person with a disability there's a lot of pressure to do everything asked and then some” that has me re-reading her narrative.

This resonates with me because I feel the same way—this need to prove one's legitimate place in academia so that we are not found out to be a fraud.

I was ambitious to think that I could read six narratives, alongside my own, and respond to the blog and co-participants in two weeks. Sitting with, reflecting on, and identifying with each of these stories has been emotionally and physically draining for me. I share many of the experiences that Dakota, Morgan, Sam, Rowan, Drew and Amy lived through in some way or another. I am both horrified and comforted by the similarity of our stories—horrified and comforted by how the issues we all face are likely systemic. If we can identify these issues as systemic, we can start to think about how to remedy them. Perhaps if we understand the emotion work and emotion labour involved in the processes to access academic spaces, we can work to develop effective accommodations.

Doing Emotional (Research) Work

In this process, I am forced to revisit a past that sometimes I just want to tuck away and hide from. It's just too emotionally painful to remember all the ways in which I had to fight for my access, and having to revisit it reminds me how little has changed. I find myself getting angry and frustrated to read that students are still experiencing stigma, are too afraid to ask for what they need, or are working harder so that they won't be found out as being disabled in grad school.²⁶⁹

Physically, this work takes me longer to do. I cannot deny my disabilities that make doing any academic work require more time, especially since I acquired chronic pain, which slows me down. In addition, whereas others might need to read an article only once in order to participate in a classroom discussion, I typically need to read it three or four times due to “slower” processing speeds. This means that in classroom discussions, where I need extra time, like my co-participants and those discussed in the literature, I risk being penalized for not being able to participate in the same ways (or as quickly) as my peers who don't necessarily have access needs. To add to my frustration, I have to muster up the courage to discuss an alternative way of participating with my professor without letting my peers know that I am asking to participate in the classroom differently. We rarely, if ever, take into account how much time and energy these emotional situations consume.

Not to mention the time and energy consumed by re-living these experiences—recounting the endless tears of wanting to just give up and quit. I want to forget all the

²⁶⁹ Aguirre & Duncan, 2013; Damiani & Harbour, 2015; Goode, 2007; Farrar, 2004.

trips to the counsellor's doors, and the meetings I had dreaded with some professors who suspected me as not "capable" of doing this "intellectual" work (especially at the grad level).

During this analysis phase, I had to literally put down each narrative and come back to it when I had more energy to confront my own emotional responses to the stories of the co-participants.²⁷⁰ I was angered by what I was reading, and this anger wouldn't allow me the clarity I needed to keep moving forward. It was like a domino effect, because this anger would then leave me feeling unproductive, or not productive enough, which led to feeling anxious. Seear and McLean remind me that the emotional reactions I am having are "[t]he unacknowledged emotional labour in qualitative research on sensitive topics [that] can produce significant anxiety and stress for researchers."²⁷¹ To combat the toll this work was taking on me, I often relied on debriefing with colleagues about how tired I was getting. I would also refer to various committee members for support. I needed acknowledgement that this was a "normal" part of doing research.

Sometimes I only needed a couple of hours to recoup from doing this analysis; other times, I needed weeks. For much of this process, I was not surprised to learn about the barriers that students continue to fight. I'm at my best when I learn how students have been enabled; but sadly, few of these stories have emerged in the initial narratives thus far. Dakota is one example of a positive experience I have read about so far. Sam and Morgan have a few good incidents; but I wonder how these experiences will continue to

²⁷⁰ As Hubbard, Backett-Milburn and Kemmer (2001) highlight, "the researcher is also involved in the interview and is not immune to emotional experiences in the field" (p. 120).

²⁷¹ Seear & McLean (n.d), p. 4.

unfold as I move through this process.

I hope that as I embody my emotions through my writing of this thesis, by showing you my process, that my work will have an emotional impact on my readers.²⁷² I want my anxiety to show through, because I want this work to be accessible to all readers, and it's part of the embodiment I aim to reveal. Bondi argues that “emotions are an inevitable and necessary aspect of doing research.”²⁷³ I want students like me to understand that writing doesn't just come easily, especially for those of us experiencing disabilities that impact how fast we can produce our work. Coylar refers to the work of Andrew Sparkes in addressing her,

...narrative insecurities. Writing is bringing the self onto a page, presented for all to see. It is a public act. My anxieties, as I have noted occasionally in this chapter, are many: commas always trouble me, clear arguments are a constant preoccupation, the right words consume me even when I am otherwise occupied. I appreciate the ways Sparkes writes into and against the anxiety. I see in his text that such writing is possible, that being a writer and being uncertain can poetically co-exist.²⁷⁴

You've read about a few of my experiences in academia so far. In the next few sections, I reveal a little more about my lived experiences, and I do this by weaving my stories with the stories of the co-participants. More importantly, let's not forget Jules, who encompasses all of us, including those silent voices that have yet to be heard.

After all, there is a little bit of all of us in Jules.

²⁷² Bondi, 2005, p. 243.

²⁷³ Bondi, 2005, p. 243.

²⁷⁴ Coylar, 2014, p. 379.

The (Un)Happy Accident

I'm not sure how I'm going to write the rest of the rest of this chapter. This concussed head isn't helping. You know how hard it is to write with a splitting headache/migraine? The constant pressure on one side of my head often moves to the other side like some sort of balancing act; the chronic fatigue I fight daily; the mental exhaustion from trying to write; or the emotional outbursts I have over what seems like nothing.

Did I mention the headaches?

Every. Fucking. Day.

I begin to question myself again.

Maybe I'm not good enough to do this. Who I am trying to kid?

Some days—days like today—I want nothing more than to give up. I mean, this would be an ideal excuse to just throw in the towel now. I certainly wouldn't have anyone to answer to, as no one would question why I didn't finish the doctorate given my situation. I imagine conversations going something like this:

I got into a car accident. I imagine myself responding to questions about why I dropped out of grad school especially since I was so close to finishing.

I suffered a mild brain injury. That would make sense as to why you dropped out.

Reading and writing just made me more symptomatic. That's too bad.

My doctor says my ADHD might be exacerbating the symptoms of my concussed head. Well, clearly you should quit!

*So much for separating impairment from disability!*²⁷⁵

But I can't stomach the thought of giving into these ableist assumptions that presume disabled bodies and minds cannot take up space in academia. I don't want to become a dropout statistic. This is the very core of my work. I can, and I will, get through my doctorate as long as I have the right support(s) in place. I ponder on what that even means.

While simultaneously working on completing this chapter, my ADHD is hard at work as I open another Word document on my computer. I just couldn't work on this chapter anymore because I was so fed up with it. I entitle the new document "Recommendations for Disabled Grads" and start typing the following in bullet points:

- Think about the ways universities can accommodate disabled grads in their studies such as alternative ways of collecting data without sacrificing key components and skills of doing research. Refer to Grundy and McGinn's 2008 article.
- What role can supervisors and committee members play in ensuring access?
- Think about the socio-emotional aspect of access. We need to review the policies to see whether there is anything that informs how relationships work. This includes training for all service providers, including admin, anyone in the role of supervisor, disability counsellors.

²⁷⁵ Thomas (2010) defines "Impairment effects: the direct and unavoidable impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course" (p. 37). See Thomas (2010) for more discussion on impairment effects that relate to disability effects.

- Mentorship—network students with other disabled faculty and disabled researchers.
- Disabled grads may not have the opportunity to be awarded with teaching awards, as they may have to opt out of such teaching opportunities. However, this is discriminatory, as they need to be offered other types of service awards, and recognized for the work and value they bring to the university that would acknowledge their worth in the academy.²⁷⁶

Hours pass by. I fixate on starting this draft for the recommendations for the thesis. I shift back and forth through the narratives on the blog and see what I am missing, if anything.

Negotiating Ableist Institutional Spaces: Doing “Extra Work”

Days pass as I continue to work through both physical and emotional pain, knowing that piecing all the bits of my writing together will most definitely *piss my concussed head off*. What does this mean, you ask? Well, tomorrow I may not get out of bed until late afternoon. I will likely need to take another day or two off from this writing spurt I’m currently thriving on. It definitely means I’ll be shedding many tears, feeling “incapable” and unproductive that I let this throbbing pain in my head stop me in my tracks.

I have to push through. I am more than capable, even with a mild brain injury. Sure, it’s going to hurt and this isn’t limited to only the head pain I feel from the collision. It’s the process of making it through the final stretch of this doctoral work too.

²⁷⁶ OMET, 1998.

But it'll be worth it.

I feel like the culture of graduate studies is shaped by neoliberalism whereby producing rhetoric around disabled bodies and minds deems this population as less valuable.²⁷⁷ Alison Mountz and colleagues explain that

The business enterprise of academic life in the neoliberal university produces a work rhythm that is rushed, riddled with anxiety and pressure to be ever-present. Sometimes life gets in the way. Overwhelming pressures can lead to paralysis, and scholarship can come to a complete halt. Collective commitments to slow scholarship, fostered by academic alliances and friendships, can help us to come out of moments of depression or exhaustion, lest we drown in shame, loss, or discontentment.²⁷⁸

Rhetorical discourse imposed through various institutional policies make students who do require accommodations feel like they do not belong in academic spaces of graduate school when they must work harder to, and in different distinct ways, access these spaces.²⁷⁹ For some students, this process shapes their embodied experiences of places of academia as exclusionary, rather than enabling spaces. Take for instance, Sam's comments on how disabled grad students are not valuable and therefore unworthy of providing support for. I'll have to find the passage to make sure I am articulating this well, so I can expand on this later in the chapter. Knowing how horrible my memory is, I write a note to myself as a reminder. I also make a note to link this to the notion of disabled grads taking up too much space in academia.

²⁷⁷ The issue of how universities have become more corporatized and how this impacts disabled students is important, but too large and complex for the scope of this dissertation. See for example, Henry Giroux's (2014), *Neoliberalism's War on Higher Education*.

²⁷⁸ Mountz, et al., 2015, p. 8.

²⁷⁹ Farrar, 2004; Farrar, 2006; Rose, 2009.

I also think about the institutional texts at my own university that pertain to students' graduate programs, such as the resource guide for graduate students that I was handed in my first year of my PhD program in 2010. This resource guide did not include any information on disability-related accommodation procedures or relevant resources (e.g., union offices, counselling office). Here disability exists in absence, under the ableist assumption that only those without disabilities will enter spaces of the academy. There is no indication that disabled people participate in this space. Titchkosky refers to this as being “essentially excludable” where disabled grads are “Those who ‘we’ can’t, won’t, or don’t imagine as potential participants.”²⁸⁰ She goes on to write,

Disability, even as essentially excludable, is still included on a case-by-case, that is, individual-basis. Individuals and their individualized special needs, imagined as possibly present in individual classrooms, and who and what typically receive accommodative attention in universities today. Most accommodation and access procedures draw clear lines between the individual and the environment.²⁸¹

This added, extra work of feeling like I have to constantly educate others is emotionally exhausting. It's this emotional exhaustion that manifests through the body and takes a physical toll that wipes me of energy. It's also constant reminder that I must legitimize my belonging here, in this space, every time I need to request an accommodation that would enable my participation in these spaces. Why can't we ensure that disabled bodies are represented in institutional text, and challenge the ways in which disabled bodies are read as “essentially excludable” as Titchkosky reminds us? These bodies should be included in the first place.

²⁸⁰ Titchkosky, 2011, p. 39.

²⁸¹ Titchkosky, 2011, p. 40.

Maybe then, I would feel like I do belong. Maybe then, I wouldn't let this added stress and frustration get the best of me. And just maybe, I wouldn't give into this internalized ableism that continues to hinder me from participating fully in my role as a graduate student when I feel like I just don't belong.

After all, I'm doing relatively OK, similar to what Drew describes for someone dealing with "the cards I am dealt."

I am doing OK.

Emotions are running high.

Just breathe, just breathe. This becomes a constant mantra for me to get through this dissertation.

I open a new Word document and stare at the blank page. In my head, I know where to start. Verbally, I can probably recite this story to you. In fact, I have, many times. But when it comes to getting the words out onto the keyboard, it's like I freeze. I sit with this for a while.

Days before I started this process again, I moved my comfortable office space down to our unfinished cold basement. I needed to get out of my comfort zone. I wanted to get everything off the floor, because my back was starting to hurt. The basement isn't the most comfortable and aesthetically pleasing space, but it's exactly what I need to discipline myself and immerse myself back into the thesis again after being away on medical leave. It was a productive move because all of a sudden, the story came together in ways I hadn't thought of before. I was able to make connections between each of the

co-participants more clearly. The ideas were flowing, probably overflowing. It was like a light bulb went off in my head—things were finally coming together. The messy parts of research finally made sense—to me—at least.

This work is starting to pay off.



Left: Image of basement with concrete grey falls. Covering the pink insulated walls are six large sheets of paper with long sheets of text on separate 8.5 x 11” sheets. Right: large table covered with stacks of printed sheets, coffee mug, scissors and a black leather chair.

I can see it now.

Look at it. Feel it. I tell myself.

Look at all the work it takes just to get accommodated.

The process of getting accommodations takes extra work. This extra work is also hidden because it’s not even formally recognized as “supplementary work”²⁸² or because students prefer to keep it hidden for good reason—like the fear of being further stigmatized. The implications of this extra work for students is the difference of feeling included and enabled, or excluded and oppressed in various spaces of academic life as a disabled grad student. And the costs of this hidden work are extreme.

²⁸² Jung, 2003.

This work is exhausting and for the most part, it's unrecognized and hidden labour.

There it is.

That's what I'll start with.

Recognizing that I just can't seem to move forward with my writing, I reach out to Jules. Jules is my springboard and my consistent source of support throughout this whole process. I'm thrilled that Jules made time to meet with me at my house to work through some of the blog transcripts to help me figure out how to piece it all together. We're in my basement where I introduce Jules to my ironing board desk and what I call my insulated walls of knowledge, where I have taped the blog transcripts.

Jules begins reading through the transcription of blogs. I can hear the sighs. I can see the fisted palms. I note the embodied reaction Jules is having and verifying my own reactions that some of these experiences just anger the shit out of me.

“What's up Jules? What are you thinking?”

“It just kind of boggles my mind that this lack of information in an institution that creates knowledge *exists*. *It's fucked up. I can't think of any other way to say it.*”

“I don't think there is another way to say it that would be as poignant as this.”

(Extra) Emotion Work to Access Information

“Like here. Sam's words resonate with me so profoundly, ‘...I have found myself increasingly understanding accommodations as a last resort, rather than a reliable part of

my education experience.... Each attempt to receive accommodation ultimately felt like a battle against bureaucratic gatekeepers'....”

“It’s actually sort of interesting that you highlight that. I’ve been fixated on this quote myself—trying to analyze it, make meaning from it. Oh my god, this is why it’s bugging me. It’s the emotional work and emotion labour that I am aiming to reveal. You see, there is an underlying assumption that accommodations are straightforward, readily available, and given easily to disabled students.²⁸³ You know, you show your papers that this is what you need and boom, your accommodations needs are granted. Sam reminds us that accommodations are not as straightforward as we are made to believe they are.²⁸⁴

SAM: By transforming the process of seeking accommodation into a series of microaggressions, it becomes possible to be an “inclusive university” while not actually investing time or resources into difficult cases, such as ourselves. (After all, we’re less profitable than non-disabled students, so as the university becomes increasingly corporatized, we are increasingly undesirable.) Because of this, I have found myself increasingly understanding accommodations as a last resort, rather than a reliable part of my education experience. Obviously this is undesirable, but there’s only so much that can be done about it. I really think it underscores the point I tried to make at the beginning of my rambles, however; I experience the provision of accommodation as a concession made by the university, rather than a site of agency or generation.

But, as Sam echoes, we know the lived realities of these practices suggest the unspoken stories that speak to the reasons why many students simply do not access accommodations.

“Check out what Dakota has to say here,” I point Jules to the transcript on the wall and begin reading aloud,

²⁸³ Hibbs & Pothier, 2006.

²⁸⁴ Low (2009) exclaims, “Practice is rarely as straightforward as policy” (p. 238). See also Hibbs & Pothier, 2006; Jung 2002; Jung 2003.

DAKOTA: I was not aware that these accommodations were available to graduate students. During my first undergrad degree, I had heard about them, but didn't feel like going through the process necessary to access them (i.e., getting a doctor's note, filling out the paperwork, etc.). I do think that what the university asked for was totally understandable; it was just a personal choice, on my part. I was informed of accommodations at the graduate level upon learning about the current study.

I have not registered with disability services because I feel that I've been able to complete my schooling thus far without them (both undergraduate degrees and my Master's). I view my ADHD as a positive thing. It took me several years to figure out how to manage it on my own, but now that I have, I believe it is the reason why I am as motivated as I am. If this journey had been easy, I would not appreciate the opportunities that have become available to me now.

“Really?!” Jules says, “Dakota only knew about grad accommodations because of your study?”

“Yeah, I know, right? It strikes me because the key informants I interviewed responded that they do all sorts of promoting awareness of accommodations at the grad level, yet we still have folks like Dakota and many others who did not realize they exist.”

I point Jules to the transcripts from the key informant interviews.

AVERY:²⁸⁵ General information about our ... services and academic accommodations is available on our web site. In addition, we do regular outreach sessions about our services to graduate student orientation sessions each year and throughout the term. We also have information about our services in various publications that target graduate students.

RILEY: Through website, GPDs [graduate program directors] and GPAs [graduate program assistants].

JAMIE: Through workshops at departmental level, through e-mail lists, and at new-student events.

LESLIE: Though educational initiatives in collaboration/partnership with [other

²⁸⁵ Avery, Riley, Jamie, Leslie are the pseudonyms of the key informants.

on-campus committees] and graduate students with disabilities.

“That all sounds well and good, but....” I reach over to my transcripts and share with Jules Morgan’s response specifically to Avery:

And for many of us it is sometimes hard to navigate this even if it is a “good” site! Our disability may be with written work so alternately we need someone to verbalize it for us. While we may get a friend to read the site to us, there still may be questions that only a SME [Subject Matter Expert] can answer. Unfortunately I find that it is hard to access those responsible for “writing the website content” so as to better understand things that are confusing.

I make a note for another recommendation that a university needs to speak to disabled graduate students to ensure they are well aware of the resources available and to ensure, that these resources are accessible as per Morgan’s point.

“I can appreciate Morgan’s contribution,” Jules says. “I find it interesting here that the key informants are addressing only one issue here, the availability of information, without addressing the humiliation or the extra work that students face in accessing this knowledge.”²⁸⁶

“Yes, Jules you’re brilliant!”

“Yes, I know,” Jules grins. “What did I say this time?”

