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Disability, advocacy and coping : an autoethnography on non-visible disability

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DISABILITY, ADVOCACY AND COPING:
AN AUTOETHNOGRAPHY ON NON-VISIBLE DISABILITY

A Thesis

Presented to

The Faculty of the Department of Communication Studies

San José State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

by

Dana L. Morella

August 2008

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ABSTRACT

DISABILITY, ADVOCACY, AND COPING: AN AUTOETHNOGRAPHY ON NON-VISIBLE DISABILITY

BY DANA MORELLA

This thesis explores the notion of non-visible disability in academic settings.

Students with non-visible disabilities, such as learning disabilities, mental health conditions, and chronic pain, often require accommodations to learning environments in order to thrive. This study explores how non-visibly disabled students perceive and respond to times when they do not receive accommodations or when they feel failed by their own and others' advocacy.

Through autoethnographic exploration and in-depth participant interviews, this study reveals coping methods used by non-visibly disabled students. The findings contain useful information that will help researchers, teachers, and non-visibly disabled students to enter into dialogue with one another and resolve perceived threatening or dangerous situations for both students, teachers, and school officials.

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CHAPTER ONE:

INTRODUCTION

Difficulty, understanding, and empathy

“Damn it! I can’t believe this doesn’t work!”

Slam! My fist hits my desk, and, almost instantly, I am filled with remorse as now my hand is throbbing. I quickly realize that this is not my desk: it’s the property of San José State; I share it with another graduate teaching associate.

“What’s wrong Dana?!”

I forget that Melissa, a much more experienced and smarter GTA is in the room with me. Well, at least it’s not *her* desk.

“This stupid fucking website! I have to access these journal articles for class and they don’t work with my reading software!”

“When is this due?” Melissa says thoughtfully.

“All I want is to be able to do my homework like any other grad student! Shit... like any other undergrad!” I say this, trying to disguise the defeated tone in my voice as it slowly morphs into helplessness and swells from my voice box to the top of my head. My eyes close and the tears roll down my face. I try for a moment to bite my lip and save face in front of Melissa, but it’s no use.

“Maybe I have the articles; I took this class last semester and...”

“No! Even if you have them they won’t be in a format I can access. ”

Geez, what a downer I am! Poor Melissa is just trying to help. I just don’t have the emotional energy to walk her through all the steps necessary for understanding. I

cannot tell my story right now, though I know if I could summon the strength and the patience to describe how my dyslexia makes it impossible to read more than a paragraph, how my reading software is the only way I can get through anything more than a page, and how the accommodations I have to ask for are sometimes denied, she would be a willing listener. If I had the courage and the will to tell her about the long process of getting materials OCR'd (put through a process of "optical character recognition") by the Alternative Media Center (AMC) for my software, she would hang on every word. I want to tell her. I want to tell her about how I could print these articles out at home, using my own expensive ink (I've already gone through two cartridges this semester), take them to the AMC to be OCR'd, drop them off, hear I won't get them in time, listen to excuses about how the other, "more disabled," students who don't have reading disabilities but physical disabilities trump my measly dyslexia, all while I watch the student workers of the AMC play online cricket instead of scanning materials for students like me. Then to complete the story, I'd tell her about the extension I'd be forced to ask for from my teacher and how it would kill me. Normal students don't get an extension because they don't have the book, why should I get one because I don't have my articles? I can tell her I can play the odds and go to class unprepared and hope I'm not questioned about the reading, but how likely would that be in a three-hour class with only ten students?

"Are you sure Dana? I can at least look..." Melissa puts her hand on my shoulder.

Damn it. My hand is throbbing.

"No Melissa. " There is no way to sound grateful through my grief.

“Maybe I can tell you about the articles? So that way you’ll have some idea of what they’re about. ”

No way. I don’t want Melissa’s interpretation of these articles, though I’m sure her findings are very astute. I want my interpretation of these articles!

“That’s nice of you Melissa, but I really need to read these articles myself. ”

“What can I do to help?” She is determined to get me through this.

I pause and rub my hand on my jeans and slide it in between my knees. I take a deep breath, hoping to regain control of my emotions. To my dismay, this only makes the tears come faster.

“I don’t know Melissa!” I sob. “Give me a new set of eyes, a new brain! I just want to read!”

I want desperately for her to know that beneath the sobs, the frustration, the curse words, I am grateful for every moment she spends dwelling in my situation. I am difficult only because my situation is difficult. Yet it is impossible for her, like all the others, to see me as grateful, only difficult.

When we think of a “disabled person,” we usually think of someone with significant physical or perhaps cognitive limitations. These areas of disability have been widely researched in the social sciences (MacKay, 2003; Williams & Collins, 2002; Molloy & Vasil, 2002; Smith, 2000; Ruiz, 1995a; Ruiz, 1995b). Though these studies are valuable in our understanding of visible disability, they leave unexplored those disabilities we cannot see with the naked eye. Non-visible disability includes conditions

that are not obvious to others or that require the disabled person to disclose her/his disability, such as learning disabilities, mental illnesses, auto-immune disorders, chronic pain, and so forth.

Disability has been the subject of many research studies in the past decade, most in education and disability studies. This research separates non-visible disabilities, which are often not perceived to be physical, into many categories including: invisible disabilities (Gerber & Price, 2003), organic disabilities (MacKay, 2003), learning difficulties (Rodgers, 1999), behavioral disorders (Heiman & Kariv, 2004), emotional disorders (Heiman & Kariv, 2003), hidden disabilities (Hurt & Gonzalez, 1988; Kravets, 1997), and academic difficulties (Heiman & Kariv, 2004), just to name a few. Yet most researchers refer to disabilities related to academics as learning disabilities or “LD” (Poplin & Rogers, 2005; Skrtic, 2005; Price, Gerber, & Mulligan, 2003; Laufer, 2000; Wilson, 2000; Kirby, 2004).

People with disabilities face many frustrations in their lives that their non-disabled peers do not, yet for those who live with non-visible disabilities, these frustrations often become critical threats in the context of education, specifically post-secondary education when parents no longer speak on behalf of their children and students must self-advocate (Kravets, 1997). Though many college campuses have disability centers that act as resources for both visibly and non-visibly disabled students, college can pose difficult situations for the non-visibly disabled student to negotiate. Not only must s/he barter accommodations with teachers and facility centers (Cornett-DeVito & Worley, 2005; Heiman & Kariv, 2004) s/he must take placement tests

(Kravets, 1997) and s/he must decipher and negotiate other cultural and social artifacts such as signage, spatial limitations, parking, and directions--all of which is complicated further by needing to access all these during "business hours," irrespective of the student's work schedule (Siminski, 2003, and Rodgers, 1999). However, there are other areas of frustration and accommodation researchers have not addressed, such as what students do when their accommodations are denied by their institutions or teachers; what happens when the disability resource center cannot meet their needs; how they respond to an advocate who has failed them in some way; and whether, when and how these students seek legal action (as well as the outcomes of seeking legal action).