“This is exactly what I am trying to address in my work,” I laugh. “Sure it’s important that we use as many avenues to ensure access to information is available, but what the key informants are not addressing is the emotional work that goes into these processes. It’s the emotional stuff that I am after. It’s not only an issue of running around to access our accommodations, but it’s the way students are made to feel as ‘less than’ in the entire process, and all of this takes energy and work. Like how we manage the

²⁸⁶ See Mullins & Preyde, 2013.

perceptions of what our disabilities are or are not. If professors are suspicious of our impairments, then there's still this extra work in managing how we negotiate this stigma.”

(Extra) Emotion Work of Managing (Mis)perceptions as Student and Academic Worker

Dakota recognizes the extra hassle of getting accommodations, but doesn't seem to see it in my own framework of extra, emotion work—work that they would not have to perform if they didn't have their particular non-visible disability. Instead, ADHD is viewed as something positive to get around—used as a motivating factor to complete their studies.²⁸⁷ Out of all the co-participants, all but Dakota identified, or recognized this work of getting accommodated as a “barrier” instead viewing it as a motivator. I am not sure how I feel reading this—I am certainly not critiquing Dakota, as I used to feel the same way at one point; that is, until I recognized that accommodations were a right, not a privilege or special treatment, as many people made me feel. Needless to say, I was relieved to read how the others responded to this as well.

Rowan illustrates the point well that I am trying to drive home—that the process to access accommodations is emotionally charged. Here, Rowan experiences humiliation specifically related to the medical documentation needed to access services and accommodations.²⁸⁸

²⁸⁷ See Shessel & Reiff, 1999.

²⁸⁸ Barnard-Brak, Lechtenberger, and Lan (2010) explain that, ...the disclosure of a student's disability obviously does not stop at physically handing an instructor a letter of accommodation but is followed by questions from faculty members. These questions can range from the highly personal (e.g., asking specific questions about a person's a [sic] disability) to the impersonal relating only to satisfying a request for accommodations (e.g., asking questions only in order to satisfy a request for accommodations). p. 413

ROWAN: I also have previously got through the schooling I have done without formal accommodations and used to feel similarly to you [Dakota]... In applying to this program I realized that my previous ways of managing may not work effectively at this level and I had to really challenge my internalized ableism in order to ask for what I need. This does not take away from the advantages I see in having my “disabilities”, though the process does highlight the negative parts to the point of humiliation at times—particularly the pathologizing language in the reports needed. I don’t believe being accommodated makes the journey “easy”... ideally it would have help to figure out what you need to manage effectively on your own (which I see as the goal) in a less stressful way in a much shorter time frame... It is not necessary to seek support from disability services if things are working well for you as is....

This is not to suggest that I take issue with viewing disability in a positive light. On the contrary, what I am trying to highlight is that while there are advantages to being differently wired (e.g., multi-tasking, being creative), this should not take away from the fact that there are still barriers that we encounter, and it’s OK to admit how frustrating the system can actually be.

NANCY: I myself, also share your views of ADHD as a positive but also, I am very frustrated with it at times when it means I cannot do what is expected of me. It’s hard to explain to folks that “hey, I am late because someone moved my keys from their normal spot and it took me 40 minutes of searching my house to find them.” I share in the belief that a few mentioned here that because of the invisibility of my impairments, I am perceived as weak-willed, lazy, making up excuses. I also battle internalized ableism daily. It’s so hard at times.

I should add that there is an accommodation for an ADHD coach that can help with managing while pursuing studies. Such a coach can also help with management during workplace responsibilities too. It’s my experience though, that at [a university], I was notified of this service whereas at [a university], I am still constantly telling the counselling office that they need to inform students about this. So far, it’s been three years and I still have students approaching me and asking what is an ADHD coach. I wonder why one institution is forthcoming with this information while another hides it. It really makes me frustrated and annoyed.

Drew further characterizes the process of accessing accommodations as not a question of whether or not one can manage without an accommodation, but rather to

suggest that accommodations need to be available and supportive to a student's needs.

Drew shares their own feelings of frustration, but makes a larger point that these are not simply individual issues, but rather systemic.

DREW: Dakota, I think you are to be congratulated for your successes and your motivation. It is wonderful that you have achieved such successes. AND I think about the system, as noted by Rowan, that the system influences or reinforces feelings of success or limitations (some would call this being disabled). For those of us living with mental health issues, reflecting on the archaic and mid-evil approaches to treatments and world views, we know that issue of language, fragmented, disorienting process and resistance within multiple systems need to be and can be overcome. Progress in this area, is unfortunately slow. But creating a change in social response and institutional venues MUST occur and this issues brought to light.

That was one of my motivations to participate in this study. Change can begin to be supported when academic studies are part of the conversation to support the need for change. It becomes a means for speaking "Truth to Power." Many strategies and experiences by those who have gone before us have created changes. Systems have been responsive, although slowly and I do believe that individuals within the system are often well meaning, yet, are not always free from their employers to advocate for changes on behalf of clients. So while they will tell us about resources, they cannot always address the challenges from within—for example the discussion of language used in documentation and processes that result in frustration and humiliation. That is our cause to take on; when we can and when we gather together to share several stories that speak to the same issues for our unique perspectives. Social justice takes time and many different voices to create a lasting change and transformation to a more humane approach to lived experiences...

Relating back to what Morgan describes, I can't help but contrast this experience to Dakota's. Dakota felt that "if this journey had been easy, I would not appreciate the opportunities that have become available to me." For me, this struck an uneasy chord. It made me feel devalued in some ways, as if my own use of accommodations was an easy way out. I think my internalized ableism is to blame for the way I am made to feel like this.

Thinking back to Olney and Brockelman’s work, they highlighted how students were “...appreciating their disabilities despite the negative messages they receive.”²⁸⁹ Their research explores the benefits associated with managing and resisting discrimination in an academic environment. For the students in their study, viewing their disabilities with positive affirmations and being appreciative of their disabilities was useful in empowering students to become leaders. I wonder if Dakota feels this way. While it’s not clear if Dakota was indeed managing and resisting their disability, I do find Dakota’s positive affirmations in appreciation for their disability has shaped their experience in feeling empowered in academia. *That’s great.*

On the other hand, the drawbacks of advocating for oneself, with little support, means that students have less time to focus on their academic work, are socially isolated from peers, and can lose their sense of belonging when “feeling included” means having to fight to access these inclusive spaces.

I’m sure Dakota is not saying disabled students shouldn’t access supports. I won’t ever know for sure though. They dropped out of the study mid-way and it’s too late to go back and ask them why. It didn’t become apparent just how uneasy I was with this until now, when I really had a chance to sit with the transcripts, literally re-reading it on the basement wall. I did follow up with Dakota, but I didn’t want to pry. I had to follow my ethical protocol, and my own researcher care, so as not to make the co-participant feel

²⁸⁹ Olney & Brockelman, 2003, p. 42.

badly for dropping out of the study. In fact, I still offered Dakota the honorarium, which was received in full, for participating in the study.²⁹⁰

Rowan articulated it quite well agreeing to disagree that while the accommodation process is humiliating at times, especially with regard to the medical documents required to get access, being accommodated doesn't make the journey to academia any "easier". It just makes it possible.

The implications of trying to perform academically, without the support of accommodations in place, leads to extra work that have long-lasting effects, such as adrenal burnout, dropping out of the academy, or challenging self-worth.²⁹¹ As Barnard-Brak, Lechtenberger, and Lan explain,

A request for accommodations should not be treated as an indication of inability (because every student with a disability admitted to an institution of higher education does have ability), but rather an acknowledgement of certain functional limitations that the student has. In life, we all have limitations. Some persons' limitations are more pronounced than others and require accommodations to be made in order to counter or remove the effects of these limitations.²⁹²

Access to accommodations is time-consuming, emotionally charged and extra work. This extra work is hidden because it is not formally recognized as supplementary work²⁹³ or because students prefer to keep it hidden for fear of further stigmatization.

It's time for another break. We've tackled the first round of analysis and discussion for a few hours now, and we're both exhausted. For me, my body is screaming for a nap.

²⁹⁰ I increased the honorarium from \$25 to \$50 in recognition of the additional time the blog was taking as I had to extend our time together.

²⁹¹ See Barnard-Brak, Lechtenberger, & Lan, 2010; Denhart, 2008; Farrar, 2004.

²⁹² Barnard-Brak, Lechtenberger & Lan, 2010, p. 424.

²⁹³ Jung, 2003.

My mind on the other hand is telling me I have no time for rest. I need to keep going; I have this momentum to keep. I'm so apprehensive at the thought that I won't finish in time and that I'll end up dropping out, that I do whatever I can to energize myself for the next round of brainstorming. Coffee is a given. But as Jules reminds me, without rest, I won't be able to give this chapter the attention it needs.

I give in.

Jules heads out for a walk. I decide it's best that I stay back and rest for a bit. I'll hit the gym after dinner. As I lay on the couch, I find myself reflecting on Cresswell's notion that "space is turned into place,"²⁹⁴ thinking about the ways people make and attach meaning to particular places. This echoes in the back of my mind recognizing the hardships that Jules, myself, and the other co-participants have encountered at a university. Though I am supposed to be taking a break, I can't seem to get that quote out of my head—"space is turned into place"—as I think about how disabled grads manage the (mis)perceptions of disability, such as the stigma attached to labels of disability. Supporting disabled students is much more than just advising them to seek the services of disability service offices.

The working conditions and the ableist expectations of academia are what disable me. Rose explains that,

Students cannot rely on faculty or even student colleagues having the knowledge to understand their disability or the skills to accommodate, a fact likely exacerbated by the expectations of relative academic independence that often accompany graduate programs of study.²⁹⁵

²⁹⁴ Cresswell, 2004, p. 2.

²⁹⁵ Rose, 2009, p. 13.

When I was assigned two courses in one term to TA for, this added more work to my plate. While theoretically, the workload was within the prescribed number of hours, I would have had to spend more time learning material for two different courses, for example. The additional work of doing two courses is like doing two part-time jobs instead of one full-time job. This was recognized by my union, but not by a university. Having to turn this opportunity down would lead me into social isolation, lost opportunities, and financial constraints. Thus, I understand the university as a place of struggling for inclusion, not one that will enhance my career, build friendships, and establish professional networks. I don't feel that I have experienced the academic environment as a place that affords me these opportunities.

NANCY: The question I want us (participants) to reflect on is: how do we understand accommodations in the academia?

I know for myself, I expect the university to level the playing field for me. It would be useful to have a collaboration of this but I am not sure what that would look like without having me do the extra work not asked by other students. By the university, I mean all the folks involved in the process of graduate school. For example, I expect that my supervisor knowing about my disabilities will support me in different ways from other graduate students so that I am level on an equal playing field. I am not expecting, nor would I want my supervisor to tell me not to do something because of my disability, rather I would hope that she and I could find ways to ensure that I am fully participating in all aspects of university life.

Because I need more time to complete writing projects, rather than telling me not to take on any other work or a conference, I would look to her for ways to support what I need to get my writing project complete while still being able to present at conferences so that I am just as competitive as my peers. Last year, when I was dealing with my struggles of being accommodated for during my comps, I had lost the opportunity to present at Congress that happened in Waterloo.

Further, accommodations, to me, is not solely my responsibility. I wouldn't need accommodations if the department would assign me a course (TA) that is in my

background of Disability Studies (Geography my discipline is very broad and my area is Geographies of Disability and only one course is offered next term; it wasn't offered in three years). Even with this course being offered next term, it will likely be a half TA-ship which means I'd have to take on another half TA-ship which I was told by the union is not reasonable for a "regular" grad student, let alone those with disabilities. I was also very fortunate enough in my academic studies to have been accommodated by my supervisor and committee member, but it was a collaboration between us. I a couple of negative situations with others profs during my studies likely due to the invisibility of my impairments which some of you shed light on earlier.

I am intrigued by your comment about "understanding accommodations as a last resort, rather than a reliable part of my education experience" as you pointed out Sam. I am also feeling the same way and I say this as on the one hand, I could file a formal complaint and see where it gets me with the university, but on the other hand, I don't have the time and energy to pursue it so I am managing to get by on my own. What does this mean? Well, I may just have to forgo my TA-ship and find employment elsewhere. I am just not sure my mental health over agonizing over this is worth sacrificing any longer when I need to focus on my studies. I think you make an excellent point about "the provision of accommodation as a concession made by the university, rather than a site of agency or generation." I'm not sure if I responding to you Sam, but this is all I have right now. Would others like to comment on these posts as well?

I'll wait for Jules to get back from their walk before I continue looking at the transcripts more closely. Since I've asked the co-participants to ponder about accommodations in academia, I'm really interested to discuss this with Jules.

And just as I am about to shut my eyes and doze off for a few minutes, Jules returns with excitement in their voice shouting,

"OK, so you all spoke about information issues for the first theme. You generated a lot of responses here. How many blog responses did you collect here? How did you move into your second theme? What happened next?"

"Slow down, slow down. While you were off enjoying the birds singing outside, I've been collecting my thoughts. Give me a minute to at least get the coffee started."

“Sure thing, Nanc.”

“OK, just to review, after everyone sent their initial narratives, I posted them on the blog and asked co-participants to comment on one another’s experiences.

“Including your own initial narrative, right?” Jules interrupts.

“Yes. Then I pulled out the three themes for in depth discussion. From this process, the six of us posted 17 blog responses on the first theme.”

Wait a minute, Jules interrupts again. “I thought you said there were seven co-participants. Are you counting yourself?”

“Yes. You’re right. There were seven, but Dakota dropped out by the start of the second discussion, so they posted only one response of the 17 comments.”

I continue, “The first discussion on the information wasn’t nearly as fruitful as the discussion on the second theme, which I called ‘(Mis)perceptions.’”

“That’s the theme about managing the perceptions of others, right?”

“Yes. It’s also where we talked the most about workplace accommodation. There wasn’t as much data about workplace issues as I’d hoped.”

“Why do you think that is?”

“Well, let me look back at my probes. Yes, I did specifically ask about getting accommodations in our dual roles. From the data, it looks at least three people didn’t even know they could ask for a workplace accommodation, and the answers were a bit ambiguous from those who might have. So in essence, there was a lack of data to draw from despite me probing specifically about both academic and workplace accommodations.”

“What do you mean?”

“Well, for one thing, like academic accommodations, asking for a workplace accommodation is linked to having to disclose. And remember when Morgan was told that it would ‘unfair to other students’ if they had a reduced load.”

“Well, doesn’t that kind of miss the point about what an accommodation is?” Jules interjects.

“This is what Morgan wrote:

MORGAN: As a TA, I often found it difficult to balance the TAship and my own studies at least in the first semester. That is why I TA the same course for the second semester. I was able to be stronger and more confident but I would have liked to get RA experience instead. Thankfully I am able to do that for this coming semester despite my concerns about time balance again. I disclosed the fact that the 10hr a week RA allotted time would likely take me 15-20, for which I am only paid for 10 however I was assured that it is the quality that the prof is looking for. This has helped to reduce some of my performance anxiety.

“So that prof actually understands accommodations.”

“What was the third theme again?”

“Extra work.” Anticipating Jules, I quickly add, “Yes, I know, I know. There is an overlap across the themes. Finding the information and managing perceptions are forms of extra work. But the idea of ‘extra work’ is so important, and besides, that’s just the way I interpreted the data.”

Jules smirks and starts singing, “‘which of these things is not like the other?’ from Sesame Street.

“Yes, yes. We’ve talked about how my LD means I don’t always categorize things the way you do.” I continue, “Amy started to get more active on the second theme, so I would say that this theme generated richer responses. I’m not quite sure if it because she

was more interested in the topic, or if it was because we were all more comfortable by this point sharing via the blog. Blogging was fairly newish to all of us, and it's not like we had enough time to build rapport with each other. Yes, and just seeing that look on your face, this was a limitation and something that I would say needed work. I should've allowed time to build rapport first, before delving into the research.”

Another smirk from Jules, that look right before I usually get, “I told you so.”

“Nonetheless,” I say, “this experience was great.”

“How so?” Jules raises an eyebrow.

Joke's on you. My turn to be smug.

“Well, you should see the quality of these responses! I just mean that the responses were much more detailed and well thought out than the first time around. I assume this had something to do with the guiding probes I offered, but whatever the reason, the responses are so articulate and thoughtful.

“I didn't want to offer too many probes, as I wanted to stay consistent with asking co-participants what they felt was most important to share. But after consulting with them, I came to recognize that the data collection was taking a bit longer than I anticipated, and I had to get us all moving to contribute to the blog. In this blog discussion, I asked the co-participants to reflect on the quote on quote “mis” perceptions of being non-visibly disabled in our dual roles in a university. I asked everyone to focus on both places of academia: academic and paid work, providing a workplace example like whether they disclosed to their students as a TA, and a classroom example, like managing relations with professors in negotiating accommodation requests. I explained that this

isn't limited to only professors and students; they could speak to negotiations with union representatives, department advisors, deans, counsellors.”

“Hmmm, I can't wait to read what transpired here.”

“Enjoy. I know you're going to love how Amy starts this discussion. I'll sit here and enjoy my caffeine while I give you a chance to read through.”

“How thoughtful of you. Now, please go and grab me a cup, so I can start.”

“Oh right. Yes. Sorry!”

Seconds later, I hear a burst of laughter.

More on Workplace Accommodations

Amy starts the discussion with, “Lol workplaces only accommodate until they can fire you or pass you off to another dept.”

It takes me a couple of minutes to get Jules's coffee as I have been negotiating my pace lately with the chronic pain I feel overall. My body is aching; my joints continue to be stiff, and negotiating stairs is a bit problematic as I am still experiencing dizziness from this concussed head. Slow and steady, I think to myself as I climb down the stairs of my bungalow to the basement office. I hand Jules a cup of coffee. I take a seat in my chair and begin following along while Jules is reading on the wall with my printed transcripts that are scribbled with pink highlights. Sam shares some stories that are painful for me to read. I wonder how Jules will react.

SAM: I fall into the camp of having not sought accommodations for any of my major degree objectives (in either my MA or my PhD.) One of the perceptions which has discouraged me from pursuing significant accommodation is that I have found non-visible disabilities to often be conflated with academic delinquency. I procrastinate by nature, and several times during my academic career I have been

(politely) accused of blowing²⁹⁶ off a deadline, when I have sought accommodation. While many professors have been able to preempt my request by identifying that I was struggling by my increasingly frantic communications with them, others have refused to even consider the possibility. This creates an environment where any need for accommodation (though note, my first instinct was to write “weakness”) carries the additional threat and stress of also being seized upon as an unfit student, precisely when we might be least ready to deal with such an accusation.

Sam’s remarks illustrate the stigma of managing this work—both emotion work and emotional labour. Again, I am not at all surprised by any of what Sam shares here. Farrar identified “concerns about the links made by others between intelligence and disability.”²⁹⁷ It is this stigma that is attached to these labels that makes it hard to negotiate how others perceive us, and in turn, how we perceive ourselves. Many of us on the blog have shared similar sentiments about not wanting to be stigmatized, and the consequences of these decisions.

DREW: I like you Sam did not request accommodation for either my comprehensive exams or my work. While I have communicated issues that have been stressors in my life, which puts me at increased risk for symptoms of depression and anxiety, time has passed and I continue to move ahead with my work. However, time became an issue and stressor that resulted in a relapse in my illness. I was denied the opportunity to ask for another LOA [leave of absence] due to illness. Of course, this resulted in a negative outcome for me.

I have worked and not disclosed my disability when working within my university and other universities. I have not disclosed due to fear of rejection for employment due to the disability. That I might need an accommodation for this or draw on sick benefits has made me resistant to sharing my situation.

As my doctor has stated I usually manage my multiple health issues very well; excessive time restraints and a personal stressful situation had resulted in

²⁹⁶ Why are deadlines so important? Why is “academic integrity” all about the individual’s contribution and originality, rather than whether the work is insightful and helpful and provided a learning experience for the student? I question what a university means when they insist on protecting the academic integrity of the institution? From my perspective, this assumes that disabled students are guilty of something they didn’t do yet. We hear little rhetoric around “non-disabled” students because this is almost always tied to accommodations.

²⁹⁷ Farrar, 2006, p. 180.

symptoms. This resulted in the need to request a LOA. I was never allowed to share this information with the director in my faculty-it was blocked at the level of the school.

My committee was coached by the school administrator as to how I was to be managed; I was asked to leave a committee meeting so that the administrator was able to speak with the committee without my presence.

I believe my experiences support the actions taken by Sam. And I agree with the comment by Sam that disability and the need for accommodation “carries the additional threat and stress of also being seized upon as an unfit student, precisely when we might be least ready to deal with such an accusation.”

As an example of this, I had received messages from my advisor that tears were not going to work in getting more extensions; the message I received from that was that manifestations of my illness were clearly seen as an attempt to manipulate professors for the purpose of extensions of deadlines. This only spurred me onward to show that my intentions were to respond to the requirements and meet their requirements. However, I also internalized the feedback as negative. And as a result, I need to spend energy to overcome these comments and move forward with the work. I believe this energy might have been better used to continue to write and work on academic responsibilities.

My fears of rejection were realized. And the messages I received were that discussion of my disability/illness was just another excuse.

Not sure if I have answered all of your questions, or that this is clear, so please feel free to ask for clarification.

“Wow, this just seems like too much to take in.” Jules sighs. It’s like ‘We can be disabled, as long as we don’t change the norm in any way or ask for anything extra.’”²⁹⁸

“That’s a good way to put it! Keep going. There’s lots more!”

ROWAN: Most of the accommodations I have asked for (mainly extensions) have been given to me but I am also very aware that I have not taken certain classes as I was not sure if the prof would be supportive, especially if there appeared to be a larger reading requirement/fast turn around on papers. This has been a big factor on choosing the course I have taken and caused huge amounts of anxiety anytime I have “taken a risk”. Because I was not able to access the financial supports

²⁹⁸ K. Roosen, personal communication, April 8, 2016.

(BSWD etc) and get the software/hardware that would help me move through the readings faster I have had extensions in almost all classes.

As my program includes summer term, it has meant course work from one term is bleeding into the next and I am always feeling behind, not good enough and highly anxious. I am now realizing I will need to extend my program by a term, which will cause financial problems as I will have no funding for that term. Again I face the “holidays” with vast amounts of work to catch up on... This is even with reducing my course load by one class this term and last in an effort to catch up. I expect to finish this terms work by the middle or end on January (putting me back to the level of lateness I was after the first term). I can afford to have a lower course load for one more term, but if I go beyond that I will need to extend by two terms, which seems financially and logistically impossible—especially given I have been denied OSAP and would then need to work even more to cover the fees as well as my living expenses.

Even after attempting to appeal, after following OSAP’s complicated (and didn’t make a lot of sense) appeal process the best as I could this summer (I was told there was no one who could help me with it). I was sent a very bitchy letter saying I, by the time of them mailing me the letter (though I sent the application in plenty of time), it was too late to submit any further documentation and that if I was going to reapply in the fall I should “READ” (they used all caps) the requirements. They didn’t say what information/documentation was missing that they needed or provided any kind of clarification and it sure as hell wasn’t apparent to me. I am not sure if my misunderstanding was disability related or just their general confusing language and mystification.

When I read the requirements the first time (Fall last year) I was so overwhelmed I had a panic attack and had no idea what to do with it (that’s when I went looking for someone to help-to no avail)... at that time I decided not to appeal as it was too mentally and emotionally exhausting and I didn’t know it would be effective. This summer I tried again and did a simple appeal, giving all the documentation I had access to—partly encouraged by my participation in this study, and emphasizing I was primarily looking for access to the BSWD and other disability related supports, as I had given up on the idea of a loan... I didn’t reattempt this fall. It seems very clear that OSAP process is not in anyway accommodating or inviting to people with LDs. While I will be glad I will be able to leave this program with out student debt it has made the whole process has been a significant barrier and made so much more difficult and stressful not being able to access those supports. I am still optimistic I will be able to complete the program but I have not been able to put as much in to it or received the grades I would have if I had received the support that is supposed to be available. This makes me feel extremely worried about my chances of getting in and succeeding in further study I was planning to take after this. If I do get in I have been thinking of trying to only take part-time program in

an effort to have some balance and quality of life while moving on... even though this has obvious disadvantages.

Extra/Emotional Labour and Emotion Work Revisited

How is it that so many of us had no idea that workplace accommodations existed either? It does seem counterproductive, because if students are not aware of academic accommodations at the grad level, would they even consider asking about workplace accommodations at a university?²⁹⁹ This would make for a useful research question in a future study. Where did I put that post-it note pad? Then I remember where to find the answer to my own question. Like the information about academic accommodations, the key informants indicate that a university was not particularly assertive in making sure students know they have a right to workplace accommodations.

AVERY: We typically do inform them about the potential for employment accommodations, but as mentioned earlier, typically employment accommodations are negotiated with the support of the relevant union/ contract bargaining unit and/or Employee Well-Being Office through [a university's] Department of Human Resources.

RILEY: Only when they request it—we only have one classroom accessible for TAs with wheelchairs

JAMIE: Through workshops at departmental level, through e-mail lists, and at new-student events. Also, when [students] call in to the [...] office.

LESLIE: Although our office does not do this specifically, we understand that letters of employment make note that accommodations are available.

Morgan brings up another critical point about the sorts of accommodations

²⁹⁹ As noted earlier, Sierra-Zarella's (2005) experiential account indicates that students who are not afforded accommodations for their academic work are also less likely to seek accommodations for the paid work (p. 141). See also Damiani & Harbour, 2015, p. 404.

available in the workplace, something that struck me as well. Morgan writes in response to the excerpt I shared by Riley,

Again, this speaks to physical disabilities. While it is only fair and just that there should be accessibility for chairs etc, there should be equal consideration given to those of us with hidden disabilities and unfortunately there is still huge stigma attached to this. And, I do not think all these “campaigns” are doing the trick. It's all nice to “learn” and advertise the value of diversity etc but unless it is truly embraced it ends up going no where.

Accessing academic accommodations is emotionally charged, invisible work, which non-visibly disabled students do in their struggle for inclusion—an important aspect of negotiating ableist geographies of the academy.³⁰⁰ Tinklin and Hall’s³⁰¹ study discusses how disabled students express the emotional struggles for inclusion in the classroom. In their study, one student described how she constantly has to remind her instructors of her accommodations support needs. She explains, “I sometimes think I am asking for too much and I don’t want to impose ... me again, ... it can get embarrassing because I don’t want to do it. And that holds me back a lot of times.”³⁰² Barnard-Brak, Lechtenberger and Lan concur with these findings. They suggest that professors do not fully understand the emotional work it takes in requesting accommodations. Another felt that “If they [faculty members] knew exactly what I go through every day, they may rethink what they say and do.”³⁰³ These findings suggest that even when accommodations are negotiated in the classroom, reminders are needed to ensure they are implemented and that they are effective for the student. In addition to dealing with the stigmatization of managing one’s

³⁰⁰ Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010.

³⁰¹ Tinklin & Hall, 1999.

³⁰² Tinklin & Hall, 1999, pp. 189-190.

³⁰³ Barnard-Brak, Lechtenberger & Lan, 2010, p. 418.

identity, there is the added work of constantly having to remind others that their needs are not being (fully) met.³⁰⁴

With this stigmatization, comes emotion work.

MORGAN: I find, of late, that the general population’s reaction to those with visible physical disabilities has come a long way. However as those of us participating in this study know first hand, the struggles of “hidden” disabilities do not seem to be met yet with the same appreciation or at least reasoned curiosity and reflection. I am also furious with the whole “mental health” campaigns that are out there now. There is so much focus that it is still up to the individual to seek help which then underlines that there is somehow a flaw or fault within them rather than looking at broad systemic reasons that may contribute to things like, particularly, depression. Sorry if I raise several ideas/ thoughts. I find it hard to login or access the chat so when I do I read alot of posts and therefore am reintegrating a bundle of info!

ROWAN: For me, having a invisible disability did not seem as valid as any visible disability and seeing my disabilities (or thinking others would perceive them) as some kind of “weakness” or laziness (just looking for an easy way out) led me to believe that I’d better keep them hidden. It is only by doing anti-ableist work as an ally to folks with visible disabilities did I begin to unpack my own reluctance to see myself as “disabled”* or to acknowledge the impact this has on me in any significant way and to realize those messages come from what I was told as a child (and some times still hear) and they carry echos of other oppressions. This is ongoing work for me.

It is this stigma that leads to the decisions that shape how disabled students participate or not in these spaces.

SAM: I find that even being conscious of how these episodes perpetuate an ableist mindset doesn’t make me immune to internalizing them. It’s so easy to blur the lines between laziness and my experiences of depression, and there’s really a tremendous amount of pressure to buy into narratives of agency. This leads me toward my answer to the first part of the prompt. I’ve made a point of trying to avoid sharing information about my disabilities with those in the academy who are less or more powerful than I am. By this I mean my students, my professors and

³⁰⁴ Tali Heiman and Dafna Kariv’s (2004) findings indicate that, “...[disabled students] frequently described being emotionally exhausted, being too embarrassed to ask for help, wanting to hide the fact of their dyslexia or not wanting to frequently justify asking for notes” (Barton & Furman, 1994 as cited in Heiman & Kariv, 2004, p. 452). See also Damiani & Harbour, 2015; Ryan, 2007.

faculty administrators. The relative equality between my peers creates a certain safety in discussing issues like anxiety and depression. (This is of course also fostered by the number of my colleagues who share my experiences...) However, when it comes to my students and my departmental overseers, I find imbalances of power to put unreasonable pressure on my identity as a disabled student.

I've had students dismiss my ideas because they seemed too pessimistic to be true for a "normal person." I've had students try to earn my approval by lavishing praise on me, in response to discovering that I struggle with esteem issues. In these cases I feel like acknowledging my disability creates a barrier to me doing my job well. For me, the necessary decision is to try and keep that part of my identity separate from my teaching identity. I do it well enough, but the necessity of it is clearly troubling. A similar threat feels present when dealing with professors, however their power over so much of our lives makes them especially threatening to me. I have once been told (unofficially, of course) that I was denied a coveted spot on a departmental committee, because there was a fear that I might "crack up" in a way which would threaten a politically important deadline. We all constantly struggle with the capricious nature of publication decisions and conference acceptances. Disappointment is part of our job, and I like to think that I'm good at accepting the ups and downs of this lifestyle, but there is something humiliating in being told that you are too damaged to succeed. That, in effect, you are a liability to the department you contribute to daily. It creates a wedge between me and my work environment, and while I'm good at surviving in that space, I shouldn't need to.

Out of nowhere, Jules begins reading aloud the next co-participant's response. I hear a soft giggle as they read, and know exactly whose response Jules is reading.

AMY: I was reading this and thought there is a disconnect between "disclosure" and "getting the fucking message across". I can tell people I'm a narcolept, and they then know hey she has narcolepsy like that chick on duece biggalo male giggalo but really what does that MEAN? People like to appear knowledgeable so they won't ask or they will look stupid. This also interferes with accomodations—okay you have epilepsy—you might have a "fit"—fits over back to studying without knowing after a seizure an epileptic is exhausted, often needs to sleep, never mind the medications are sedatives, and many epileptics have seizures when they sleep... And we're asking non medical people (profs, and our helpful university disability coordinators...) to understand, and support. Of course they fail miserably. This also brings up the issue of sympathy.

Get cancer and watch people try to get you. Get a chronic illness watch them yawn

and look for reasons its “in your head” or you caused it yourself. Ultimately it also brings up how punitive the system is for everyone. The able bodied, minded and normal people. We have a system designed to humiliate and break students—this karate style of testing measuring learning is antiquated and stupid as the retention rate is minimal. A disability can be used for “better marks” lol because we’re given “special treatment” um?

Oh the treatment is special alright... Hence why asking for accommodations is the LAST thing any of us want to do and I know my marks have suffered because of my reluctance to ask for accommodations, or inability to admit I needed them beforehand. I fare better as my disability is legitimately “medical” and “physical.” People with mental illness, invisible, nondiagnosed, adhd, anxiety, panic, depression are received with distain. When a mobility issue may make it harder and take longer to get somewhere...an agaraphobic can’t get out, period.

“Period,” Jules repeats, pointing at the word.

“Yes, I know. Amy has a way with words and she just calls it as it is. This is what I really enjoyed about doing this research—the candour of the co-participants. I wonder if I would’ve been able to capture the same sort of response if we were doing this face-to-face. I’m not sure. Her responses were just so relatable—at least for me. They certainly put a smile on my face when this research process got intense with reading some painful experiences these students lived.”

Jules and I continue to discuss how what Amy highlights as a similar rhetoric that has been repeated throughout the blog. Amy is particularly helpful in pointing to the stigma attached to managing the perceptions of what it is to experience non-visible disabilities. She illustrates how “punitive the system is for everyone” who is experiencing a chronic illness because they are misperceived in comparison to other types of disability or illness.³⁰⁵ Many of us on the blog have shared similar sentiments about being non-

³⁰⁵ Devaney, 2008.

visibly disabled, and how this affects our daily academic lives.

Manuel Madriaga wrote, “Disabled students have to contend with issues that non-disabled students may not experience. A major issue that disabled students have to confront is the anxiety and worry that their impairments remain invisible to university administrators and academics.”³⁰⁶ Managing perceptions of disability,—their own and those of others—takes an emotional toll in worry and anxiety, which we can think of as one aspect of the embodiment of that disability. In some circumstances, students may choose not to disclose, which requires emotional energy to maintain. In other circumstances, they may need to disclose, and therefore manage the perceptions and biases of those in authority, and this also takes emotional energy, though of a different nature. Both types of situations demand that students deal with the internalized ableism of feeling “not good enough” or potentially deceitful, which also takes a toll in worry and anxiety.³⁰⁷

I hear another burst of laughter from Jules as they blurt, “*‘Being disabled is f*ing expensive!’* Amy certainly sounds like a feisty one! Good for her. All students need to speak up like this.”

Jules continues laughing, “I love what she says here: ‘Also poverty. Students are poor. Being disabled is f*ing expensive. Supports are expensive, we all spend more \$ to compensate for our issues—medication, herbal remedies, special diets, counselling, equipment, transportation.’ I couldn’t have written it any better myself.”

“Yes, it’s certainly true, isn’t it? And not to disregard any other students’

³⁰⁶ Madriaga, 2007, p. 401.

³⁰⁷ Fuller, Healey, Bradley, & Hall, 2004.

experiences of poverty, Amy is highlighting that there are additional costs when you have a disability. Rowan shares this sentiment. I wonder if the others have had similar experiences, but they didn't speak to it at the time of the blog. This was mostly a conversation that Rowan and I seem to share. Amy was a bit late with adding her contribution, so we never did address this any further. I often wonder if I could have done more to tackle this theme. I also wonder if I could have accommodated Amy's need for 'extra' time. I'm empathetic about her needs, but I also need extra time because of my disability. I just couldn't drag this out any longer—with my funding running out."

"That's a shame that you didn't get to explore these issues further. But I do understand. You have time constraints. All research requires compromises. And you also raise an important point about being a disabled researcher, working with disabled co-participants."

"Thanks. I did keep a log of various issues like poverty, amongst other important intersectionalities like race, age, class, sex, and noted how I couldn't cover all of these important topics in my thesis. But they are definitely important issues to explore in future studies."

"Indeed."

Chapter Five: Methods (Re)Considered

... I found that writing about one's self is both daunting and invigorating: daunting in that sense that in weaving my *self* through the threads of other people's lives, it is difficult to sort through what is important, what is muck, and what is fluff; yet invigorating in the sense that in placing my *self* more widely, new connections emerge through which I forge links with other people, other places.³⁰⁸

Autoethnography provided me with an opportunity to be self-reflexive. It calls attention to emotions experienced by both the researcher and participants during the research process³⁰⁹—something that other types of methods used in interviewing might not be able to capture. This can be especially true when researching sensitive topics such as experiences of disability.³¹⁰ This was an important consideration in deciding which methods were most suitable for research such as this project, in which I was trying to meet the access needs not only of myself as a researcher, but also those of the co-participants. These methods are also highly compatible with the premise of emotional geographies in that I am also interested in how the co-participants attach meaning to their experiences.³¹¹

Borrowing from Mike Hepworth,³¹² “One significant feature of emotional geographies refers to the social prescription, distribution, location and situating of human emotions. In other words, what society considers appropriate for individuals to feel in specific situations.” For me, calling attentions to emotions in academia achieves this goal.

³⁰⁸ Moss, 1999, p. 156, (original in emphasis).

³⁰⁹ Bondi, 2005; Ellis, Adams, & Bochner, 2011.

³¹⁰ Bondi, 2005; Dickson-Swift et. al., 2009; Seear & McLean, n.d.

³¹¹ Dickson-Swift et. al., 2009.

³¹² Hepworth, 2005, p. 178.

My interest in this study was to “...convey the *meanings* [I] attached to the experience” of struggling for inclusionary spaces in academia.³¹³ As Mike Hepworth points out, “It’s not easy being vulnerable, especially in the academy, where you’re expected to be in control and keep your private life removed from your professional life.”³¹⁴ As both researcher and participant, I wanted to share my lived experiences to, as Ellis and Bochner explain, “evoke my readers to feel and think about your life, and theirs in relation to [mine,]...to experience the experience [I’m] writing about.”³¹⁵ To do this, I storied my embodied disability in the academy. Ellis and Bochner describe this process in autoethnography as “emotional recall”:

Not like just writing about your life. You have to confront things about yourself that are less than flattering. Believe me, honest autoethnographic exploration generates a lot of fears and doubts—and emotional pain. Just when you think you can’t stand the pain anymore, well, that’s when the real work has only begun. Then there’s the vulnerability of revealing yourself, not being able to take back what you’ve written or having any control over how readers interpret it. It’s hard not to feel your life is being critiqued as well as your work. It can be humiliating.³¹⁶

By sharing stories in evocative ways, both the participants and I benefited from understanding how and why we experience academic and employment accommodations the way we do. As such, autoethnography provided a well-suited and innovative methodological approach for generating this data, which can be used as a springboard for both scholarly research and disability advocacy.