As a non-visibly disabled graduate student myself, all these issues concern me. My interest in this topic was born of selfish interest; that is to say it was born of my own frustrations with my campus disability resource center, failures to reach mutual understandings with my counselors, and the disappointments I experienced the times I thought people who were my advocates failed me. However, through my research, my writings, and my interaction with both disabled and non-disabled peers, my interest has undergone a metamorphosis. I have been part of a non-visibly disabled culture for my entire academic career and not known it. Not only have other non-visibly disabled students on this campus faced similar frustrations, but other non-visibly disabled people have told me their stories of pain, frustration and, at times, failure in academic and workplace situations.

I have come to realize that the outcomes and implications for those of us with non-visible disabilities affect us much more than I had thought. The very vernacular we

use to describe those with non-visible disabilities, the very language we use to describe ourselves and the words we use to ask for help are much more dangerous and full of contested meaning than we realize. We have learned that we are “mixed up,” “difficult,” “special,” and “broken,” that we “learn wrong,” are “slow,” and that we are, in fact, hopelessly “disabled,” often with no medicine, no treatment, and no cure.

Buy this book and never worry about dyslexia again!

Bling, bling, bling! Ruby shows me her brand-spanking-new engagement ring. I learn the good news over dinner. So it is with light hearts that we enter the Borders bookstore to pick up a little post-dinner reading about trendy wedding locales and the latest fashion in bridal gowns. Ruby has been my friend for quite some time and is very familiar with my thesis on disability. She has endured more than one of my proverbial “soap box” speeches and has been quick with a joke to lighten my spirits at my frustrations with school. We snicker and giggle as we sashay past the “serious” reading sections of history, medicine, and education that seem so irrelevant today. Today is for fun. Today is for looking at pictures and cooing at the idea of Ruby in a bridal gown.

As we walk side by side through the store, Ruby stops quickly; something has gotten her attention. With an inquisitive look on her face, Ruby holds up a book to show me: *Dyslexia: The Miracle Cure*, by Wynford Dore (2006). Without thinking and without a word, I rudely grab it from her hand.

The words “shut up” escape my mouth.

For a moment I remember the old rule: Never judge a book by its cover. Maybe this isn’t as bad as I think. Maybe this person really knows there is no such thing as a

cure for learning disabilities and certainly no miracle cure for dyslexia. Maybe this person meant it rhetorically, sarcastically. Maybe this person used that title because s/he wanted to call into question the idea of a cure. Maybe this person just used that title to sell books. But then an orange star sticker in the corner of the book catches my eye. “Also covers ADD/ADHD!”

I stare at the title. These words are printed clearly (obviously by someone who is not dyslexic) on a small chalk board that a child holds in front of his face. It occurs to me that this Wynford Dore might just be out to exploit the desperation of parents of dyslexic children.

Seriously? I never thought I could conduct a rhetorical criticism on, literally, the cover of a book. But here I am, forgetting about my friend’s happy day, falling into a frenzy of thoughts. I think of how much this pisses me off. I think of the passively ignorant but well intentioned parent of a newly diagnosed dyslexic child who will pass this display stand and consider the discovery of this book serendipitous. I think of the sadness that parent will experience in the coming months after learning there is no cure for dyslexia, or ADD, or ADHD. I think of the false hope this parent will instantly feel just by seeing this book’s cover. I think of the child of this parent, the children of all the parents who have purchased this book, who, after seeing just its cover, will know there is something wrong with them. I think of the frustration and self-denial these children will have in their coming years. I think of all of this, and I want to cry.

How do I even begin to examine this?

Who is this author?

What is his/her authority on this subject?

How do I negotiate what this means?

Is this book even worth opening?

Should I complain to the manager?

How do I...

“Do you know who he is?” Ruby asks innocently.

My attention snaps back to her. After staring at this book so intensely it would seem obvious that I have at least heard of this person before.

“No. ” I say, still distracted. “Do you Ruby?” Taking a shot in the dark...

“No. I just thought that you did since. . . ”

“You know this kind of shit just pisses me off! Just pisses me...” Her ring catches the light and I remember why I entered this store in the first place. “Forget it,” I say as a smile slowly crawls back onto my face. She is a good friend and there will be other times for her to listen to my rants and diatribes about disability.

“Let’s go plan you a wedding!”

The outcome of these expectations, these beliefs, this language that we use to describe disability run deep in our culture, both in and out of the context of school. Our culture creates a double bind for non-visibly disabled people. As opposed to a dichotomy where two distinct categories are mutually exclusive and/or opposing, a double bind is a situation where one values or is called to act in two conflicting ways. With disability, the double bind exists on many levels but the first way in which we

encounter this double bind is with the myth of disability and ability as discrete categories. Non-visibly disabled people are often seen as able bodied. While non-visibly disabled people may not need assistance walking, seeing, hearing, or with dexterous activities of daily living such as showering, dressing, or brushing our teeth, we may need assistance with other parts of daily life. For example, a dyslexic or dysgraphic person may need help reading signs, though s/he does not have any vision impairment; a person who copes with chronic pain may need assistance up stairs where there is no elevator available though s/he does not use ambulatory aids such as a wheelchair or walker; a person who struggles with dyscalculia may need help calculating an eighteen percent tip at a restaurant.

These situations occur everyday, and, everyday, the non-visibly disabled find ways to cope without formal accommodation, or, at times, formal diagnosis. Non-visibly disabled persons are expected to behave just as their non-disabled peers do; holding doors for those who use ambulatory aids, leaving the handicapped parking spaces and bathroom stalls open for those for whom they are designated, and helping those who have manual (hand) related disabilities with simple tasks like putting a dollar in a vending machine. Yet when the non-visibly disabled disclose their disabilities or request assistance, often they are met with animosity, disbelief, and denial. This may happen when a person who copes with chronic pain requests assistance with mobility, when a dyslexic person requests access to reading resources typically available to the blind, when someone who copes with depression requests an extension on class assignments, or when a person with a speech impairment refuses to speak in front of a group or asks someone

to speak for her/him. These people must advocate for themselves in these situations or deny their disability. They are expected to succumb to social pressure to value what physical ability they do have, and, at the same time, expected to perform tasks impossible to accomplish without assistance or accommodation.

Often times this can create hesitation on the part of the non-visibly disabled to seek out accommodation and assistance as this usually requires some kind of inquiry or testing in their particular area of discomfort and struggle. After this testing is complete they are formally diagnosed and are given a label. This labeling can have a very negative effect upon the non-visibly disabled person, yet it is the only way they are able to pursue accommodations and assistance. Many non-visibly disabled people suspect they have learning disabilities or other disabilities they have never sought help with, for fear of being labeled. I did not receive my own formal diagnosis until I was 23, though I had suspected I was dyslexic for years. I resisted testing for learning disabilities because I did not want a label (and the stigma that came along with that label) to follow me through my academic career. Yet, when I was tested and diagnosed, I felt a profound sense of relief since now my flaws had a name. I knew I could seek out others like me and begin to cope. This mixed sense of relief and dread further complicates the double bind that characterizes non-visible disability.

Interrogating this double bind that non-visibly disabled people find themselves in is imperative for both scholars, teachers, students, and leaders to implement social change in our communities. The double bind calls us to value what perceived powers of ability we have and how we use them (i. e. , use them for good--holding a door for someone in

a wheelchair--and not for evil--beating up someone physically weaker than us and taking her/his valuables) and also distinctly acts to have us efface the realities our bodies and minds know to be true. These disabilities alter our embodied visual, emotional, academic, mental, and spiritual selves. This interrogation must look at the behavior patterns, communication patterns and language that constitute this reality. If we do not interrogate these practices, we cannot change outcomes, identities, or cultural phenomena problematic on so many levels for the non-visibly disabled.

Impressing Preston

“If you would have told me when I was in high school I’d be teaching college, I’d have called you a liar. ”

Preston smiles at me from across the table. “Why is that?” The corner of his mouth slides up to one side as though he knows something that I don’t.

“Well, I almost didn’t graduate from high school. I was failing so many of my classes no one, even my parents, was sure if I was going to make it. My parents did everything they could, but no one told them I might be dyslexic. If they knew, I’m sure they would have tried to help me instead of punish me. ”

Preston shifts in his chair and looks at his plate. He pushes his peas around with his fork. This concerns me. Our relationship is only two weeks old, and I’m worried that this news has lowered his opinion of me. I try to reassure myself and remember that I’ve told this story a hundred times.

“What is it? Does that bother you?”

Silence.

“Please tell me Preston. ” If I’m gonna get dumped because of my dyslexia, I won’t wait to hear it. I want to know now. It wouldn’t be the first time. I’m ready to fight, ready to make a scene if he rejects me for my disability.

“I probably shouldn’t tell you this--since you’re so educated, it might lower your opinion of me--but I didn’t graduate from high school. I got my GED. ”

I’m stunned. My turn to be silent. I was ready to throw my drink in his face and storm out, and now all I want to do listen. He tells me his story. The same story that I have, that all my dyslexic friends have. The one where we don’t know what’s wrong with us and end up fighting with parents over homework. He missed Nirvana’s final show before Kurt Cobain’s death because he got a D in algebra.

As I listen to him, I realize our stories transcend physical attraction, transcend friendship and trivial perceptions of one another. Our connection is on a much different, deeper level. We know rejection, failure, and self-denial, as well as the guilt and self-loathing that comes with it all. We understand one another in such a special, familiar way. We understand the double bind (though we’d never call it that) that dyslexia brings. We know both the security and the stigma that our diagnoses mean for one another. For a moment I attempt to verbalize this, but there is no word, no name for this type of understanding, this connection.

This is a date. I should be more concerned with how much garlic I’ve eaten when he leans in for a kiss, but I’m not. I’m thinking of my thesis. I want to tell his story. How do I work that into my research? I know now that before I am a researcher and a scholar, I am a storyteller. His story brings comfort to my soul. What I wouldn’t

have given for this comfort back in high school: The fights it would have saved. The hurtful words that can't be unsaid. I want to seek out and tell the stories of all who want their stories known. Stories of people, like Preston and me, who just want to be understood.

These stories and research have led me to my research questions. First, how do non-visibly disabled students perceive discrimination or unfair treatment? And, second, how and when do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated? This thesis will incorporate review of published research, inquiry and analysis, as any thesis would. Yet my thesis will also contain other elements that are vital and crucial to the study: Understanding of and respect for people with non-visible disabilities. Not only will I tell my stories here, but also the stories of others who have been marginalized, swept aside, forgotten, hurt and sometimes helped by the process called American education. Through the processes of literature review, autoethnography, and in-depth interviewing, I will gather and share these stories so that we may research the social and scientific phenomena, and cultures, that create and reify such stories—stories of good people, smart people, people who are not unlike ourselves, but who have been hurt, and in some instances, helped by labels of non-visible disability.

These stories will not only address the double bind of non-visible disabilities, but also the coping skills of those who face this culture of disbelief (Fraser, 2007). These stories—my own and others'—will include how we “out” ourselves or are “outed,” how

we respond to the struggles and roadblocks we experience with advocates, and how we struggle with self-acceptance.

Chapter 2 reviews extant research on disability and communication, including attention to the history of studying both visible and non-visible disabilities. I also include literature from other areas of scholarly research, though they lack the focus, and sometimes the values, of communication scholars. After I flesh out major themes found in communication studies and out of communication studies I examine seven themes that cut across both sets of research.

Chapter 3 explores the method for this study—a combination of autoethnography and in-depth individual interviewing.

Chapter 4 reports findings collected in participant interviews. Here stories of participants are told and grouped into meaningful categories. Autoethnographic data is also weaved into the stories in this chapter.

Chapter 5 discusses what the stories told in chapter 4 mean for researchers, teachers, and students. Suggestions for future research are also discussed here.

CHAPTER TWO: LITERATURE REVIEW

To begin our investigation into disability and communication, we must examine existing research both within communication studies and outside of our field. Though I am a communication studies scholar who focuses on disability (and not a disability scholar who focuses on communication), we must acknowledge areas of research not within communication studies that have made progress in the examination and analysis of social artifacts and phenomena that create societal norms surrounding disabilities. This exploration and analysis will surface research questions: First, how do non-visibly disabled students perceive discrimination or unfair treatment? And, second, how and when do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated?

This chapter is an overview of the published scholarly work on disability and autoethnography from communication studies and other fields such as disability studies, social anthropology, and education. After reviewing this research I have found areas that have not been studied before, and it is my intention and my calling to conduct further research into precisely these areas so that scholars, teachers, and students can begin to cope with and understand non-visible disability. For example, I found the voice of people with disabilities was infrequent or missing. Though a few of these studies included interviews, it was often with caregivers of visibly disabled individuals (e. g. , Rodgers, 1999) and had little to do with education and the difficulties public education held for the non-visibly disabled. There was also no information on how students coped

with not only their disability, but the threatening situations they experienced in public education.