(Un)Anticipations

Due to the nature of this research, much of what I anticipated about how I would

³¹³ Ellis & Bochner, 2000, p. 751.

³¹⁴ Ellis & Bochner, 2000, p. 755. See also Bochner, 1997; Bondi, 2005.

³¹⁵ Ellis & Bochner, 2000, p. 755.

³¹⁶ Ellis & Bochner, 2000, p. 738.

write and do this research changed. After being away from this work for more than a year, I've had some serious time to reflect. I realized that while I followed what some of my committee suggested, such as interviewing key informants, for example, some things simply didn't work. For example, I received no response from the key informants at one university. The responses that I did receive from the other university sounded as if they were read directly from policy documents. Perhaps the fact that I conducted these interviews by e-mail facilitated this shortcoming.

I can't blame the key informants. They work for a university. Given the small number that I interviewed, how much can they really talk to me without risking exposing their identities?³¹⁷ Identities I promised to protect.

Morgan also noted my ethical concerns and responsibilities as a researcher. With one particular response to one of the questions, Morgan writes to me, "sounds like policy statement and verbatim!" Doing a quick Google search, I found that Morgan wasn't that much off. If I write about this and include the key informants' text verbatim, it wouldn't take much to figure out which universities are under study. Thus, by trying to compare institutional policies, I risked identifying the universities and possibly the key informants. I simply can't risk it. While I did think about this in the early stages of this study, I wasn't anticipating such literal responses from the key informants that could trace back to their identities.

I anticipated and even drafted several fictional scenes where the key informants

³¹⁷ To safeguard against loss of privacy and reputation, I will not be revealing the identities of the key informants.

were around the table speaking to Jules and me. I shared these narratives with several others for feedback—soliciting advice on how to best represent these data. A couple of readers told me that I was too negative, that I sounded like I was blaming the individuals, and not the structures of a university that were disabling students. Other readers didn't find it negative at all. It was another challenge to reflect on the contradictory feedback I received in how I would represent the data.

Instead of using all the information in the key informant transcripts, as I originally thought I would, I was selective. The strength of the contributions from the co-participants led me to focus on them and I used data from the key informants primarily as it related to the co-participants' experiences. For example, I compared what the key informants had to say about the availability of information with the co-participants' experiences of accessing it.

I had to compromise.

John Creswell³¹⁸ reminds us that subjectivity is inherent in all types of research; all research is situated politically. The same holds true for autoethnography.

In this qualitative research study, I don't claim to represent all non-visibly disabled graduate students in Ontario. Of course, I can't generalize my findings based on seven participants. That was never the purpose of this study. This is also why I didn't choose to outline a demographic picture of each co-participant. These decisions were made from the onset of this project.

My purpose was to start a dialogue to explore various issues by examining the

³¹⁸ Creswell, 2003.

perspectives of selected students and key informants (such as administrators and academic workers), through an autoethnographic lens of my own embodied experiences. I want to start and maintain a dialogue, and it was evident that a few of the other co-participants shared in this.

Christina Kiesinger cites her supervisor, Art Bochner, in her autoethnography of experiencing sexual abuse and bulimia, with the aim of making her study “expressive rather than representational.”³¹⁹ Like Kiesinger and Bochner, my aim with this study is to allow for an in depth look and “thick” descriptions³²⁰ of how this sample of students experience negotiating disability in the spaces of academia. I’m aiming to reveal the systemic issues that have real consequences, but I am starting with the experiences of a few disabled graduate students.

“I imagine that online research methods can be challenging,” Jules curiously inquires.

“Yes, that’s one of the neat things about this project—it was the unexpected—unanticipated challenges that emerged from the research process. I didn’t anticipate the emotional exhaustion I’d feel as a researcher when I felt like a “nag”! I remember apologizing several times to the participants for the multiple friendly e-mail reminders as the blog awaited contributions. What I had anticipated would only take about six months, took almost two years! My committee (and many others) assured me that this was just

³¹⁹ Kiesinger, 1998, p. 74, originally cited in Bochner, 1994.

³²⁰ Geertz, 1973.

part of the messy process of research, that no matter how much pre-planning I did, it would never work as planned.

“The anxiety set in when the first participant dropped out of the study a few short months into the study. I was left with six stories to tell. This is scary. All I could think about was, ‘What happens if another person drops out?’ It was a chance I had to take in spite of the skepticism I received about doing this work with a small sample.

“I recorded all of this. I know it’s important to include in my thesis. I hear the voice of one of my mentors echoing, ‘This is all good. This will all work out in the end; this will become part of your implications for future research methods.’”

With those words, a sense of relief washed over my body.

Shit’s Always Hitting the Fan...

12:13 a.m. I get a text message waking me just as I’ve finally fallen asleep after a long bout of insomnia. The message reads, “Hey, I’m sorry I couldn’t make it to the online focus group blog today. Shit’s always hitting the fan over here. Dad’s working from home tomorrow. I will try and get onto the blog then. Baby is crying, needs a feeding.”

Baby is crying, needs a feeding? I can barely read the message as I struggle to find my glasses that I had just knocked off of my nightstand. *Who’s text messaging me at midnight about a crying baby? It’s Amy.* I had wondered what happened to her earlier that day for our blogging session. I certainly wasn’t anticipating hearing back at midnight with a text message. I have to laugh this off as I imagine Amy trying to respond to the blog

with her blackberry in one hand, and trying to settle a crying baby in arms. Don't get me wrong, I'm not complaining, but I am torn between meeting the access needs of the co-participants and my own needs for self-care as a disabled researcher. I know I promised to ensure flexibility to the co-participants, but what about my own access needs for flexibility, in this case for sleep, that is sacrificed for that flexibility.

I'll respond to her tomorrow.

The next day, I reflected on my choice to use online methods. I recognized that even though I spoke to all the co-participants about their comfort levels with using online blogging for data collection, it didn't work well for all the co-participants. Life happens. I'm sure this is true of any research method, especially when working with a population with unique characteristics.

Amy encountered some difficulty with participating on the blog as the mother of a breastfed infant.

I reflected on this process in the shower—this is one of three places where I get the most conceptual work done—the other two being the gym and Francie's Coffee Shop.

What else could I have done to ensure that I captured this co-participant's voice in the research?

The next day, I responded to Amy's text message. "Should we talk? I know I have nagged you via text and e-mail messages several times with reminders, but I'm wondering if I can do more to help?"

Having come to know Amy's comical nature, I jokingly said, "Would it help if I came over for a 'face-to-face', where I could record your thoughts while you attend to the baby and read over the blog? That way, you wouldn't have to worry about typing your responses; I could do the typing for you."

Amy replied, "Well it's an accommodation and no one ever thinks disabled people have kids.... Disabled women have it tough."

Amy was right—I know other researchers have given this some thought.³²¹ Amy never took me up on my offer to modify the data collection process. I'm not even sure this would have passed with ethics. But, it would make for an intriguing future paper on how much of a role a researcher can take on to accommodate.

I continue to nag to solicit participation.

That didn't work either.

"E-mailing is easier than logging on [to the WordPress research blog site] as I can blackberry and breastfeed lol," Amy writes back.

In light of this, I told her to e-mail me her responses instead of going straight to the blog, so that I could post her responses on her behalf. Admittedly, I did worry about the differences in how Amy was reading the blog via her blackberry, as opposed to reading the blog via a full screen on a computer. This was an implication to blogging I didn't fully think through. Although I do recall telling the co-participants that it would be better if they had access to a full screen, as the blog was set up to the computer screen, not to a mobile device. I did explain that it would be harder to follow along with the thread while

³²¹ Tarasoff, 2011.

continuously having to scroll down on a mobile device as the blog was set up for a desktop screen.

Amy wasn't an isolated case.

Sam also expressed struggles with writing and being self-conscious about what they produced. Sam attached a note alongside their e-mail to me:

Hi Nancy, I can't recall the last time I've felt so self-conscious writing something (I think on account of the open-ended style requirements,) but I hope it's alright. I tend to be very self-conscious anyway, so it's possible that the strangeness doesn't show through. I'm worried that I wrote far too little. Hopefully that's not the case. It's also a bit rambly, but I attended to your guiding questions, so with luck I've hit what you need.³²²

Since the inception of this research project, I aimed for all aspects of the project to be accessible. This was not only important for myself as the researcher, but also for the other role I play as a co-participant. In thinking about access, I aimed to make this research blog site a comfortable space for all of us. My aim was to provide co-participants with an opportunity to share in a safe environment, where we could collectively reflect on our experiences in relation to each other, as a way of understanding and make meaning of how we negotiate spaces of the academy. I took precautions such as noting that grammar and spelling don't matter. "Be free to express yourself as you would like," I wrote to the co-participants individually, in addition to adding a reminder on the blog; maybe that wasn't enough though. To model this, I ensured that when I wrote my own blog responses, I did so without worrying about grammar and sentence structure. I too, felt "self-conscious" in writing on the blog in relation to the other co-participants. I often

³²² Sam, personal communication, May 14, 2013.

found myself taken aback by many of their articulate responses, far more eloquently written than my own. I'm not sure if this is where I found myself having trouble participating more. I did make note of it throughout my research process, and I spoke with scholars in the field of autoethnography about it. I never did come up with a solution for how to resolve my own issue with posting more. I continued to write with candour, the way I had anticipated I would from the start. In retrospect, I'm not sure how I would have changed the precautions I took as I checked in regularly with the co-participants to ask them if they had any concerns.

Then there's Rowan, who also shared some confusion about the blog. But this wasn't explicitly noted until near the end of study, when we decided it was time to do our last blog discussion that looked more like an (online) focus group. We agreed on a set time and date to meet on the blog for about a ninety-minute session. In the end, Rowan didn't participate in the final theme until the discussion was over. They also misplaced some of their responses under theme two, but noted they noticed the overlap of their responses with those of other co-participants, which was great.

Morgan also expressed some of the barriers to online blogging as well: "Sorry if I raise several ideas/ thoughts. I find it hard to login or access the chat so when I do I read alot of posts and therefore am reintegrating a bundle of info!" This raises an interesting point about the layout of information. I took a lot of time to ensure that the blog design did not have too many visuals; in fact, I purposely chose a template with the most white space available. I wanted to avoid information overload.

Sam reminded me that while I did use this blog as an opportunity to provide flexible time to sit and think with the text, this didn't always work even with allowing extra time to complete each theme discussion.

SAM: With apologies for the forced tone, and incoherence—I've been struggling to organize my thoughts, but I'm being crushed by the pressure to produce something. As always, I would be pleased to address any ambiguities the reader experiences.

Thanks Sam. No apologies needed. I too felt the “pressure to produce something” on the blog. Not only to produce something, but also to articulate it as well as Sam and the others did on the blog.

As Sam and the others note, I too, also needed extra time. This is important, because I observed that I didn't give myself enough time. Therefore, I played more of the researcher role, and less the role of a co-participant. What I didn't take into account were my own health issues. I had written back many times with apologies for delays due to a sudden health condition that landed me in the emergency department at one critical stage of the blog.

Of course, all of this didn't become apparent to me until I actually read all the transcripts in my basement. I'm told this is important—it happens—it is part of autoethnography.

On Being Divided

There was a blurred line between my place as a researcher and co-participant. As a researcher, I felt divided between what I *could* write and what I *should* write in two places—one private (the research blog) and one public (my dissertation). I have made

decisions that were hard—how do I, as a researcher and co-participant, decide what to include and exclude from this story without feeling guilty? Oftentimes, I felt like I was doing a disservice to the co-participants, to whom I felt powerfully connected. Every time I had to cut or strike out a line, a word, a phrase, a paragraph, guilt overshadowed me, followed by “command Z” to undo and re-paste. I wonder how the co-participants would react if and when they read the story I’ve written here—the story that has taken years to come alive. A story filled with tears and laughter, hope and despair, feelings of survival. I feel guilty for not allowing enough time for us to collectively discuss the final writing of this work. If I could do it all over again, that’s definitely one thing I would propose. I could always follow up with the co-participants in future work—yeah, that’s a good idea!

For instance, I think about Rowan’s and my struggles to access the bursary. While it’s an important topic, and one that needs to be followed up, I didn’t have room to cover it in this project. Both of us wrote about this at some length, but I have to wonder why the others didn’t share any experiences with it. Perhaps they didn’t know the bursary existed. This knowledge should be shared at the disability office, but if they were not registered with these offices, how would they know this exists? Maybe, like so many other grads, they are ineligible for OSAP, which is required to be eligible for the bursary. This is often the case when grads are TAs and work, because they are seen as having too much income. But then, I have to ask if they might not be aware of the special appeal for full-time

students.³²³ This works need to be taken up; but sadly, I cannot do it all in this story, so I will continue to share what I know and raise these questions.

I'm grateful that Amy reflected on the poverty issue to start this discussion.

On Being Vulnerable

Jules looks confused.

I explain, “I remember receiving an invitation from a Master’s student recruiting participants for his study. While I was extremely busy trying to finish up with my course work, I was empathetic to this student. I noticed that this was a repeated call for participants—so I reached out. The interview was face-to-face for about two hours. I was told I would receive the transcription so that I could omit any information I didn’t want published. I was very passionate about the topic, and I found that I ‘talked too much’. I divulged way too much personal information and felt bad for having to repeat, ‘don’t record that please’, especially when the research student insisted how important this information was to the study. I didn’t have time to think about what I wanted to say (you know, the way I could behind a computer) before I just blurted it out. There was way too much pressure to respond quickly—without leaving me time to reflect on what I wanted to contribute.”

Jules interrupts me, “I never thought about any of this with traditional methods.”

³²³ During the time period of when I applied for this “special bursary appeal”, I was told this was called a “negative needs assessment.”

I go on. “I was even more upset to find out, after the interview was completed, that I was *one of only* two participants who completed the interviews.”

Jules interrupts me again, “But aren’t you collecting data from a small number of students? Why would this upset you?”

I smile at Jules, trying not to show my frustration with this inquiry. I can almost hear Ellis: “You’ll need to explain in your dissertation the kinds of decisions you made and on what grounds you made them. You owe that to your readers.”³²⁴

“Yes, yes. That’s true. But unlike that study, I informed the co-participants of my study that there were only seven of us participating. I also made everyone aware when my one and only participant who dropped out in the middle of the study. No one took issue with it. The reason I was disturbed by having only two students, from one university, from a particular marginalized group, and then having verbatim quotes published was that I was potentially identifiable,” I politely respond. Admittedly, I found myself a bit annoyed.

“Gotcha! I can see why you were angry, and this makes sense to me why you are so careful with your study. I am sure your participants appreciate this,” Jules apologized.

“Yes, I’m sure they do too. This whole experience helped to shape my understanding of ethics, confidentiality, establishing rapport, and informing participants along the way in the study. I was so upset with this student-researcher, but I didn’t have the heart to call his supervisor about my concerns. So much for consent forms as a

³²⁴ Ellis & Bochner, 2000, p. 758.

protective measure for participation and/or dropping out of a study! But like any other institutionalized text, it is only as good as it is practiced.” I say.

“Wow! That was quite noble of you Nancy.”

Ha, noble. I actually regret not calling the student out, but I don't share this with Jules.

I leave it at noble.

Jules stumped me that day when they asked about my inclusion criteria. “Did any of the students speak about the particular challenges of non-visible disabilities? I know I had to jump through such hoops and had to provide all kinds of invasive medical information to the counselling office to get access.”

As I reflect about this, I start to feel guilty as I think about some of the limitations of this study. I'm doing it again, I think to myself. I am questioning my research decisions again: Did I make the right decision in only including non-visible disabilities? Am I placing non-visible disabilities over visible disabilities into a hierarchy; is this divide and conquer? I've pondered on this since the inception of this project. It was a tough decision to make when I set out my inclusion criteria.

With this, I turn back to Morella-Pozzi's work. I'm fascinated with her work. I have my chaotic highlights all over the photocopied pages I made, scribbled with notes like: why not “invisible” disability? identity politics; taking away our legitimacy; interesting, and the list goes on. I circle her words like “still angry”, underlining phrases like, “Those of us with disabilities, both visible and non-visible, are more at the mercy of bureaucracy

and administration.” All while in the back of my mind I’m thinking: *Thank you, Tony, for informing me of this brilliant scholar!*

Morella-Pozzi got me thinking about how I identify. I’ve always preferred “non-visible disability,” but this changed over the years with my own thinking and even more so with writing this dissertation. I question exactly what it means to be “non-visible”. How can I be non-visibly disabled when I am physically exhausted from all the extra work I must do to navigate spaces of academia as a disabled graduate? Is my disability visible to others when I am not able to participate in ways my body won’t allow for? I find myself visibly absent from contributing to various spaces in the academy when I can’t participate in conferences because of the extra work it requires to prepare a paper, or most importantly, when my energy is used up in negotiating ableist practices.³²⁵ As an academic worker, I am limited in similar ways—I cannot attend additional teaching and learning workshops that would benefit me in my teaching role because I simply have no time, or I am too exhausted from advocating for myself.³²⁶

While I am not marked on the body, that is, I don’t have a visible marker like a wheelchair, my impairment often becomes apparent—I fidget, I talk faster, I jump from one topic to another, I am easily fatigued. I am not suggesting that these are negative

³²⁵ Farrar, 2004; Farrar, 2006.

³²⁶ People may assume that, as a non-visibly disabled graduate student, I have the privilege of passing. However, I argue that this privilege is ambiguous, as I am met with extra work in order to conceal the characteristics of my impairment through management techniques that allow me to pass. Strategies of passing do not come without effort; rather they are learned behaviours involving “self-monitoring and self surveillance” to ensure I conceal attributes of impairment in academic spaces so that I am not labelled as problematic, fraudulent, or taking advantage of the system. Though this is not always possible, I try my best (Lingsom, 2008, p. 4).

characteristics to display, only that they visibly mark me as “being different”. I agree with Morella-Pozzi when she argues,

I have issues with referring to disabilities not marked on the body as invisible. They are most certainly visible to those of us who live with them. To refer to them as invisible is to deny a part of our identity.³²⁷

Like Morella-Pozzi, I reflect on how on my own use of identifying with non-visible disability and what meaning I attach to that label, identity, name.