Research outside of communication studies

There is a lot of literature that attempts to examine disability from the vantage point of the disabled, yet it does not exist within the boundaries of communication studies research. Research outside of communication studies is more comprehensive. This research can be approached by exploring three salient themes: ADA and workplace concerns, accommodation, and recreating/reconstructing disability. These themes help us as scholars and teachers more fully understand disability from the vantage point of the disabled and the problems that people with disabilities address. Through these readings, we can see the risk involved with disclosure and the need for protection.

The Americans with Disabilities Act and workplace concerns

The Americans with Disabilities Act of 1990 (ADA) provides protection from discrimination for people with disabilities. However, this document falls short of the needs of many disabled people. Wording of the ADA poorly defines disability and requires accommodations to be “reasonable,” yet it is unclear who decides what reasonable accommodations are and how they will be implemented (Braithwaite and Eckstein, 2003; Fraser, 2007). This theme in the disability literature focuses on the workplace as opposed to school. For example, Gerber and Price (2003) justify their research on work as opposed to school due to the fact that many non-visibly disabled

students who are frustrated with school choose to join the workforce instead of pursuing post-secondary education.

Research in this area of disability is greatly concerned with civil rights and discrimination and less with mutual understanding (Kirby, 2004; Ho, 2004; Gerber and Price, 2003; Price, Gerber and Mulligan, 2003). Discrimination is hard to prove and “civil rights” can be a slippery term; for example, learning disabilities can be construed as mental retardation (Gerber and Price, 2003). Here we see that disclosing a non-visible disability, or coming out, can be very dangerous (Kirby, 2004; Ho, 2004; Gerber and Price, 2003; Price, Gerber and Mulligan, 2003). If a person does not disclose his/her disability at the time of hire, and performance becomes an issue, an employee coming out may be a matter of too little too late to save his/her job (Gerber and Price, 2003).

These studies are a good starting point to shift the study of non-visible disabilities from the academic setting and into mainstream culture. I am greatly disappointed that these scholars and researchers do not call out the choice to work instead of pursuing post-secondary education for non-visibly disabled. How many of these people chose to work because they felt higher education was not an option for them? How many of these participants thought a post-secondary education would be a safe place for them and would benefit their lives as their non-disabled peers do? Scholars should be focusing their research efforts on creating dialogue between disabled individuals, and non-disabled peers or, more importantly, on advocacy, action, and what happens when advocacy fails.

The DRC, EOC, and AMC

Deanna, my committee chair, had what she calls a “good” meeting with the Disability Resource Center (DRC) and the Equal Opportunity Center (EOC) rep on campus. They proceeded to enlighten her about all these wonderful things that can help make my life so much easier.... like Kersweil, the Alternative Media Center. Oh... my.... God!! Seriously, I have been trying to make those things work for years now! Kersweil is a fancy-schmancy reading software that costs \$5k, but I could use it at school for free as long as I do my studying during the hours that are convenient for the AMC: Monday - Thursday 7AM-6PM. Fabulous, I guess dyslexics can’t work during the day. Who thought those hours were a good idea? Then there’s Sara at the Alternative Media Center (AMC) who doesn’t return phone calls and then claims she never got emails or voice mails. She must have picked that up from Ann at the DRC. After chasing her around for a few weeks, I finally got a chance to sit down with her so she could show me Kersweil. She couldn’t answer any of my questions. The graduate readings were too long and needed to be saved and converted. She had to call a student assistant over to help her. Yeah she’s a real resource for me.

Sigh. This is a huge setback. Now I have to go back and school Deanna on my history with accommodations and all these fancy gadgets that are just pieces of shit waiting to be broken so SJSU can shell out big bucks to get them fixed. Now I have to go back to the start and tell her all the things that I have tried and failed with, all the things that work and don’t work. I have to tell her many, many things. Things that the

people in her meeting should have known and disclosed. Things that should have been documented in my file. Things people who have worked with me for the past year should know. Things that I shouldn't have to keep telling people over and over and over. Non-disabled teachers and staff should know that students have exhausted their resources by the time they've reached a crisis like this. I'm the dyslexic. Why don't I get to come up with the big ideas around here?

Accommodation

Studies exploring accommodation look largely at college students with hidden disabilities and their willingness to seek help in class and within team based learning settings (Skrtic, 2005; Heiman and Kariv, 2004. ; Gregg, et al. , 2002; Harman-Hall and Hagga, 2002; Sweeney, et al. , 2002; Treise and Wagner, 2002; Laufer, 2000; Kravets, 1997; Penrose, 1999; Rodgers, 1999). Within these studies, we can see the inequities that exist concerning accommodation in academic settings. Students with non-visible disabilities struggle with many aspects of college both in and out of the classroom. These struggles include students not being made aware of disability resources available to them (Kravets, 1997), schools responding to mandates rather than individual students (Skrtic, 2005), poor definitions of learning difficulties and disabilities (Rodgers, 1999), and learning disabilities viewed as social deviations by those who hold positions of power (Siminski, 2003). The problem is that these studies ignore the emotional needs of the student. It is impossible to succeed in an environment where one is not validated.

The right to be righteous

I can't explain it – this sense of self-validation and determination. I know I'm right, and I refuse to quit. I know what I'm feeling is valid though others seem to think it's not. I know what I know and it seems to have become my mission to show others what I know. I can't explain it. I am strong in knowing I am right, but I am humble at the same time. I suppose I am struggling to package this knowledge in a way that the scholarly community will accept. Funny, they are supposed to create knowledge yet they are the last ones to get it.

I'm sick of the pompous attitude of the academy. What sickens me even more is that I find myself bowing to their demands and trying to re-work, re-phrase, re-think, remold my ideas into some abstract and offensive form that they finally consider worthy of higher thinking.

These studies call out the negativities and frustrations that many non-visibly disabled college students face. The authors use largely critical theories and methods, such citing non-visible disabilities as an extension of the emancipatory paradigm (Rodgers, 1999), employing “third way” which engages local educators and community stakeholders in dialogue (Skrtic, 2005), advocacy and action (Kravets, 1997), disability as social phenomenon (Siminski, 2003), and other phenomena such as students desire to look competent versus being more competent (Harman-Hall and Hagga, 2002). Faculty members are more comfortable with accommodations that don't require anything on their

part, like extended time on tests, but tend to feel more uncomfortable with accommodations that require time and effort on their part (Sweener, et al. 2002). Yet this attitude of minimal accommodation does not help anyone in the long run and certainly acts as a barrier towards mutual understanding, which is necessary to better the situation for non-visibly disabled students.

Accommodation is a very important concept in the culture of disabilities. We cannot better understand disabilities without examining this process, yet accommodations are much more than extended time on tests. There is great meaning that is constructed with accommodation. It is this meaning that is created and how it shapes both students and educators that needs to be further examined.