Non-visible disabilities become *visible* when social processes require disability labels to be claimed in order to allow non-visibly disabled students to fully participate in spaces of higher learning.

Not only do I have an ethical responsibility to the co-participants who agreed to take part in this study, I also have a responsibility to myself as a doctoral candidate. I do recognize my own privilege in having access to do this work; I am white, and I have the support of an incredible family to continue my studies. However, I also have no security in employment, thus making me even more careful not to risk my own reputation as I seek employment in the academy, nor to implicate others. I am but one graduate student with no secure job in place. My impairments also mean that I may be up against discrimination when I apply for a job. Another reason I need to be so careful with this work.

³²⁷ Morella-Pozzi, 2014, p. 180.

I'm conscious about how I frame the implications of my study. I have learned so much since I started, and I'm repeatedly reminded that I cannot "do it all". This is not the point of a dissertation; it would be impossible and irresponsible for me to assume I can in the short amount of time I had to complete this. In reflecting on Jules's query that day, I recalled how I came to sample for this study.

Non-visible impairments have been a topic of interest for me since my first year of university when I was first medically labelled at the age of 27. Because I was experiencing an identity I didn't know much about, I delved into the literature with every course paper or project I could. I gained as much knowledge as I could on the experiences of non-visibly disabled students in university. I was disappointed with the dearth of literature, even more so when I began looking into graduate student experiences. I knew I wanted to do more in this area. It was important to me that my co-participants also experienced non-visible disabilities. This is in large part due to the fact that I wanted to explore how grads negotiate academic spaces as a non-visibly disabled.

I wanted to address the lack of attention devoted to the actual experiences of non-visibly disabled students. I also wanted to know more about how my experiences related—or not—to those of other students. What was different about our experiences? What was similar? What solutions are there to combat the barriers that continue to exist?

I remembered the first time I was handed a departmental handbook that offered advice on how to navigate my program. Turning to this institutional text, I noted the absence of disability. How do I belong in this space as a disabled graduate student if the text doesn't make a mention of "disability"? Where disability is excluded, we feel we

need to shout at others to say, “Hey, we do exist so please make sure you are making all spaces inclusive so we can feel like we belong!” These acts of “shouting” come in the form of constantly writing e-mails inquiring about access, including pleas to remind others why it’s important to not wear perfumes on campus (chemical sensitivities); asking for materials in accessible formats or asking for accommodations that are not listed in graduate resource guides (departmental handbooks).

Where disability is recognized, we understand it as meeting the needs of people with physical disabilities. Little has been discussed about non-visible disabilities, other than more work needs to be done in this area. This is also evident in the literature I reviewed. One of my co-participants noted that their university has one accessible classroom for a TA who uses a wheelchair. There was no mention about needing an accessible classroom for TAs experiencing non-visible disabilities, such as chronic fatigue, where stairs would be a barrier for them. Responding to a comment about one accessible classroom being available, Morgan wrote,

Again, this speaks to physical disabilities. While it is only fair and just that there should be accessibility for chairs etc, there should be equal consideration given to those of us with hidden disabilities and unfortunately there is still huge stigma attached to this. And, I do not think all these “campaigns” are doing the trick. It's all nice to “learn” and advertise the value of diversity etc but unless it is truly embraced it ends up going no where.

When key informants were asked about any constraints they had in their roles in providing accommodations to academic students and workers, Jamie added the layer of intersectionality, which I did not address in this study. This was not an oversight on my part, and I have kept note of this missing aspect in my research journal for future reference. However, the aim of this study was to explore lived experiences shared

amongst the seven co-participants; that is, I wanted disabled students have a voice in what they felt was important to share as we explored access in academia. Issues of race, sexuality, religion, were not brought to light by any of the students. I was intrigued when Jamie responded:

But I would add that the attitudinal barriers are significant, as well as the lack of intersectional approach to both individual interactions and systemically-focused activity. For example, in a graduate program focusing in [interdisciplinary studies],³²⁸ a racialized TA with a mental-[h]ealth disability is seen only by her white peers (also people with disabilities) as racialized only, and she must deal with everyday workplace racism like that described in the OHRC policy on racism (subtle racial discrimination section). White managers also do not see this happening: she is taking the minutes, getting photocopies made etc while they are doing more substantive tasks. And her disability is exacerbated by the tasks she has to perform but the environment is too unsafe—due to racism—to seek an accommodation. She must “fly under the radar” and “not rock the boat”.

In future work, and with a larger sample, I would like to complete a study that explores the tensions of intersectionality to include race, religion, sexuality, ageism, illness (e.g., cancer). For example, is cancer considered a disability? And if so, how would one access accommodations?

Initially, I felt like the co-participants were speaking highly of their experiences with access and accommodations. While this is great, I had a hard time coming to terms with the idea that things were as rosy pink as I was reading. Many of them expressed gratitude; others used the word “supportive”. But what I noticed after placing the sheets on the wall is that some of the narratives changed. Co-participants moved from speaking about gratitude and feeling supported to “Shit, I didn’t realize that I had rights!”

³²⁸ The program name was removed to protect identities.

A year has passed. Because I have a dissertation to write and defend, all of which has been severely delayed by a concussion, I don't have time or energy to properly to follow up with everyone. Once I am finished, I would like to. I want to address what we didn't have time to address here. Did their thinking about accommodations change as a result of this study? I assume it that it did, judging by the e-mails that I received after the study was completed. But this is my perspective only.

Chapter Six: Hitting the Brakes

This assumption—that we can live *with* story—is one way to understand the connection between story and theory: stories *are* theories that we use to understand experience.³²⁹

I'm sitting in front of my laptop thinking about how to write up the end of this work. What does that even mean? Throughout this process, I've acknowledged the work merely as a starting point, one that doesn't actually end. With this in mind, I never intended to write a conclusion because I don't think writing a conclusion is possible until there is a conclusion—that conclusion being change in favour of disabled students.

The Merriam-Webster dictionary tells us that a conclusion is “the act of concluding or finishing something or the state of being finished.”³³⁰ This work is definitely not in the state of being anywhere close to being finished. Is any doctoral thesis really finished? The point of my work is an attempt to start a dialogue, one that has no end because, to me, there is always work to be done when it comes to making spaces fully inclusionary.

If anything, this last chapter is a beginning.

Not an end.

Today is another pain day. I'm pretty pissed off about it. While my work draws on the social model of disability, I don't entirely agree with it. Nothing in the social realm of disabling barriers can help me get rid of this physical pain I endure daily. Since being hit

³²⁹ Adams, Holman Jones, & Ellis, 2015, p. 90, (emphasis in original).

³³⁰ Conclusion (n.d.) in Merriam-Webster Dictionary. Retrieved from <http://www.merriam-webster.com/dictionary/conclusion>.

by a car last year, I have been battling constant pressure in my head. No assistive devices can help me. Sure, I could reach for a painkiller, but even they don't help much.

I feel like I've hit the brakes as I take another week off from writing because of chronic pain.

The severity of pain has decreased a bit, so I'm basically coping with it now. It's as if my body is now just used to negotiating the pain as I distract myself from it as I delve into this writing. I still need to dim the screen on my laptop to write and read on my computer; there's not much I can do about the cognitive and mental fatigue I experience, which is a day-in-the-life for a disabled grad student with a brain injury, in addition to the other non-visible disabilities I experience. Taking breaks is helpful, what they call "pacing", but then I get so anxious about how time is fading from me. It's a vicious cycle in my head that I simply can't shut off. This is not your typical stress that we're told every doctoral student nearing the end goes through.

This is my reality.

It's days like today that I let the pain get the best of me. I used to be such a resilient person, optimistic about a full recovery. Now, I'm just damn straight scared. I wonder how much of this has to do with the fact that I'm finally feeling that the end is near—that I am actually going to complete and defend this thesis. Surely this is just the hypersensitization of anxiety I am feeling that many students call "normal PhD stuff." I'm tired of people saying this to me. I want to respond with: *there is nothing normal about a brain injury and finishing a doctorate degree, so please stop using this to try and support me through this. It's not helping. I need tangible support.*

Talking about the tangible support I feel I need, and likely other disabled grad students need, surely there are ways in which we can enable students to complete their studies. It's about support. Isn't this obvious? Of course, I'm not saying anything new. I also don't want to reinvent the wheel. I mean, Farrar wrote about the type of support I'd like to see happen in graduate schools:

Helping students to plan their thesis, assisting them to work to realistic deadlines based on an understanding of what tasks are difficult for them and what will demand additional time, breaking the whole into manageable chunks become part of the role of research supervisors. The thesis is a formidable task for all research students but can be made achievable for those with additional issues through judicious support.³³¹

Farrar goes on to quote one research supervisor who exclaims, "Having accepted mentally that this is a good student, but an unconventional one, then the rest seems to be, 'Right, how do we get through this and around this and enable him to achieve his potential?'"³³² It's this very type of attitude shift I think the academy needs to embed in policies and practices if we can expect to enable change for supporting disabled graduate students. One way to address this attitude shift would be to change the ways people in academia often thinks about disabled students.

Interestingly enough, Drew brings up this very point too. Drew writes,

What I have heard so far is that when we have faculty who have a background that might inform them in their understanding of the issues, accommodations appear to be provided with less resistance....????....It would be interesting to know how many faculty feel supported and knowledgeable in understanding these unique learning needs. Perhaps Nancy, you may have heard back from your key informants about this...I look forward to hearing about this in the future. Or perhaps this is an area for further research?

³³¹ Farrar, 2006, p. 181.

³³² Farrar, 2006, p. 181.

I'm not sure I entirely agree with Drew. I have been met with resistance by faculty who have an understanding of disability and access too. However, I definitely agree that this is an area for future research! It would be really interesting to build upon this project to include the relationships between disabled students and their academic and employer supervisors. For example, what are disabled students' experiences with their academic and employer supervisor? What sorts of accommodations and supports are in place (e.g., monetary, advocacy, emotional)? How well do disabled students feel their academic and employer supervisor understand the nature of their disabilities? How well do academic and employer supervisor feel they understand the nature of students' disabilities?

Of course, a change in ableist attitudes is not a simple solution. I mean, how do we ensure an attitude shift? Perhaps, as Farrar explains, “Awareness of disability issues and good practice amongst those who promote, interview, inform, induct, support, supervise and access disabled research students will go a long way to enabling students to tackle more tangible barriers.”³³³

Elizabeth Marquis and colleagues³³⁴ concur, as their findings suggest that while awareness training for educators is necessary, but not necessarily sufficient. Stakeholders in their study, including instructors, pointed out that they also need resources and supports to change their practices. They highlight how, “Participants described not knowing where to go or who to talk to about accessibility issues on campus, recounted stories in which institutional actors unknowingly undermined accessibility efforts as a

³³³ Farrar, 2006, p. 185.

³³⁴ Elizabeth Marquis, Bonny Jung, Ann Fudge Schormans, Susan Vajoczki, Robert Wilton, Susan Baptiste, & Anju Joshi, 2012. See also Dunn, Hanes, Hardie, & MacDonald, 2006, p. 14.

result of failures in communication, and expressed frustration about the fact that, as one instructor put it, ‘this campus likes to have eight thousand departments doing similar things.’”³³⁵ Wow, this sounds just like what Rowan, Sam, and I have shared in our experiences too.

I turn my attention back to Farrar’s work. It brings me back to the first time I disclosed my disability to a university. Recounting these painful memories re-inspires the purpose of my thesis and, reminds me of the first time I met Jules.

“Grad accommodations are a joke!” I vividly recall Jules telling me during a recruitment phone call. We both laughed hard at the understatement. It didn’t take long for our laughter to turn to sadness and disappointment at the painful memories of struggling to access grad accommodations. I think about our commonalities in that non-disabled students don’t have to do the types of work we must do to access our spaces, because these spaces were made for non-disabled bodies.³³⁶

How well I remember.

It’s time. I have 10 minutes left before the clock strikes 3 p.m. I can’t be late, so I make sure I arrive on campus early. I’m soaking wet. It feels like I’ve been pacing outside in the rain for almost an hour now. I’ve been coaching myself for days on what I’ll say.

³³⁵ Marquis et al., 2012, p. 12.

³³⁶ Morella-Pozzi, 2014; Titchkosky, 2003.

What more can I say that hasn't already been addressed with Dr. Admin³³⁷ when I approached them about my past accommodation issue? Why am I putting myself through this? Better yet, why is Dr. Admin making me go and meet with Charlie? Why must I continue to undertake this amount of work to access accommodations? Especially since Dr. Admin agrees that what I am asking for sounds like a reasonable accommodation.

I have been fighting for accommodations since I first started at a university. I have validated medical documentation supporting my needs that qualify me for accommodations; yet the fight seems to be ongoing with no end in sight. As if the fight for my accommodated comprehensive exams wasn't enough, I had to endure that struggle while tending to a terminally ill family member. I wonder how much more my body can take. I just want to complete my doctoral degree without any more barriers.

Access shouldn't be this hard.

I think about all the things I should be doing right now—where my time should be spent. I should be working on my thesis. I should be at the gym working out to de-stress from the overload that writing a dissertation puts on my brain. I should be reading more literature. I should be doing anything else other than standing here, in the rain, waiting to be put through another humiliating process, where I need to plead my case to get the support I need and *deserve*—support that I'm legally entitled to.

These days, most of my academic days are filled with multiple meetings with various administrators at a university. From endless trips to the counselling office, to

³³⁷ Dr. Admin and Charlie are social actors at a university. I have changed their names to protect their identities.

medical practitioners, to meetings with each member of my supervisory committee—how much more can I be expected to do to get accommodated? I simply don't understand any of this. I've followed the accommodation protocols. I've done my part. Who's going to be accountable for the unacknowledged, invisible work I continue to endure? Or the aftermath of the mental health experiences of struggling to belong?

I feel like a puppet, dangling from strings, forced to perform day after day, night after night to reaffirm the bureaucratic system that keeps disabled students where the system believes they belong, doing what is deemed appropriate for us, trying to normalize our bodies and minds. Nonetheless, I follow the advice given. I play the role of a grateful disabled student. I meet with yet another administrator knowing all too well that this just might put me over the edge. *Maybe it's time to finally call it quits*, I think as my emotions take over.

I want to cry.

Is this what a meltdown feels like?

I feel as if strings are pulling me into the office. A gentle nudge from one side of my face to the other cheek forces a fake smile, which I try to embody as authentically I can.

Shit, it's time.

I make my way into the office. My pace is slow and steady, as if resisting what I know lies ahead. I'm far from comfortable. In fact, I told them I was uncomfortable going into this meeting alone; yet, here I am, *all on my own*. I'm feeling isolated, with no

protective layers. In hindsight, I should have asked my union representative³³⁸ to accompany me, but I didn't. I didn't want to piss anyone off; I didn't want to make matters worse. Anyway, this should be a professional encounter not needing any witnesses. It should be a safe space for me to address what I need.

It should be.

Suddenly, I feel goose bumps running up both of my arms as I see Charlie sitting behind their desk in front of their computer. My newly forced smile quickly vanishes as I'm caught off guard walking into the office. Just as I am about to shut the door behind me, I notice Charlie's assistant walking in. I nearly slammed the door shut on the assistant and abruptly ask, "What are you doing here?"

As quickly as I mutter the question, I turn and apologize for being rude, "I asked for a private meeting to discuss a private matter between the two of us. You didn't tell me that we'd have company."

If I wanted an audience, I would have invited my supervisor and union representative and probably a whole herd of other supportive colleagues.

I don't feel safe.

Without so much of a smile, Charlie stares straight at me with what sounds like a perfectly rehearsed line, "It's standard protocol to have my assistant present during all meetings."

³³⁸ While this meeting was not about an employment issue at a university, I was still able to ask for a union representative to come with me to this meeting that involves academic matters. However, they wouldn't be able to speak to the matter; they would just attend to support me.

I take note of the pen and pad of paper Charlie's assistant holds tightly in their hand before placing it on the table.

That's weird. Charlie and I have met before to discuss similar important issues, and this is the first time this policy was put into practice.

This policy must be new.

I can't help but ponder the fact that I disclosed that "I have non-visible disabilities; I need to talk to you about workplace accommodations," at our last meeting. Is this why I'm now being denied my request for privacy? The presence of an additional gaze suggests to me that Charlie might want a witness so that they can refute anything that was said. I imagine Charlie saying, "I didn't say that, Nancy. You must have misunderstood. Here, my assistant will verify that I never said that during the meeting."

I wish I had the confidence to speak up. More importantly, I regret having made it this far through the office doors in the first place. I should have left. No, no. I should never have been here in the first place.

From the outset, I feel like I'm being interrogated. Charlie patronizingly asks me what I am doing in their office— as if they don't know what this meeting is about.

"Dr. Admin asked me to meet with you about my accommodation request," I say, confusion wrinkling my brow. I'm trying desperately to manage myself in a professional manner, but this doesn't come easily—especially when I am being spoken to with such disdain. I'm having trouble following what Charlie is asking me.

What I really want to say is, "You know why I am here. Dr. Admin has arranged this meeting, and I know Dr. Admin has filled you in."

I'm getting more pissed off by each word I hear. Trying to control my embodied reaction is getting much harder.

Don't cry. Don't cry. They are simply not worth it.

I'm reminded of the coaching I received before walking into this meeting. I was told not to show emotion. I never questioned this at the time, but looking back now, I have to ask why it was so important that I not show emotion? Perhaps it was a gendered response, because crying is equated with weakness? How do I maintain my composure when all I want is to pound the desk and walk out of the office? My mind begins to wander as it so often does in anxiety-provoking spaces like this, where I am subjected to social interactions with hostile social actors.

I'm immediately taken back to something Drew wrote on the blog and now my experience is echoing what they wrote.

DREW: I had received messages from my advisor that tears were not going to work in getting more extensions; the message I received from that was that manifestations of my illness were clearly seen as an attempt to manipulate professors for the purpose of extensions of deadlines, This only spurred me onward to show that my intentions were to respond to the requirements and meet their requirements. However, I also internalized the feedback as negative. And as a result, I need to spend energy to overcome these comments and move forward with the work. I believe this energy might have been better used to continue to write and work on academic responsibilities.

Reflecting on Drew's experience, and drawing on my own here, I recall how many days it took for me to recover from the various meetings I have had to negotiate to access spaces of the academy. The process of asking for an accommodation and once again receiving a negative response just moments after stepping a few feet past the door only

reminds me again that *maybe I just don't belong here. If I need an accommodation in grad school, maybe I just shouldn't be here. Is this the unspoken message?*

It also reminds me of the emotional labour and emotion work I do, to perform in certain spaces, like that of academia where grad students are met with endless pressure to compete and demonstrate their merit.