Recreating/reconstructing disability

The third theme seems to branch out into more new territory than the previous two. Here scholars draw largely from social construction models and pose questions and theorize about how to reconstruct society's perception of both visible and non-visible disabilities and what that reconstruction would look like. There is also discord in this area as well since many scholars disagree about social problems that penetrate the disabled community. Poplin and Rogers (2005) suggest that the field of disability studies should begin this process by overcoming its own low expectations for its members. Armstrong (n. d.) suggests there is no such thing as learning disabilities since no chromosome or tattoo exists that defines them as such. Armstrong also put out a call for stories of learning disabled students who were now home schooled so we can focus on how and why our school system has failed. Dudley-Marling (2004) questions

the pathology of learning disabilities and suggests that learning is not in the head but in relationships. One cannot be learning disabled all on his/her own; it takes a set of circumstances to transpire just so for it to happen. MacKay (2003) argues that medical ideology equals hegemony and oppositional reality, while Molloy and Vasil (2002) call for us to examine the personal pathologies that we have been given.

Though the solutions vary within this body of research, authors have managed to bring to light the nature of the problem in fascinating ways. One of the most common descriptions of this problem is how we challenge labels we have been given, how this morphs into stigma (Armstrong, n. d. ; Dudley-Marling, 2004; MacKay, 2003) and how stigma gives rise to self fulfilling prophecies (Kalyanpur and Harry, 2004; Dudley-Marling, 2004; Molloy and Vasil, 2002; Penrose, 1999; Ruiz, 1995A; Ruiz, 1995B).

One of the more fascinating sub-points of the recreation/reconstruction theme is the idea of the myth of independence (Kirby, 2004). The argument here is that no one is completely independent and that our able bodies will at some point fail, thus proving we are only temporarily able-bodied (TABs) (Kirby, 2004). We have constructed a way to view ourselves as independent through constructivism and reductionism (Poplin and Rogers, 2005). Scholars who examine the idea of dependence on others look at it from a visibly disabled viewpoint. Observing the inequities of the visibly disabled, Rodgers (1999) uses the idea of emancipation to discuss the need for social justice for those with disabilities. The emancipatory paradigm is used to demand justice and support for the visibly disabled. Independence can be seen not only in terms of physical ability but also academic achievement, memory skills, financial security, marital status, and social skills.

Bartering for support

I want to be recognized as a competent adult. I want a viable system where I can sustain myself and not be a burden to others because I am disabled. I was never disabled until I came to San José State, I was just dyslexic then. Now, somehow I've become a minority. People in wheelchairs don't ask other people to carry them around. Why do I need to ask other people to carry my academic weight? I was advised to find a support system outside of school, barter and trade with others. I even had to barter with friends to proofread these very pages—all the commas and headings I cannot recognize. Some kind soul reads my paper and I baby-sit, wash their car, and quiz them on their thesis defense. Usually they want me to take them to coffee or lunch, but I have no money to support that. My friends say they support me but then tell me they cannot get involved. Why? Why can't the DRC help me with this? Do people in wheelchairs barter for their mobility? Why do I have to be the burden?

Writings in this area end on a largely critical note, which is the plea for mutual understanding by having the reader become an active participant in the subject rather than a passive vessel for the knowledge of the pages s/he has just read. Within research dealing with independence, there is a call to action. Though the action that the reader is called to varies from author to author, the sentiment is clear: Interrogate your own biases, remake your own definition of disability and independence, be careful who you speak for, and actively seek justice within your own workplaces and institutions (Poplin and

Rogers, 2005; Dudley-Marling, 2004; Kalyanpur and Harry, 2004; Kirby, 2004; Molloy and Vasil, 2002; Williams and Collins, 2002; Smith, 2000; Penrose, 1999; Ruiz, 1995a; Ruiz, 1995b).

Though these studies are the most empowering from a disabled point of view, they still fall short of the goal of mutual understanding. Scholars focus largely on refuting the idea of diagnosis, accommodation, and the formation of the neuropathways that create conditions we call disability. If we were to start society over again, perhaps these would be achievable goals, yet they are incompatible with societal values that are well established.

Research in Communication Studies

Within the field of communication studies, research on disabilities is limited and insufficiently theorized; that is, disability is seen as uncomplex and is not recognized for all the ways it is problematic. Communication studies fails to look at the meaning making involved in being disabled and interacting with those who have been labeled or identified as disabled. Most of the published materials in this vein within communication journals are in communication education and focus on college education (Cornett-DeVito and Worley, 2005; Braithwaite and Eckstein, 2003; Wilson, 2000; Stromer, 1983) though some focus on K-12 (Hurt and Gonzalez, 1988). The research that exists within the context of college helps us understand the polarizing positions that teachers find themselves in when wanting to accommodate students but also wanting to preserve the academic integrity of their curriculum (Cornett-DeVito and Worley, 2005; Braithwaite and Eckstein, 2003; Wilson, 2000); this points to another underexplored

double-bind. The research in communication studies can be broken down into three groups; communication apprehension between the non-disabled and the disabled, looking at disability as culture (having the most research and the most in-depth analysis), and autoethnographic research.

Communication apprehension between the non-disabled and the disabled

Research on disability in communication studies appears to have been strongly influenced or framed by the instructional communication focus on communication apprehension. Communication apprehension here is studied between non-disabled children and adults and disabled children and adults. Mostly this research focuses on the discomfort and tension non-disabled people have when discussing disability with those who are disabled. Though some of the studies collect data on how the disabled individuals feel in this communication process, though the focus here is largely on the disability itself being the communication barrier. This is problematic as now disabled children see themselves as what's "wrong" in the situation. Education becomes an unsafe setting for them.

Though there is much missing from this work, it does have value. We learn here about the uncertainty non-disabled individuals feel when entering into communication with people who are visibly disabled and who may, as in the case of Deafness, speak another language (for example, American Sign Language) or use a form of communication unknown to most non-disabled peers. This line of research establishes the existence of not only communication apprehension of both disabled and non-disabled individuals, but also helps bring to light ways in which we might begin to overcome this

tension, for example by having social exchanges with peers at a young age (Hurt and Gonzalez, 1988).

Culture

More recent communication studies research has taken a more useful perspective towards disability: looking at disability as a culture rather than a barrier.

Communication studies that relate disability back to culture in some way are more numerous than those that relate disability to communication apprehension. These studies focus more on how disabled people manage assistance and helping behaviors (Braithwaite and Eckstein, 2003; Thompson and Cusella, 1988; Stromer, 1983), negotiate accommodations and advocacy (Cornett-DeVito and Worley, 2005) and how we look at disability as individualized accounts of disability just happening or appearing rather than as familial or inherited traits (though many people don't want to see them this way), which is precisely what many disabilities are including learning disabilities, many mental illnesses, and so forth, are. They are genes passed to us by one or both of our parents (Wilson, 2000).