Suddenly, I forget what I'm doing here in the first place. I never wanted to go to this meeting. I told Dr. Admin I couldn't handle this situation on my own. I told other people, including folks I assumed were supposed to advocate on my behalf, that I couldn't do this. I didn't have it in me to advocate on my own, and I didn't feel like it was my responsibility to do so. If indeed I need to learn how to be an advocate for my needs, in ways that other students don't have to (sacrifice their self-worth, confidence, mental fatigue), then I want no part of it. Sam articulates the extra work of embodying the role of doing advocacy:

SAM: ... 'being our own advocates'—as I've indicated previously, I'm stuck on these sorts of issues. On the one hand, I think it's important that we control how our issues are represented and advocated for, however at the personal level, I also know that it's often the case I don't have the tools I need to effectively represent myself in the face of a large bureaucratic institution.

Managing and resisting such ableism by being our own advocates can have both costs and benefits. On the one hand, processes of disablement whereby we must become our best advocates may exacerbate our various impairments, especially when we are too exhausted to continue managing stigmatizing encounters by fighting the system. The additional responsibility of being an advocate takes emotion work.³³⁹

³³⁹ Goode, 2007, p. 44.

On the other hand, some students use their frustration to fuel social change by advocating not only for their own rights but also for the rights of others. They become informed of their legal rights, which, in turn, has been found to empower disabled students.³⁴⁰

In thinking this through, I recall how Riley responded in their key informant e-mail interview. Riley highlighted that disabled grad students face many constraints, including having “to be their own best advocate.” Riley goes on to write that, “There is not a lot of understanding in the university community of mental health issues and accommodations for students with disabilities.” Riley couldn’t have said it any better.

When I shared the e-mail transcripts with the co-participants, Sam also responded with, “At the risk of being presumptuous, I do hope you’ll forge the connection between the responsibility of advocating for oneself, and the perception that competent advocacy is proof of the absence of disability.”

I am trying Sam. I really am.

Back to the meeting.

Why didn’t I just cancel this meeting? Why didn’t I bring in a union representative with me? Oh right, I was scared that this would only make things worse. I didn’t want to be perceived as a problem when asking for my entitled rights. I just wanted to access my right to participate in academia without barriers. Really, is this too much to ask for? Dr.

³⁴⁰ Goode, 2007, p. 44.

Admin assured me that what I was asking for was a reasonable request: “It shouldn’t be a problem—you’ll be fine.”

Others concurred.

My intuition told me differently.

She was right.

My mind races back to the pen and pad of paper that Charlie’s assistant brought into the meeting. It sits untouched on the desk beside me. Nothing is written other than my name in full: Nancy La Monica.

I’m mindful of what else might be written. I carefully watch for any movement being made by the ink. I glance over a few times during the meeting. All I read is my name on the top corner of the right page—the rest is blank and stays blank for the remainder of the meeting.

I wonder why my disclosure brings on this type of surveillance. I want to leave the meeting but my body won’t move. It’s stiff. I feel like I have no control over any of my body parts. My brain feels frozen—*Move, I tell myself*. But I can’t. Instead, I hear myself stumbling on my own words as I often do when I am under this amount of stress, as I respond to Charlie.

Then the stuttering begins.

Before I have time to catch my breath, Charlie speaks, and they interrupt me every time I try to get a word in. If I had any doubt of the power dynamics³⁴¹ between the two of us, I can feel them now!

I barely have the space to explain how I entered into my studies without any academic and workplace accommodations in place. I did, as outlined on the institutional accommodation policies, disclose my disability earlier into my program. I met with the appropriate offices about accommodations before the start of the academic year. I even went a step further and disclosed on my entry application. I never received an academic accommodation letter—I was told that these are not given to disabled graduate students at an institution, that accommodations are negotiated between the professor and the student, in person, first. When the professor and student agree to the accommodations listed, a contract is drafted for the student.³⁴² But none of this matters; Charlie doesn't give me a chance to explain any of this. I have to wonder if Charlie is even aware of these institutional protocols. Because if Charlie did understand this, then maybe I wouldn't be treated the way I was: questioned and patronized. I'll never know. I can only speculate that Riley was right about the little understanding around the lived experiences of disability in the academy— that as Riley adds, “Way more needs to be done.”

I negotiated all my academic accommodations one-on-one with each of my professors. However, this was only possible because I was comfortable enough to

³⁴¹ See Bochner, 1997.

³⁴² I never did find this model of accommodation helpful, and I resorted to not having my counsellor involved, knowing many of my professors would not give me a problem at the graduate level. If they did, I was confident in speaking to my supervisor to help me address my needs. But not all students are as comfortable as I was with my professors or to have their supervisor involved. I should also add that this information was given to me orally. I was not able to find any of the written policies, despite my inquiring with the appropriate offices at a university.

disclose my disability to them, as they are well versed in disability studies. For the most part, many of them understood my lived realities. They had no issue in providing me with the extra time I needed to complete assignments, and made me feel supported because they noted how I was not appropriately accommodated during my time working as a teaching assistant. Simply put, they never made me feel guilty for asking for more time. They were empathetic to my situation, which helped me greatly to combat the internalized ableism I often struggle with.

“The problem,” I try to explain to Charlie, “is that I was assigned two part-time courses to TA, despite having requested a lighter workload, months prior to the schedule being made. Having to TA for two part-time courses is not meeting my needs for a lighter workload.”

I made my academic needs known well in advance, before the teaching assignments were filled; yet, here I am again, trying to explain this to Charlie. I already spoke with the union. They agreed that the assignment of two part-time TA assignments involves more work and responsibilities than one full-time TA assignment. I was simply following Dr. Admin’s instructions that I needed to negotiate this with Charlie, as I was told that this was not Dr. Admin’s decision to make, but rather Charlie’s.

What is so hard to understand about the request I was making? I echo Morgan’s experience of having to do more work due to disability for the same amount of pay as everyone else.

“I cannot TA for two-part-time courses. Instead, I’d like to be exempt from a departmental policy whereby internal scholarships are clawed back when graduate

students hold an external scholarship, like SSHRC [Social Sciences and Humanities Research Council] funding,” I continue. “I have medical documentation for accommodations that support a release from teaching assistantship work so that I can solely focus on my studies without financial implications. I also have support from my academic supervisor and medical professionals. I am simply asking to retain my internal scholarship along with my SSHRC funding, so that I don’t have to TA.”

It was not only my opinion, but the opinion of a few others at the university level that what I was asking for was not unreasonable. In fact, Dr. Admin was the one who told me to meet with Charlie about this. According to the university’s policy, when a student is awarded a major external scholarship (e.g., NSERC, SSHRC, and OGS), they “normally” will not be offered an internal graduate scholarship.

I quickly learn just how ambiguous the term “normally” is.

I think about the long list of institutional recommendations in the Report from the Access to Graduate and Professional Education (AGAPE) committee³⁴³ dating back almost two decades. In this report on disabled student experiences in graduate and professional programs, funding alternatives are recommended to combat financial barriers disabled students face. Researchers cite, “It is not unfair to provide more support to those in greater need both among students with disabilities and between students with disabilities and other students.”³⁴⁴ Specifically, recommendation 25 reads as follows: “that individual universities explore means of making their awards to graduate and professional school students with disabilities as flexible as possible to ensure that one

³⁴³ OMET, 1998.

³⁴⁴ OMET, 1998, p. 29.

source of income is not cancelled by another.”³⁴⁵ This also echoes Rowan’s experiences, when they talk about the financial barriers, specifically having to qualify for OSAP to access funding for assistive technology.³⁴⁶

Shit, I knew I should have brought this report with me! But I have to wonder what good would it have done. I mean there are some scholars that refer to the list of recommendations that universities should invest in, such as Marilyn Rose at Brock University,³⁴⁷ but clearly, many of these recommendations haven’t been put into practice.

Charlie is staring at me for a brief pause.

Instead of discussing this matter further, I am silenced. I would have appreciated an explanation as to why this can’t be done. It was like I was talking into thin air. I felt patronized as Charlie continued to tell me that there was nothing they could do for me. I was also made to feel like someone who was looking to take advantage of the system when I am accused of wanting “free money” where other students are working for their TA ships—as if being disabled affords me instant privileges not available to other non-

³⁴⁵ According to the OMET (1998) report,

Because of the complexity of matching the needs of the students with the requirements of various forms of funding for persons with disabilities, universities must be careful not to put all their targeted funding into one form. All the usual means of funding graduate students should be used with either some reserved for students with disabilities or with students with disabilities being given priority. Ideally, universities could offer graduate and professional school students with disabilities funding of a certain amount that best suits the student’s financial situation. Such funding would not be in a predetermined form, such as an assistantship, but could be packaged as a bursary, tuition waiver, reduced rent for on-campus housing or assistance with other living costs. Similarly, the timing of the award by the University could be flexible so as to increase the possibility of avoiding conflict with other funds. (p. 29).

³⁴⁶ It is worth noting that part-time disabled graduate students are also ineligible for most funding opportunities, including those for assistive technology. Ironically, part-time study may be the best option for people with certain visible and non-visible disabilities. This is an important issue for future study.

³⁴⁷ Rose, 2009.

disabled students or other marginalized students. I wasn't looking for special treatment—far from it, actually.

Goodley has this to offer on my insights into what transpired with Charlie. Citing Karen Jung on inclusion, whose work I've been using since my undergrad studies, she writes,

Increasingly fierce competition among students for limited funding and enrolment restrictions in particular courses of study give weight to the argument that chronically disabled students unnecessarily drain or waste scarce educational resources (Jung, 2002, pp. 184-185). Becoming visible as a disabled person in the neoliberal educational context puts one in a vulnerable position, as 'they' raise questions about 'fairplay' and 'educational quality' (Jung, 2002).³⁴⁸

Aside from the neoliberal bullshit I was living through, I can't seem to get past Charlie's lack of understanding my issue. *Why doesn't Charlie understand that accommodations are not the onus of the student or academic worker; accommodations are a shared responsibility and I have done more than my share of this work?* But before I can go on about this, I grapple with what I was just told: I must disclose my disability and my access needs to all of my employer supervisors.

As I recall this encounter, preparing it for this draft of this chapter, I review my notes that I made after I came out of that meeting to ensure I captured it right. I immediately sent a message to my supervisor about the meeting and then texted Jules about what transpired.

Disclosure is a sensitive and complex topic. It is not simply a matter of revealing to others, "Hey, I'm disabled and you need you to accommodate me!" With disclosure

³⁴⁸ Jung, 2002 as cited in Goodley, 2011, p. 147.

comes the emotion work of negotiating to whom one discloses, when, and in what spaces.³⁴⁹

Disclosure was also a theme that emerged several times during the key informant interviews. Avery mentioned how, “Graduate students may have more concerns about disclosure to faculty members with whom they may eventually be colleagues and this poses operational challenges that can be difficult to navigate.”³⁵⁰ Adding to this, Riley suggests that there is “little understanding of graduate student needs and graduate students fear of disclosure....” So while this is recognized as a barrier, we still have much work to do in creating ways to dismantle this fear of disclosing. Or perhaps, through universal design, dismantling the need for disclosure in the first place. The question for me becomes, why then do we need to disclose to feel safe enough to access the academy? What purpose does disclosure serve when its attached meaning is filled with fear of not being able to find or retain employment?

I think back to the paper my friend and colleague Katie Aubrecht and I wrote on our co-constructed autoethnography about disclosure in the academy, as both instructors and grad students.³⁵¹ For fear of disclosure or being “found out”, we wrote how disabled instructors (including in our roles as students) *pass* on needed accommodations that are available to us.

³⁴⁹ La Monica, 2013 (unpublished). Negotiating Accommodations in Places and Spaces of Academia: A Matter of ‘Emotional Work’. Conference paper presented via Skype at the: Fourth International and Interdisciplinary Conference on Emotional Geographies. University of Groningen, The Netherlands.

³⁵⁰ Damiani & Harbour, 2015, p. 402.

³⁵¹ Aubrecht & La Monica, 2016 (forthcoming) to Canadian Journal of Higher Education.

I am a bit caught off guard as to why my needs for privacy wouldn't be respected by a university. How is this even questioned in the first place?

For those of us studying issues of social justice, we understand that accommodations are meant to ensure that disabled students have a level playing field with their non-disabled peers in the academy, and in the case of working academic students, in their workplace. We understand that to level this playing field, for example, by providing learning disabled students more time to complete an exam, we are treating disabled students differently, but only so they can be assessed fairly. Accommodations do not provide an unfair advantage to non-disabled students.³⁵² Rhoda Olkin articulates this in her work, where she explores the rights of graduate students in social work programs. Her work is applicable to other types of graduate student experiences that we can build on and use. Olkin explains,

Programs erroneously may promote the value of equality (i.e., sameness) over equity (i.e., fairness). But students with disabilities have individualized needs which require individualized solutions. They have the right to equity, i.e., to appropriate accommodations, and to receive these accommodations without being made to feel that they are being advantaged over other students. Reasonable accommodations are not “special needs,” but a civil right of students with disabilities.³⁵³

In my case, I was asking to be treated differently in order to receive what I understood to be a reasonable accommodation. I was not asking to take advantage of the system as it was subtly expressed to me. I'm sure Charlie didn't mean to be as malicious and hostile as I perceived them to be. But one has to remember that Charlie is not the first

³⁵² Hibbs & Pothier, 2006; OMET, 1998; Rose, 2009.

³⁵³ Olkin, 2002, p. 70.

person who has met my requests with such resistance at a university. I'm tired of feeling like I have to legitimize being in this space.

When I walked into Charlie's office that day, I was simply asking for an exception to a policy, based on the premise that being disabled does come with added work and disadvantages.

"So you want to get paid for not working Nancy?" Charlie asks with a grin on their face.

"That's not what I said." I quickly respond.

"Really, then what is it that you are here for? I cannot give you free money. It wouldn't be fair to the others. If Dr. Admin has extra money, then by all means, I'd be happy to sign off on that. But, we don't have extra funds."

There it is again! I'm made to feel like I am trying to take advantage of the system for simply asking for an accommodation. And it wouldn't be fair to whom exactly? I have heard this line before within this same space, but with a different social actor. Only that time it was during a meeting about my accommodation request for my comps exam.

By this point, I feel the blood rushing to the top of my head. I thought I was going to burst a blood vessel for sure.

"With all due respect, if you'd stop interrupting me, maybe I could explain my situation to you. Please stop speaking over me!" I glance at Charlie's assistant to see whether anything new is written. It's still blank.

"I never suggested that I be paid not to work." My voice is growing angry now. *So much for retaining my composure.*

Charlie rudely interrupts me again telling me that none of this matters anyhow, as this is an employment matter relating to my union contract. Charlie continues to tell me that this is not an academic accommodation request. And just as I think it can't get any worse, Charlie proceeds to offer a "solution": that I should discuss my TA work with my employee supervisors to have my work modified so I can handle it.

Um, did I just hear that right? So my accommodation request is an employment matter? How so? I am a bit confused. The scholarship I'm referring to here is tied to our role as a student, which means this has nothing to do with my employment role as a teaching assistant.

I move back and forth in this space of confusion. Not only am I struggling with the academic and employment issue, I am realizing that I was just asked to disclose my disability to my employee supervisors. *What does my wanting a university to allow me to keep both my internal scholarship and my external scholarship have to do with my role as an employee exactly?*

Well, it turns out that a "scholarship" is not always a "scholarship" in the dictionary definition: "an amount of money that is given by a school, an organization, etc., to a student to help pay for the student's education."³⁵⁴ When a university offers graduate funding, part of the money is considered a scholarship and part of it is earned through TA or RA ships. In practice, however, one is linked to the other. In other words, students will not be able to access the "scholarship" portion of their graduate funding unless they also

³⁵⁴ Scholarship (n.d.) In Merriam-Webster Dictionary. Retrieved from <http://www.merriam-webster.com/dictionary/scholarship>.

take the TA or RA ship. Furthermore, students may not hold both an internal and external scholarship at the same time.

What I was proposing as a means to accommodate a non-visibly disabled graduate student—at no extra cost to a university—was that I would be able to withdraw from teaching for a term in recognition of my disability, but not lose the scholarship portion of my graduate funding. Suddenly the line between the role of student and the role of academic worker became very blurry—almost as blurry as the use of the term “normally” in the policy that says “when a student is awarded a major external scholarship (e.g., NSERC, SSHRC, and OGS), they *normally* will not be offered an internal graduate scholarship.”

My understanding after speaking to numerous people in various capacities at a university from the union to the human rights office to disability services to the dean’s office was that “normally” is a “weasel word” that allows a university to be flexible with this rule, if they so choose. There is also the provision that a department and/or individual supervisor can “buy out” the TA ship, allowing the student to keep the scholarship portion (through a research assistantship). A university was unwilling to do this, and I was unwilling to have my supervisor use their own money, because I felt that having a university buy out my TA ship was a reasonable accommodation for my disability, particularly since I had been successful in bringing two prestigious external scholarships.

I was adamant that my supervisor should not have to buy back my TA ship from their pool of money, because this acts a disincentive for professors to take on the supervision of disabled graduate students. Why would a professor agree to supervise a

disabled graduate if they were going to cost the professor money from their own research grants? Rather, (in my opinion) it is the university's or should be the university's duty to accommodate to the point of undue hardship. I was posing no financial hardship!

Further, disability is a private matter, not for public display.

“So you want me to disclose my disability to my employer supervisors, two different professors whom I barely know and who may become my colleagues in a few years when I have completed? I'd rather not disclose my disability to others, and this is within my rights.”

I think back to the key informants and how they are at least *aware* of the stigma attached to being disabled by the academy. I also think of Jules's comment: “We can be disabled, as long as we don't change the norm in any way or ask for anything extra.” *That is kind of the definition of ableism, isn't it? How is it that Charlie doesn't seem to acknowledge this?*

“Why do you want to keep your disability secretive?” Charlie goes on to ask.

And there it is. The final moment where I have now just lost any sense of hope of being accommodated for, and any respect I had left for this individual sitting across from me.

Secretive? Charlie asks me this question *twice*.

Umm, for one, I have the right to privacy, not to disclose. It's my choice if I choose to offer this information. I choose not to. If Charlie only knew the amount of work that goes into performing a non-disabled identity, especially as a graduate student, perhaps then such an intrusive assumption wouldn't be made. But I am not sure.

As I have outlined in this work, the extra work required of disabled graduate students can be detrimental to their academic progress—not to mention what it can do to a person’s mental health as someone who is already struggling with ADHD, like I am.

When students feel the need to constantly educate others about their rights to access inclusionary learning spaces, this means that instead of focusing their attention on completing their programs, they have to engage in time-consuming tasks associated with working towards getting accommodated. Instead, we should be thinking about ways to make it so that disabled students don’t have to fight for a place in the academy. We need a more dialogical approach so that we can continue with this conversation. I mean, it would great if taking on the task of this extra work came with some acknowledgement that can be written onto one’s CV, but we know this is not the case.³⁵⁵

Chouinard and Grant argue that, “Performance standards which value quantitative output (such as grants and papers) and frequent conference travels, for example, not only devalue ‘ordinary’ academic activities such as teaching a class, they fail to recognize just how amazing it may be for someone who is mentally or physically disabled to produce even a single paper.”³⁵⁶ In that space and in this place of academia, I do not feel valued for the work I have accomplished and contributed to a university.

³⁵⁵ My committee member Ann Fudge Schormans pointed out to me that in the field of social work, at least, these activities are increasingly recognized as legitimate skills and experiences for CV as advocacy and leadership. She writes, "The fact that these activities are not typically incorporated into a traditional academic CV keeps the labour hidden and discounts their value to social change" (Fudge Schormans, personal communication, June 16, 2016). See also Mountz, et al., 2015.

³⁵⁶ Chouinard & Grant, 1995, p. 150.

To illustrate how I felt like I don't belong in this space, I note how I won an external grant and had just returned from a successful paper presentation at an international conference. I had progressed well in my academic studies, maintaining my A-average in spite of the barriers I faced thus far. All of which was not mentioned during my time with Charlie. All I kept hearing is that I wanted to be paid for not working? How are my academic contributions not valued as work?

“Well, there is nothing I can do for you here,” Charlie continues. “As I said this is an employment matter and it's in your union contract. You have to work for your scholarship. I cannot simply give you money.”

Interesting, so you mean I didn't work for my scholarship? Last time I checked scholarships weren't just handed out like candy—unless I missed that memo?

I smile and respond back, “That's great because I didn't come in here asking for you to give me money.”

“Is there anything else you'd like to discuss?”

What would be the point? You've done nothing for me.

This isn't over!

I gather my belongings and quickly get up to exit the office. I'm working hard to not to show the tears that flood my eyes. I make no effort to thank Charlie for meeting with me, and I fail at faking a smile as I look up at Charlie's assistant.

I simply walk out.

Knowing I shouldn't have walked in there in the first place.

Epilogue: (Imagining) The End

It's here.

The day has finally arrived.

Most of the time, I felt like I'd never make it. This is especially true after the car crash happened.

But here I am.

It's D-Day—final defense day. It's time for the final PhD milestone. I've been waiting for this day for what seems like forever. I treated myself to a new hot pink blazer with a bright, white open-collared blouse. I'm ready to rock. Of course, I also needed a new pair of pink stilettos to match. You know it's a big deal when I go out to buy new shoes to match my blazer and purse.

I arrive an hour early. I want to get a sense of the room before the others arrive. I also need some time to reflect, a chance to calm my nerves, and maybe cry a bit too.

I need some alone time.

However, I'm far from being alone. When I walk in the room, I notice a thick glass wall, and behind it are Sam, Drew, Amy, Morgan, and Rowan. Dakota also made it even though they dropped out of the study mid-way into the data collection. I'm absolutely thrilled to see each of their faces as they are chatting away with one another. But I hear nothing. It's soundproof. I have no way in to say hello so I mouth to them: "Thank you!"

Tears begin to flood my eyes.

I begin to sweat. Off comes my blazer.

I invited the co-participants to the defense in anticipation that they'd like to see how this project unfolds at its completion. I worried whether this was ethically responsible, but I felt that it would be unethical not to give them the option. While I didn't want to risk their identities being public to anyone else in the room, I did outline the risks to each of them so they could make an individual informed decision on their own. I felt that their right to participate in the end was more ethically responsible of me than it was to worry about identities, as long as they weren't concerned. When I didn't hear back from any of them, I assumed they wouldn't show up. Yet, here they are.

It's their voices that make up the core of this story. I couldn't imagine being at this point without them. A few minutes pass before they take their seats in the room. Their presence made me feel like I was walking into a stadium, where the fans continue to cheer me on, as they had so often done throughout the research project. They've been a great source of support and motivation for this project—a benefit I had no idea I'd be the one receiving, as the researcher.

My mind wanders back to my ethics protocol application when a researcher must outline the risks and benefits of the proposed research and the ways in which I would manage these risks and benefits. For co-participants, I included supports for the anticipated psychological risks (having to recall painful experiences of barriers they experienced) by directing them to campus resources, as I do not claim to be a counsellor. Some of the social risks included being inconvenienced by the time commitment of the project. I reiterated that they could withdraw from the study at any point in the study. For

the key informants, I also included on-campus resources such as counselling and wellness offices, as well as ensuring that I would safeguard against any loss of privacy and reputation by not revealing their identities or that of their universities.

Finally, I had to take the same measures in managing the risks and benefits to myself, as the researcher.³⁵⁷ I outlined how I would manage and minimize these psychological risks to myself that I may feel in listening to other student's stories by debriefing with my supervisory committee and trusted colleagues. I also consciously chose e-mail interviews for the key informants as a way to avoid the anxiety associated with certain offices at a university.

What I didn't anticipate when I was preparing my ethics review proposal was that I would also benefit from the collective support I received during all phases of the research blog collection from the co-participants. Often times, during the research blog, we'd collectively cheer each other on. (This is in no particular order):

DREW: Morgan: Bravo for helping your students when you wondered if they too had an unique learning issue! And thank you for sharing that point.

NANCY: Drew et al., yes this is great! I want you all to feel a part of this research so please don't feel like you're stepping on toes. This is precisely what I want to hear.

DREW: Dakota: I think you are to be congratulated for your successes and your motivation. It is wonderful that you have achieved such successes. AND I think about the system, as noted by Rowan, that the system influences or reinforces feelings of success or limitations (some would call this being disabled).

³⁵⁷ Gill Hubbard, Kathryn Backett-Milburn and Debbie Kemmer (2001) highlight that "The importance of protecting the respondent from emotional threat regularly appears in methodology texts. However, these warnings fail to acknowledge that when a situation evokes emotions on the part of the respondent, it might also be an emotional experience for the researcher" (p. 120).

ROWAN: My apologies if this is coming across as unclear or confrontational at all... I am trying to write something complex and personal on my way out the door, but I don't know when I will get to it next and I know there is a time sensitivity on out comments. My aim here is just to open up conversation about how the "information" we are given regarding disabilities (generally and specifically) can be a significant barrier to accessing accommodations—especially if we can get by in the system as is (the cost of this is perhaps another discussion!). * I do (now) believe that it is the systems we live in that is disabling rather than I am disabled/flawed.

MORGAN: I am glad to have been able to read/share these experiences with you all. I am only a humble MA student and with your comments, on one hand I am inspired to eventually pursue a PhD but on the other am forewarned that I am just in for more struggle. I will complete my MA first and reserve further decisions til later!

SAM: Morgan—I hope you'll forgive me for cherry picking just a few points to respond to. It has much more to do with my own way of thinking through things than it does any sort of commentary on the value of the rest of your post! Please don't feel disheartened about the prospect of continuing your studies!

SAM: I don't have much to add/ask Drew, but I thought you should know this is a strong response. :D Thanks for sharing it.

I feel like we built this sense of community with each other in these relational dynamics.³⁵⁸ I labelled the participants as "co-participants" in the final writing of this work out of respect for the important role I wanted them to play and that they did play. But I was struck by the extent to which the co-participants influenced my thinking about the analysis to the point where we were co-producing knowledge.³⁵⁹ "Nothing about us without us" became a reality!

I was just as satisfied that the great pains I took with ensuring the research was "care-full",³⁶⁰ inclusive, and ethically sound, also were realized. I wanted to take care of

³⁵⁸ Tillman-Healy, 2001.

³⁵⁹ Fudge Schormans, 2011.

³⁶⁰ Fudge Schormans, 2015. See also Fudge Schormans, 2011; Mountz et al., 2015.

the co-participants to ensure they were safe to participate freely without having to feel threatened or attacked. I also ensured various ways of allowing for flexibility to contribute to the blog (e.g., allowing Amy to send me messages that I would post to the blog, so she didn't have to navigate the site since she was busy with being a mom to an infant). I began to notice that there was this shift when the co-participants started to take care of me, in terms of motivation and being there for support.

Mostly, I'm grateful and honoured.

When the discussions felt a bit tense, I found that some of us prefaced our contributions with an apology. I think, for the most part, we all understood that tone via text might be understood differently, so we were very mindful of this space. During the completion of the data collection, no one reported any unease with any of the discussion threads. I made a habit of checking in with co-participants individually via e-mail and offered my phone number or e-mail as a way to connect in case someone wasn't feeling comfortable.

I was also privileged to work with these co-participants, as they were also graduate students themselves. At some points throughout the research blog, the co-participants helped to generate some of the themes and analysis for me. I smiled when I read Drew's post, "... ps: don't mean to step on toes, just find myself moving from plain old participant to participant with research background and hypothesis generating approach. :)."

Drew, you're certainly not stepping on my toes; this is the sort of collaboration I was hoping would come up during this process, and something I'd like to continue when I apply for a post-doc.

I snap out of this daze when I hear chatter behind me. My supervisory committee is next to walk in. Following right behind them is the exam Chair and the external examiner. After some quick formal introductions and handshakes, I'm then introduced to the person facilitating computer-aided real-time transcription (CART) services.³⁶¹

After speaking with the facilitator, I turn to see Jules walking in. I am relieved to see more friendly faces, Bonita, Fady, Susan, Alexis, Chels, Halifax, Katie, Sheila, Kat, and Kim.

Tony's here too!

“Oh my God, you made it!” I hug each of them and direct them to their seats, “right behind the glass wall,” I say. I'm beside myself to have this support, but anxious at the same time. *Dear God, don't let me fail in front of my peeps.*

³⁶¹ This is a specific accommodation I requested for my PhD comps defense. I remember asking for CART services for my oral comprehensive exam, and I was told that this service is typically reserved for d/Deaf students. I felt guilty for possibly taking away this “expensive” service from a marginalized group that “really needed it”, as it was explained to me. I opted for an inexpensive alternative where the office secretary would come in and transcribe questions for the group. In the end, the alternative didn't work to meet my access needs, and I almost sacrificed my exam at the expense of feeling guilty for using an accommodation that is typically reserved for d/Deaf students. This also speaks to the history of asking for an access need and then being guilted not to take it because this accommodation doesn't fit the preconceived notion of what ADHD students might need. As Price (2011) notes,

An important assumption to avoid here is that particular accommodations are “for” particular kinds of disabilities. For example, while it might be assumed that printed copies of papers are only for people with hearing impairments, in fact they may aid a wide range of people, including those who have difficulty focusing on, remembering, or processing oral language, whether that difficulty stems from fatigue, an illness, AD/HD, or a brain injury. With that said, however, it is notable how few of the statements mention disabilities other than those that involve impairments of mobility, seeing, and hearing. (pp. 122-123)

It's time.

It's 3 p.m. We begin with formal introductions and go over the rules of the exam.

The audience is reminded that they are not to speak during the exam.

The drilling starts. It's time for my presentation to begin. I take a few deep breaths focusing on my supporters. Again, here's the emotion work at play as I try and manage how nervous I really am. I'm looking directly at my friends, and I crack a smile when I see everyone, including the co-participants, holding up a sign that reads: "YOU GOT THIS!" I instantly laugh, trying so hard to hold back the tears of comradeship I have for the wealth of support each of them has brought to me as I travelled on this journey.

The first-round of questions begins. The external examiner is first up. I hear the question. I take a moment to process it. I wait until the monitor with CART services has completed typing out the question for me, so that I may be able to re-read it and allow time to process what is being asked of me. My head begins to throb.

I take a deep breath in and grab a sip of coffee before I respond. With a sigh, I finish with what feels like the longest response ever. It doesn't help that I'm completely distracted as the co-participants are trying to shout responses to me.

They can hear me.

But I can't hear them.

What are they trying to say to me? They're too far for me to read their lips. Their voices silenced by the glass divider that separates them from me.

Did I capture our experiences in a way that reflects what they've contributed throughout the research blog?

“Nanc! You OK? Where’d you go? You looked like you spaced out for a bit.” I realized I was staring out the window, with my pen in my hand.

“I did. I had this dream of being at the defense. I must have been imagining things.”

“It’s probably your subconscious getting ready. You’re so close. Keep writing. You’ll get through it before you know it. By the way, how did it end?”

“It didn’t,” I laugh. “I snapped out of it just after my first response to the external’s question.”

“Sounds like a happy ending to me.”

I put my pen down, and smile.

“It was just a ‘dream.’”

Or was it?

The Pen Starts

“What’s up? You sounded frantic on your text.”

“Yeah, well, I guess the end of doctoral writing will do that to any grad student.”

“Enough said. Where you at?”

“The concluding thoughts. I need to brainstorm with you about the implications of the study now. I’ve already woven the future study questions throughout the narrative.

But I am stuck on the implications of my research now. Why does everything feel so damn hard lately?”

“Oh I don’t know, maybe because you’re trying to complete and defend your dissertation while still recovering from a mild brain injury. Does this sound about right?”

“You’re quite the comedian aren’t you?”

“No, just trying to show you that you’re way too hard on yourself. Isn’t much of the work you’ve written about speaking back to the internalized ableism we are trying to fight? You really should give yourself more credit.”

I smile back at Jules with a smirk.

“I wouldn’t dare turn this into some overcoming story.”

“That’s wise of you because you know that would just put me over the edge of my seat and want to smack you.”

Jules laughs.

“Let’s get started then. Do you have a pen?”

Jules laughs again, as we both start to search for a pen. When I find one, Jules begins to question me again as though we are in some kind of interrogation room.

“Let’s start with your favourite: theory. What have you contributed theoretically?”

At this moment, I feel as though someone just punched me in the stomach. I feel like I’m never going to get this theory confidently under my belt. Deep breath in.

“Well, for one thing, I have tackled how the social model is not intended to ‘do it all’ with respect to how to improve the lives of disabled people. It was never intended to, either. It’s a model, that’s it. But it’s a model that has changed the conversation about

disability from a focus on individuals and pathologies to the social causes of disability. That said, even if we did remove the disabling barriers that students experience in the academy, and in particular, those experienced by disabled grads, I argue that barriers still exist. You could give me all the extra time in the world to complete my studies, but that doesn't erase the internalized ableism I live with. I will still feel less confident in my academic abilities in comparison to my peers (both disabled and non-disabled)."

"Wait a minute," Jules interrupts. "So it's not just that you need extra time. It's the judgement and attitudes of the academy about needing extra time that's the problem. Isn't that the barrier you are trying to eliminate?"

"Yes, as the stories of the co-participants show, we are so far away from that, it's hard to imagine what it might look like. We just don't know what the hell we are doing when it comes to accommodating non-visible disabilities like ours."

"That's an understatement."

"But it's more than that. Even if the social and physical barriers are removed in academia, there are still individual barriers and limitations that disabled graduate students will face. Barriers that we won't fully understand or address without understanding the emotional geographies of disability. With that, this is where emotions come into place."

"Tell me more."

"It's important to understand just how much work actually goes into the processes of accessing academic and workplace spaces. I often say that being a disabled student is a full-time job! Especially as a grad student when the competition and the demands of academia are so high."

“And what if we could remove some that extra work from the life of a disabled grad student? What if, for example, there was one place on campus, and only one place, that handled all your accommodation needs?”

“Well, I guess that would be a start, but what I want people to understand is that no matter what you do to remove the barriers, I will still be in pain, and this affects how well I can perform as a grad student. Pain may slow my ability to be and feel productive. And unless that is well understood and ingrained in how things are done, I will internalize this as not being cut out for grad school. Sure, there are cognitive strategies I can do to combat some of these symptoms, but I still haven’t been able to access the right support for that. Nor is there any agreement about what those supports would look like. And how these supports fit into the whole idea of ‘academic integrity’? There’s a whole post-doc idea right there!

“Then there are the strong meds I can take that only do more harm than good to my body. The stress of trying to make this work just exacerbates my symptoms and makes me feel like shit. By telling my story, these experiences I live through, and those of the other co-participants, I am giving voice to those that are missing as a way to begin and continue this dialogue. Non-visibly disabled graduate student’s experiences are missing in the literature thus far. An understanding of emotions and emotion-related work is missing in the conversation about access and accommodations. My contribution is to add emotions to the dialogue to reveal how they manifest physically and mentally.

“My friend Stacey helps to validate this for me in her comments on my previous thesis draft. She explained that non-visible pain is too often overlooked even though it is clearly an experience that impacts academic production and student life. She wrote,

This is extremely important work and I think it will add so much to the discipline. I love how you take extremely complex theory and not only make it accessible, but something that non-disability scholars will be interested in and internalize. I also think the mention of emotional, psychological, & physical pain is VITAL. It is something professors don't consider in accommodations or have no idea how to approach. It came up many times with my participants as well. As I realized yesterday and many other times, when we're having such intense embodied experiences of pain, it is impossible to get any academic work done because our physical/embodied experiences are so immediate that they just halt the entire experience, no matter how badly we'd like to continue to work.³⁶²

“And so much of that pain is related to our non-visible disabilities, either directly or indirectly.”

“So what does your study add to the literature?”

I pause and think for a few moments before responding to Jules. I decide to read from my partially written “conclusion.”³⁶³

“The examination of the added work faced by non-visibly disabled students is an important area of inquiry in the emerging field of geographies of disability³⁶⁴ and contributes to furthering its ‘interest in shaping policy and agendas and the *place* of disabled people in contemporary society’.”³⁶⁵

“OK. How?”

³⁶² S. Rosen Coffman, September 04, 2014, personal communication.

³⁶³ I'm aware of how a ‘conclusion’ is traditionally written (i.e., there should be no introduction of new ideas), but like the rest of this thesis, I am writing this in an unconventional way.

³⁶⁴ Imrie & Edwards, 2007.

³⁶⁵ Chouinard, Hall, & Wilton, 2010, p. 4, (original in emphasis). See also Dyke, 2010.

“I often think about what makes my study original and there isn’t much literature on non-visibly disabled graduate student experiences in academia. This is what I have to contribute to literatures of emotional geography of disability. You might remember from my literature review that the literature talks more about emotional labour—done in paid work environments, like the study about college instructors³⁶⁶—and how they talked about the complex and varied roles they had to take on to be successful teachers. And the toll it took on them.”

“Yeah, those were interesting. But how important is the distinction between paid and unpaid emotional labour/emotion work, anyway?” Jules muses.

“Well, for my work, it’s important mostly to make the distinction between the paid work of a grad student, like TAing, which requires one kind of accommodation, and academic accommodations, which might be different. Though, in my experience they get muddled up together pretty easily.”

“Ah yes, Charlie,” Jules nods.

“Yeah, Charlie,” I wince at the memory. “And I find some scholars have started to use the terms interchangeably. What’s more important to my work, I think is that this work is, as Scully points out, ‘hidden’.”³⁶⁷

“Why is that important?”