Communication studies of culture normally focus on a set of people in a given group. I make the argument here that disability is a culture; though these people are widely dispersed, and may not know one another, they hold the same traits, values, and frustrations. These studies may not call disability "culture," but the focus is less on the apprehension that people feel communicating about disability (though that is mentioned) and more about the shared values, frustrations, and forms of advocacy and self-advocacy that are used by many disabled people. Though the idea of communication and

apprehension are still present in this research, the meanings go much deeper than communication apprehension. Communication apprehension stops short of legitimacy, validation, and acceptance of disability. The culture of disability is does not fall into the typical definition of culture. We are a culture of people who have had to address issues of identification, rigorous testing to come to such identification, outing this new identification to others in positions of power, and ultimately, we hope, self-acceptance. Each of these pieces of research contains elements of this more broad definition of disability as culture.

These studies all look at disability as problematic to the disabled person. We can see here what traits, behaviors, and social support cues disabled people find most valuable in their lives (Cornett-DeVito and Worley, 2005; Braithwaite and Eckstein, 2003). This is helpful in some very important ways: Non-disabled readers can understand ways in which to best help their disabled students, colleges, peers and strangers. Readers get to see situations from a disabled point of view, and this can help them re-frame how they would react the next time they find themselves in a situation where they must interact with someone who is visibly or non-visibly disabled, and how the disabled culture is approached or in some cases disregarded completely. Yet these research studies still fall short of the goal of mutual understanding. The focus of these studies is still on the disabled person and not on the societal values and cues that create environments where assistance is necessary for disabled people to thrive. Though communication and apprehension are still present here, the challenge to us as

communication scholars is to recognize this embedded culture of disability and how the disabled advocate themselves and their culture to others.

For example, non-visibly disabled students may place value on stories of conflict and strife with teachers. These stories are told, re-told and traded among this community. Students advise one another on which teachers to avoid at all costs, which teachers are the most likely to be open to accommodations, and how to go about approaching these teachers. Though these students have created meaning within their community it is important to examine how self-reflexivity plays a role in this process. When and where do students fault themselves? How aware are they of the situations that surround them? When do students back down from confrontation? Where do they dig in and take a stance? These questions are left unanswered by these researchers.

Autoethnography and self-reflexivity

One way for communication scholars to further interrogate and explore the notions of visible and non-visible disabilities is through a method that has been around for some time but is still quite controversial: autoethnography. The autoethnographic work I have reviewed is actually not on disability, yet I included it in my analysis as this is becomes very important when discussing situations of non-visibly disabled strife, especially when told from the perspective of the non-visibly disabled. Autoethnographic work is much easier to find in communication studies than is research based on disability of any kind. Though I have read quite a few autoethnographies in my preparation, I have only come across one that is related, even loosely, to disability: Fassett and Morella, 2008. I will unpack further implications of autoethnography in the method section to

this text; however, there are salient themes that cut across the autoethnographies contained in communication studies journals. These readings encompass notions of language, expression, identity and resistance to traditional standards of academic research, which will be expanded upon in chapter three.

The idea that words fail many groups of people, even scholars, is addressed in these readings (Jones, 2005; Gingrich-Philbrook, 2005; Banks and Banks, 2000; Ragan, 2000; Pelias, 2000; Pelias, 1997). All this is related back to the power of naming and that language is, in fact, constitutive. There is some notion in all of these autoethnographies and commentaries on autoethnographies that the language that is possessed by the writer is not enough to express his/her feelings, thoughts, and ideas. This can be seen in how scholars explore the experiences of losing a child (Jones, 2005), living a critical life (Pelias, 2000), performance (Pelias, 1997), or the frustrations and limitations of writing research other scholarly work (Gingrich-Philbrook, 2005).

The down side of finding what you love to do

I could walk away from all of this. Well... not really, but I wish so badly that I could. I wish I could be a receptionist for the rest of my life and love it. I wish I didn't feel academia was my calling. I'm on a mission and that brands me both as a student and as a teacher, like I cannot acknowledge an opposing point of view.

I'm mad not because people don't know what to say to me, but because society says that they shouldn't know what to say to me. Dr. Fassett says people don't live in

conflict very well, and that may be why I get so many “what do you want to do Dana?”s. At least she lets me be mad.

Communication studies is not a vacuum in which scholarship and knowledge happen. It is important for our field to embrace meanings, experiences, and the language of disability. Disability is evident in our society and communication studies is not exempt from this. Communication studies should be looking at how ableism is present and shapes what it means to be disabled rather than how to communicatively manage our interactions with those who we can see are disabled and those who are brave enough to disclose their disability to us. There is anger, frustration, and oppression that exists with the institutions we tout as enlightened and open to students from all walks of life. The institutions we struggle to get into, get jobs at, and are proud with which to align ourselves. It is pertinent that we conduct interrogations into ourselves, our pedagogies, and the cultural values of our institutions.

The response paper

I don't think this process is ever not going to be crazy making. We were assigned about 80 pages to read last week on social constructionism. The author of this reading spends a total of 4 paragraphs on disability including Deafness and in that time not only does he grossly misrepresent disability and mis-quote a Deaf activist with whom I am very familiar, he uses oppressive language by referring to them as “sub-species”. In

my response paper, which was limited to 1 page by the class requirements, I proceeded to let my opinion be known in no uncertain terms. My teacher hands back the paper with comments to be “more inclusive of the rest of the reading”.....NO!!!

First of all, I’m a grad student lady; you want proof that I have read it? Give me a test on the reading and move on - I’ll ace it. Secondly, this is not a comprehensive review of the material, it’s a RESPONSE PAPER! It is dangerous that we are reading someone who is putting hegemonic chains on people’s ankles and not to call him on the carpet. He uses oppressive, subversive language and which puts me in the most dangerous place I could be as a student. If I didn’t know her better I’d say this teacher is touting this reading because it’s reading. Look, books are not to be trusted. I learned that in 1st grade, and it’s still true today. She cannot think critically about the reading she assigns in her own class.

This is not to say that I have no respect for her. For some reason people think once I’m angry with a person I don’t respect them. Why is that? I don’t understand why we deny our emotions. People get angry and their parents, spouses, children, siblings and still love and respect them. This “lady” is very smart, much smarter and more accomplished than I will ever be. I know that. I took this class because I like the ideas she has and the compassion she brings to her emphasis in the field of communication studies, which as you may have guessed, is not disability. Yet she doesn’t seem to “get it”. I’m frustrated and, yes, outraged. And like it or not, that’s O. K. ! It doesn’t mean I can’t get along with others! My problems are not her fault, but for her to deny me the intellectual room to explore that with my peers does me harm.