“Well, for one thing, it’s not recognized, either in terms of negotiating accommodations, like extra time, or as the important skills you need to manage all the stuff that goes into having a disability of any kind. So disabled grad students are doing

³⁶⁶ Zhang & Zue, 2008. See also Bellas’s (1999) work on the study of emotional labour in the academy.

³⁶⁷ Scully, 2010.

more work and getting less recognition.”

“I see what you’re saying. Like when Amy said, ‘Get cancer and watch people try to get you.’ Everybody understands the emotion work involved in getting really sick, or getting a divorce, or having kids. But as soon as you have a disability, especially a non-visible one, it’s like they think you’re faking.”

“Yes. And that’s what I want to bring attention to. It’s like our extra work is hidden in plain view!”

I read again from my written conclusion. “In places of academia, students find themselves engaging in added work, when they have to educate the educator on the right to their accommodations. Even when accommodations are in place, for example in the classroom, disabled students still find themselves having to remind their professor about their accommodation. This in turn, makes students feel like they need to prove their right to belong in academia. In the process of struggling for accommodations, students are also often (just to make it clear this doesn’t universally apply) “misunderstood” as seeking “special treatment”. The invisible emotional work that professors may not be aware of, work that is required specifically of disabled students, is important to further explore if we want to make our places of the academy inclusive to all.”

“So tell me more about how the conversation about access and accommodations would change if we listen to what you have to say.” By now, Jules knows how to probe so that I will get into more depth.

“Oh shit, that’s easy! I would want the academy to think about the socio-emotional aspect of access. I’d want to debunk the myths that disability means providing an

advantage to disabled students.³⁶⁸ This is far from the fact when we think about and recognize all the work that disabled students do to negotiate academic spaces. It's not enough to just review policies and make suggestions; policies have little weight to the way disabled students are made to feel especially when they exclude us and/or single us out when we have to fight the ableism. All sources of training materials, and awareness campaigns *for all* service providers (including admin staff, deans, program directors, disability counsellors, and academic and employment supervisors) need to include our lived experiences.”

“Yeah, well how the hell do you propose we do this?”

“Sounds like you are asking to start my recommendations.”

“Yeah, I guess am.”

“I know. I am making this sound easy. It's not. We need disabled grads facilitating these materials or at least, having an opportunity to have their voices included. The point needs to be made as to not add more work to their plates, so why not include this as part of their funding package if they choose this as an alternative to teaching assignments?”

“One of the best practices I found to be fruitful for my academic studies was being asked what I needed by the accessibility librarian. She literally took the time to sit with me and listen. She never imposed anything on me. She actually took notes and took my stories back to the university. I know this because I sat on some of those committee meetings—of course, she never identified me. But this is something all educators can do.

³⁶⁸ Dunn, Hanes, Hardie and MacDonald (2006) recommend that “Myths need to be dispelled: that accommodations means standards are being lowered, or that students with less visible disabilities exaggerate their needs” (p. 14).

And this doesn't have to be about disability, per say. This falls within the notion of universal design which is applicable and beneficial to all students and academic workers. I really think this is about collaboration and working together, instead of in isolation where disabled students feel like they are being passed around from one office to another. I think this would be a start. And it reminds me of the work on slow scholarship.”

“Slow scholarship? Have you mentioned that before!”

“I think so. It's just such a good example of some of the practical implications of what I've been researching. There is a group of academic geographers who I am following on their notions of slow scholarship, and I think this would be a good place to start in thinking about how to rethink academia. Look at this. They argue,

Good scholarship requires time: time to think, write, read, research, analyze, edit, and collaborate. High quality instruction and service also require time: time to engage, innovate, experiment, organize, evaluate, and inspire. This kind of slow work both defies and is threatened by the myriad demands on our time as academic laborers.³⁶⁹

Jules exclaims, “That sounds bang-on!”

“Yes. That's where I wish I had been able to get more into issues of poverty and the whole neoliberalization of post-secondary education. That's a huge area. I guess that's another limitation of my study. And an area for further research.”

“Way to go,” says Jules, “You've managed to put three categories into one: limitations, future research, and recommendation!”

“Will you stop? These connections are important!”

“Yeah, yeah, go on.”

³⁶⁹ Mountz et al., 2015, p. 3.

I continue to read. “This says it well:

...we find a need amid the chaos to slow—things—down. In this collaborative article we explore the isolating, embodied effects of neoliberal temporal regimes, and we propose collective forms of resistance: strategies to work together to slow scholarship down as part of challenging the growing inequities in higher education.... As such, we support Martell’s (2014) observation that the ‘slow’ in slow scholarship is not just about time, but about structures of power and inequality. This means that slow scholarship cannot just be about making individual lives better, but must also be about re-making the university. Our call for slow scholarship is therefore about cultivating caring academic cultures and processes.”³⁷⁰

“This stuff is great! Why haven’t you used it before now?”

“Because of my concussion! I got this article from a listserv ages ago. But it wasn’t until a friend of mine, Kim Collins, reminded me about this movement that I realized I had read this before. I found their paper sitting under a pile of books scattered on top of my desk, and I had all these passages highlighted.”

“Good thing you plan to do future research!” Jules laughs. “But since we are kind of into the recommendations, let’s go with it.” Jules pretends to clear their throat and tries to sound professorial: “If you had to summarize your recommendations for making grad school genuinely more accessible, what you would say?”

“Well for starters, I would begin with how disabled students feel like they don’t belong in academia in the first place when they are not represented.”

Jules’s look probes for further articulation on my part. I continue by reading from what I have written, “Dunn, Hanes, Hardie, and MacDonald recommend that,

Students with disabilities need to see a mirrored reflection of themselves in faculty and staff. Such a reflection would demonstrate acceptance, provide knowledge/mentoring resources, and normalize their situation within the school...If

³⁷⁰ Mountz et al., 2015, p. 3.

students with disabilities are not represented at the doctoral level, schools cannot recruit faculty with disabilities (MacDonald et al., 2003). Physical barriers need to be addressed and accompanied by accommodations such as flexible workloads, doctoral studies supports, and opportunities for advancement. The knowledge of faculty and staff with disabilities needs to be welcomed for the contribution it makes to different ways of knowing.³⁷¹

“I found it interesting how the co-participants discussed their curriculum experience in the classroom performing their roles as a TA. Drew revealed that they were better able to perform in their teaching positions when they could relate to their disabled students simply because of their lived experience. I read from Drew’s transcript:

DREW: I too found that I was quick to encourage students who had extremely difficult life situations (such as living in a woman’s shelter) to seek support within the faculty. Many of these students expressed fear that they would be seen as “less than” by the faculty. I was also quick to refer students for assessment and support when it appeared that conversation and writing showed a disconnect for them. I too shared information about services that were available. I was often surprised that others were not aware of these services and gave administration feedback that we should include this in faculty orientations.

I also had a student who was displaying some unusual behaviours in a tutorial, so I asked to speak with him privately. He had a mental health diagnosis and was in the process of changing his medications. I encouraged him to see help and support for the necessary accommodations. He however just wanted to push through so that he could graduate with his peers, I am aware that the disease can impact judgment and struggled with allowing this student autonomy (as is his right) and pushing that the decrease in medication and gradually replacement with another, could greatly impair his abilities to perform. I decided to gently remind him of some of the possibilities he might experience and that services and accommodations were available. And after that interaction, I wondered how many others who had that student, would understand his experience in medication transition, it’s impact on his performance? Had I not gone through similar experiences, would I have thought of this? How well are we educated and informed of the multiple issues in preparing for our roles as educators? And is this one of the issues that results in the responses we ourselves receive? I welcome the comments of others.

³⁷¹ Dunn, Hanes, Hardie & MacDonald, 2006, pp. 14-15.

These anecdotes highlight the value that making disabled grad students *visible* can add to the academy. It's like what Grundy and McGinn have written about in their work,

Students with disabilities have legal and moral rights to participate fully in graduate education and reap the resulting social and economic benefits. Their participation in graduate education is essential to building vital research capacity. As Giroux (2004) has argued, society cannot afford to exclude and disenfranchise individuals with disabilities from fully participating in the scholarship of the future.”³⁷²

“But hold on, Jules interjects. “How does this issue of being visible in the academy affect the right not to disclose?”

“That's a good question—for future research, dare I say? But if we could reduce the stigma and find good ways to accommodate, then disclosure might be less of an issue. But each thing depends on the other. It's like research. It's messy. But we need to start thinking in these terms. And more to the point, if we could encourage slow scholarship the way Mountz et al. are suggesting, that would also help reduce the stigma for everyone.”

“Sort of like the principles of universal design.”

“Yes. That's a whole other area that my research contributes to. It's almost as if we need disabled students to be visible, so that we can make disability invisible through universal design in education. But it's not just in design. It's also in the curriculum, as Sam points out.

SAM: Of tertiary relation, I'm teaching this [...] article for my tutorials in the coming week. I'm intending to steer the discussion toward how disability fits into hierarchies of (in)appropriate accommodation. Historically I've found students fairly competent at discussing this issue in relation to race, but I'm interested to see how (motivated by my experiences with this study) a less easily untangled situation

³⁷² Grundy & McGinn, 2003, under “Conclusion”, para 4.

will resonate with my students. Apologies for the giant wall of text. Let me know if I've missed anything!

SAM: Hi again, The tutorials turned out to be a bit of a bust. Everyone was much more preoccupied with the forthcoming reading week than they were by the discussion. One interesting tangential point, however, was that by moving the discussion away from race (which is apparently difficult to empathize with?) I was able to get students to identify the problems with various sorts of “try harder” arguments which are brought to bear on equality issues. I'm not certain whether this is a result of the “invisibility” of certain disabilities, or if it might be attributed to the fact we are socially conditioned to take up certain psychological discourses without reflecting on their deeper meaning. (“This is driving me crazy” and “my ex was a total psycho” being two of altogether too many obvious examples.) Sorry for the anticlimactic response!”

Again, I read from my written conclusion:

“The extra work of disabled students is distinct from the work that non-disabled students have to negotiate in their daily academic lives. I stress that I am not arguing that emotion work and emotion labour is only an aspect of academic work required of disabled students. We know that single student care-givers must negotiate their study time around family obligations too, for example. But I am simply stressing that disabled students do emotion work and emotional labour that is distinct from other non-disabled students because of the physical, social and emotional barriers to their academic environments that is manifested in added work. Amy demonstrates the added work of motherhood in addition to having a disability while completing grad school can be challenging. In other words, disabled people face much of the same emotion work as others do in the many areas of life, but must deal with physical and emotional work of having a disability in addition.

“Drew articulates my point further about the interaction of everyday stresses in academic life when you're disabled,

DREW: I know I have shared stories about stressors in life. I do this as they are triggers to exacerbation to our unique learning needs; relapse can be triggered when life becomes extremely complex. And at the graduate level it is, I believe, one of the unwritten measures we are expected to overcome. I had often heard that other students have stressors in their life (having children, partner breakups, financial issues, no vacations, etc.) so my stressors were just part of life as a graduate student. However, these stressors are triggers to increased (dis)ease symptoms(inability to focus and comprehend what is read, inability to sleep, eat or care for oneself, increased anxiety, and inability to write effectively to name a few). So the suggestion to compartmentalize life is not at all helpful in overcoming the impact of these stressors have on us. And it is within this context that the accommodation must occur. However, this is often seen as being an inadequate and incompetent graduate candidate.

NANCY: ... This is an interesting question regarding faculty and whether they feel supported. I have not interviewed faculty members, but this was something I wanted to do. Yes, maybe future research.”

“OK, while we’re on the topic of future research, maybe you should list all the areas for future research.”

“I told you, I wove all that stuff into the rest of the thesis.” I respond.

“Yes, I know you like lists about as much as you like outlines, but for people whose minds aren’t—how can I put this?—as agile as yours and mine, maybe a list would be helpful.”

I roll my eyes, though I know Jules is probably right.

“Well, at the top of the list, I think I would put educating university faculty and staff about the nature of non-visible disabilities and the need for flexibility in accommodations. And I mean really educating them, taking emotions and emotional labour directly into account. I would emphasize that this onus of educating the educator shouldn’t be placed on the disabled student either!”

“Like how it seems like I am getting “extra time”, but I am actually doing more work than other non-disabled students to accomplish the same thing.”

“Yes, and it’s all kinds of work. You may need a tutor, so you may have to run around to get funding. Then you have to actually go and work with the tutor. And you are probably doing more intellectual work to get a paper done, for example, when you have to read the same article several times. But what I really want highlight is the emotion work of still feeling ‘out of place’, even when you are doing so much more than others are. That’s what I think is missing in the understanding of non-visible disabilities. And that’s why we don’t accommodate properly.”

“And it strikes that if we could eliminate some of the stigma, we’d also eliminate a lot of the extra emotion work.”

“Exactly. Let’s try to eliminate the extra work that can be eliminated, because all disabled students are still going to have to extra work in other ways.”

“Now, is this clear that we also need these kinds of changes regarding workplace accommodations?”

“No, I don’t think so. That will be trickier because there might be funding issues involved.”

“And now back to neoliberalism. Did I say this is messy?”

“And what about the contribution you’re making just doing your dissertation with this flaky methodology?” Jules jokes.

I shoot Jules a weary look. *I’m not in the mood for this.*

Jules responds, “You’re right. Sorry. No more flaky jokes. I saw how much care and thought you put into your methods. How hard you worked to walk your own talk about respecting people’s emotions. And to make your data collection and writing of this thesis accessible. And how careful you were not to generalize your findings. You’re right. How can we possibly understand the importance of emotions if we don’t have the lived experiences of those feeling them?”

“It so happens that I have a *list* of methodological considerations that my work contributes to.”

Jules bursts out laughing.

“Yeah, you’re a bad influence on me,” I quip. “Let me do a quick search of my thesis draft. Hang on. Right, right, here it is. For one thing, I am contributing to innovative ways of doing research.

“Details please. We need the trees here, not just the forest.”

“Well, at the top my list...I tried to make my research process both more accessible and more “care-full” by bridging the gap between virtual methodologies and autoethnography. By using online methods, I was self-accommodating my disability; while trying to reduce my own extra work that would have been required had I tried to get the funding for transcription services. Not surprisingly, the article on slow scholarship talks about this too. I read,

Care-full scholarship is also about engaging different publics (not least our own research subjects), refining or even rejecting earlier ideas, engaging in activism and advocacy, and generally amplifying the potential impact of our scholarship rather than moving on to the next product that “counts” to administrators.³⁷³

³⁷³ Mountz et al., 2015, p. 9.

These and other experiences have taught us to be compassionate to one another (and to our scholarship) as we navigate the difficult realities of daily life with the support of our colleagues.³⁷⁴

“I also used online methods out of consideration for my co-participants, both in terms of being flexible time-wise and discrete because we were talking about personal, sensitive issues. Allowing my co-participants to use online methods, particularly the blog, meant they could take their time and make changes before their writing was available to everyone else. Another advantage of these methods for people with memory and motivation issues, is the blog provided reminders and notifications when people posted. Of course, that could also be a disadvantage. Some co-participants said the reminders helped, and other said they sometimes felt overwhelmed (including myself), but they were able to turn off these notifications if they wanted to.”

“On balance,” Jules asks, “do you think your co-participants appreciated the online methods?”

“Yes. I had one co-participant who told me that this study influenced how they were going to conduct their research, both in terms of online methods and autoethnography.”

“Well, you certainly challenged my ideas of what scholarly writing is.”

“No kidding. You were my biggest skeptic. But I think you can see that autoethnography makes the work more accessible, both for the researcher and the reader.”

“And more fun! What I love about this is that it gives us a glimpse into how a person with learning disabilities and a mild brain injury operates, but can still produce scholarly work.”

³⁷⁴ Mountz et al., 2015, p. 11.

“Exactly. It’s all about getting to the same place in a different way. Isn’t that what an accommodation should be? And speaking of accommodations, this concussed head needs a break.”

“Good idea! I don’t know about you, but I could use more coffee. My treat!”

I smile as Jules goes for coffee. Though I need a break, I just have to write this down before I forget.

If the purpose of academia is to provide a good learning experience, so that everyone can contribute as best as they can, then there should be no stigma to remove. If the purpose is efficiency and elitism, then accommodations are just a barrier to that. However, I do have to wonder what it would be like if we changed the markers of what it means to be “successful” and competitive—maybe then, likely only then, I wouldn’t be comparing myself to others and feeling less than “competent” in grad school.

Yes, it feels much better when the pen starts.

Post-Script

As I wrap up with this writing, I am reminded of the last email I received from Sam. I had forgotten about it for a little while as it was so painful to read. I've worried about this myself with my own studies especially after having been involved in a car accident that had delayed my completion time.

Sam writes me,

Of tertiary relation, it might interest you/your project to know that as of this September, I've actually been forced out of my graduate program because the department is unwilling to continue to support my research. This came at the same time as the head of my department began publicly discussing my accommodations and disabilities with other students. (In the context of complaining about the "waste" of departmental funds on "unworthy" students, and the deprivation this leads to among "worthy" students.)

I'm doing well in spite of this, so I don't want it to cause you worry, but I thought it might be useful to you - even if it's just in forming a postscript or something on our time together.

I write back,

I am so very sorry to read this. This is actually interesting timing because I am just writing about how my emotions played into the research process and how I felt like I had to "shut up" or tone it down as I would typically react to these sorts of responses. I talk about wanting to reach out to each of you, and offer moral support, but feeling like I couldn't do this as it might compromise my research. Perhaps we might write together, one day ;)

Yes, I'd love to use this as a post-script, of some sort. Thank you for your offer.

Sam makes it clear we still have more work to do...

I will be forever grateful to Sam, Drew, Morgan, Rowan, Dakota, and Amy. I have learned so much from each of you. Thank you for being on this journey with me and making this work come alive.

Special thanks to *Jules!*

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Appendix A

Recruitment Poster for Student Participants for Listserv

GRADUATE STUDENT PARTICIPANTS NEEDED FOR RESEARCH ON ACCOMMODATIONS

A Study About Academic and Workplace Accommodations for Non-Visibly Disabled Graduate Students in Academia

I am looking for volunteers to take part in a study of academic and workplace accommodation experiences for current non-visibly disabled graduate students (e.g., ADHD, LD, or mental health disability) pursuing their Masters degree or PhD doctorate degree.

You would be asked to participate in an “asynchronous” (you don’t have to be online at any particular time) private on-line interview blog for a six month period. Your participation will involve approximately 4-8 hours of time (in total), depending on your interest in this study.

In appreciation for your time, you will receive a \$25 Chapters gift card.

For more information about this study, or to volunteer for this study,
please contact:

Nancy La Monica

School of Geography and Earth Sciences

416.560.9166

Email: lamonican@mcmaster.ca

You can find more information about the study here:

gradstudentaccess.wordpress.com

This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board and York University’s Ethics Review Board