I know I'm pissed and somehow this manages to take away from my credibility... like I'm more dyslexic when I'm mad. I'm an advocate and somehow this becomes polarizing. This is a heart-breaking, gut-wrenching, soul-stealing process, how am I not supposed to be emotional?

Self reflexive research includes not only autoethnographies, but also editorials and other forms of research where the researchers' or participants' positionality and privileges are named and interrogated. These kinds of stories create new meaning and are worthy of close examination (Jones, 2005; Gingrich-Philbrook, 2005; Banks and Banks, 2000; Regan, 2000; Shields, 2000; Pelias, 2000; Pelias, 1997). The self-reflexive studies that exist in communication studies fail to call out the situations that create problems for both disabled and non-disabled people. This research is very useful for recognizing the subjective within scholarly research, and how this subjectivity is fluid and moves throughout our lives (Pelias, 2000), yet it could go further. This kind of research can help us create better situations for others we communicate with everyday, not just the disabled.

Intersectional themes

These categories are important as not only are they salient in research both within and beyond communication studies, but all are concepts that are found in life outside scholarship and research, which make them much more meaningful and powerful. Though we may not realize these ideas are in play, such as language and resistance, they

are nonetheless there, and they are ideas that we all can stop and reflect upon, regardless of power, privilege or education.

For all the disagreements that exist in the research inside and outside of communication studies, there are three concepts that cut across the themes of ADA and the workplace, accommodation, and reconstruction and recreation: Language, resistance, and outside support. These concepts intersect in complicated and intricate ways, not only in the lives of people with disabilities but also with concepts that have been studied within communication studies. Language and resistance tie strongly into communication apprehension, while coming out, negative stigma, and social deviation have been studied in autoethnographies and studies of sexuality in communication, and advocacy and support have been widely addressed in relation to power and social justice.

Language

The experience of being disabled lacks its own unique words to describe it. Words like frustration, complicated, inconsistent, helpless, self-denial, and legitimacy have far reaching meanings. Though they are often used in describing disability, they are often used for other contexts as well. How do I describe words on a page? Ants on a white wall? Letters in alphabet soup randomly scattered about between peas and carrots? The headache you get from gazing too long at a loud paisley pattern on an ugly shirt? All these are correct, but much less than accurate. Words fail me.

Language is central to the discussion of non-visible disabilities. Whether the argument is that language is essential to learning and naming issues in non-visible

disabilities (Rodgers, 1999; Ruiz, 1995A; Ruiz, 1995B) or if the argument is that language is a misnomer and there is no such thing as learning disabilities (Armstrong, n. d. ; Dudley-Marling, 2004; Molloy, and Vasil, 2002), language is at the center: It is the crux of the argument. Language is essential for meaning making, and that is exactly the idea with which scholars are grappling. The way in which non-visibly disabled people make meaning is the very thing that defines them as disabled. It is key to gain mutual understanding between all visibly disabled, non-visibly disabled, and non-disabled peoples in order to begin social change.

Resistance

Resistance is a theme that can cut many ways. Often in the literature authors speak of the teacher's resistance to the student's accommodations, but it can exist in many forms on the part of the student, parent, or school administrator. Resistance is a key concept in all these articles; in some way the status quo is challenged (Poplin and Rogers, 2005; Dudley-Marling, 2004; Kalyanpur and Harry, 2004; Kirby, 2004; Molloy and Vasil, 2002; Williams and Collins, 2002; Smith, 2000; Penrose, 1999; Ruiz, 1995A; Ruiz, 1995B, Armstrong, n. d.). These authors take a stand in their research to say that what both visibly and non-visibly disabled people have been handed is not good enough for them to thrive. The workplace is an especially dangerous area for those with disabilities. Often employers reward based on output without examining the kinds of efforts people put into a task to achieve the same output or the extra steps that have to be taken to achieve the same outcome (Ho, 2004; Kirby, 2004; Gerber and Price, 2003; Price, Gerber and Mulligan, 2003). Even in education, there is resistance to the

accommodations that are given (or not given) to the non-visibly disabled (Poplin and Rogers, 2005; Skrtic, 2005; Siminski, 2003; Sweeney, et al. , 2002; Treise and Wagner, 2002; Laufer, 2000; Rodgers, 1999; Kravets, 1997).

Resistance also exists on the part of the non-visibly disabled. Rebellious acts, back talk and disruptive behavior on the part of students are often indicative of other issues students struggle with. Resistance to testing or even the curriculum itself may be present as well (Poplin and Rogers, 2005; Sweeney, et al. , 2002; Laufer, 2000; Kravets, 1997).

Outside Support

Once the non-visibly disabled person has come out, s/he often seeks outside support. This is often called an accommodation, but it can take many forms. Most commonly we see accommodation as extra time on tests, extensions of deadlines for academic assignments, and tutors for students who struggle with the material of a given course (Poplin and Rogers, 2005; Siminski, 2003; Laufer, 2000; Rodgers, 1999; Kravets, 1997). Yet accommodations can come in many more forms for the non-visibly disabled. Augmentative speech tools can be used for those who live with speech disabilities, screen readers and reading software can be made available to those who have reading disabilities, alternative methods of turning in work can be made available for those who struggle with chronic pain, and extra office hours and outside class meetings can help those who deal with psychoses and neuroses. The most important part of negotiating accommodations is to let the person with the disability decide what is helpful and meaningful for her or him so she or he is not under-accommodated and denied services

that would be useful or over-accommodated with access to services that do not help her/him (Poplin and Rogers, 2005; Skrtic, 2005; Heiman, and Kariv, 2004; Ho, 2004; Kalyanpur and Harry, 2004; Gerber and Price, 2003; Price, Gerber and Mulligan, 2003; Siminski, 2003; Molloy, and Vasil, 2002; Williams, and Collins, 2002; Laufer, 2000; Smith, 2000; Penrose, 1999; Rodgers, 1999; Kravets, 1997; Ruiz, 1995A; Ruiz, 1995B).

When formal accommodations from the institution are insufficient or fail the student, they may seek help outside the academic environment by bartering or paying for services that would be helpful to them. The danger in this is that the student entering into agreements without the protection of a larger entity. Exploitation and abuse are possible. Non-visibly disabled are left to ask favors from friend who they trust, though their friends may not be in a position to help them.

That's what friends are for...

"Let me read it!"

"No way, Maureen. You have enough on your plate, and this is seventy pages!"

"Dana! I'm your friend. Let me proofread the first three chapters of your thesis so you can go to your prospectus defense. The sooner you let me read it, the sooner you will get there. "

"But, it's not your responsibility to..."

"Just e-mail it to me. Let me worry about my responsibilities. Remember when you had no one else to proofread and you used that copy editor you found on the internet?"

“Yeah, that was a fiasco. Such a bad experience...”

“Exactly. You should let someone you know and trust proof it for you. ”

“Okay, Maureen. You’re right. ”

Having found myself in these kinds of situation where I have had to barter with, borrow from, and beg friends to grant me accommodations for school, it has led me to question what other non-visibly disabled students do in similar situation. Do they have better advocates that I do? Surely someone must have had accommodations fall through, what do they do? How do these students advocate for themselves? What happens when all forms of advocacy fails? These thoughts have led me to my research questions.

Research Questions

The extant research does not adequately examine the strife of students with non-visible disabilities when their disabilities, academic integrity, or work ethic is called into question. This leads me to my research questions: First, how do non-visibly disabled students perceive discrimination or unfair treatment? And, second, how and when do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated?

These questions can help us reach mutual understanding, not only by examining disability, but also by examining the reasons behind certain behaviors and attitudes displayed by disabled college students. Chapter three will provide more details about the participants of this study.

Given the gaps in the literature, it is imperative that we, as communication scholars, continue to examine disability and the communication phenomena that surround and constitute it. There are several methods to accomplish this, yet I feel strongly that the two described in Chapter three, autoethnography and in-depth interviews, are the most powerful ways to begin mutual understanding.

CHAPTER THREE:

METHODOLOGY

Autoethnography: Imperative to social justice

Privilege is a buzzword I have heard repeatedly in the academy recently. So many critical studies (Fassett and Morella, 2008; Fraser, 2007; Jones, 2005; Miller and Harris, 2005; Shugart, 2003; Wilson, 2000) call for us as scholars and people to recognize our own privilege as white, male, Christian, heterosexual, youthful, mature, able-bodied, and able-minded, privilege that allows us to settle into our comfortable lives as educators and authors and generally productive members of society. Though I am in the process of examining what all these categories mean to me and how I fit into them (not to mention how they shape me), I cannot help but realize one huge privilege I have that has been overlooked by these other names of privilege: autoethnography.

I have been braced for harsh criticism of my chosen method both by professors and scholarly articles and books, though I have yet to meet the scholar adamantly opposed to autoethnography as epistemic, as a way of knowing. This is not to say that I never will, nor that I am unprepared for such a moment, but I must recognize this as a privilege in itself. I have been fortunate enough to find myself in a graduate program that fosters this kind of research and knowing, and more importantly, fosters my growth as an autoethnographer. I have seen the calls for social change in the field of communication studies. I have participated in the conferences, written abstracts, and

engaged discussion panels, and I have conducted my own inquiry into how communication studies can participate in social justice, and I fail to see how this can happen without a method such as autoethnography. Without knowing the stories of those whose lives we wish to touch, how can we possibly know where to start? How can we begin to define social justice (or make calls for it) without knowing what social injustices look like? We need to hear from those who are suffering, downtrodden, marginalized, and the silenced. And we need to investigate our own assumptions, experiences, privileges and oppressions in order to interpret what they share.

These methods are the strongest way for me to address my research questions: How do non-visibly disabled students perceive discrimination or unfair treatment? And, how and when do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated? Though these questions could be answered to some extent through surveys or other methods, I would lose much of the rich descriptive qualitative data that is the focus of my study. Through autoethnography, I link participants' stories to my own. Though participants may not realize it, they share their stories with me in ways that parallel and lend themselves to autoethnography. Participants chose stories that illustrated the details of given interview questions. When a participant tells me a story to answer a question in the interview, and gives me permission to re-tell that story, it informs and becomes part of an autoethnographic narrative.

Introduction to Autoethnography

We all have epiphanies, some large, some small. We all have ideas, thoughts and experiences that make us stop and think twice about something. Yet without reflection and self-reflexivity, what we take from our ideas, thoughts, and experiences is greatly diminished. These points of discomfort and dis-ease are opportunities for learning and mutual understanding, yet without self-reflection, they pass us by as moments of conflict, embarrassment, or worse, opportunities to retaliate. Autoethnography invites exploration of these moments of discomfort, betrayal, rage, or the awkward or upsetting moment, the self-reflection upon that moment, and the opportunity to express what we have learned from these experiences. This is what makes autoethnography distinct, that it is all these things as well as a method. Through it, we examine theory, culture, and communication and the experiences of self and of others.

Autoethnography goes by a number of names (Lindlof & Taylor, 2002) including the new ethnography or postmodern ethnography (Goodall, 2000). “Each of these terms connotes a unique interdisciplinary heritage and set of writing practices” (Lindlof & Taylor, 2002, p. 288). Autoethnography is the use of ethnographic writings, that is the writing of lived situations or experiences that is generally free of jargon or technical language to examine cultural and societal norms and the interrogation of values through metacommunication practices. These narratives are writings of moments that are good examples of cultural situations to examine depending on the research subject (Jones, 2005).

Autoethnography has become more than a method; it is also a perspective that calls into question the readers’ own prejudices, values (both scholarly and political), and

ideally the readers' own power and privilege. Unlike research studies conducted using the scientific method, autoethnography deliberately calls upon the readers' emotions and personal experiences and thoughts in order to analyze ideas (Goodall, 2000). This makes autoethnography an appropriate method for communication studies. Autoethnography allows us to see how theory forms us and our cultural practices. Autoethnographic narratives are used by researchers and scholars (including me) as evidence and are themselves the subject of interpretation and analysis. Often it is the author's or researcher's own experiences that undergo scrutiny as opposed to aspects, or details of the experience of anonymous subjects. This can be difficult for scholars and researchers to read since there is no margin of error, statistical significance, or even description of participants. Reading autoethnography requires a shift from the positivist and post-positivist paradigms to the interpretive and critical paradigms. Many would say that autoethnography is part of the interpretive paradigm, as a means of understanding, with greater depth and nuance people's experiences. . In addition to I will discuss more in chapter 5. Though some scholars may not give much credence to the interpretive or the critical paradigms, it is essential to embrace (at least) some values from these paradigms in order to consume autoethnographic work; otherwise, autoethnography will appear as useless ramblings and emotional babble.

Readers must be ready to confront situations where emotion is central to ideas we examine. Readers must also be ready to embrace their own emotional and visceral reactions (positive or negative) to autoethnographic narratives. These emotions are what tie scholarly experience to human experience, though some argue that these two should

never professionally meet. The nexus of scholarship and humanity is what makes empirical, scholarly knowledge worth knowing. If what we know does not help, or prevent harm to, the human condition in some way, it is not worth knowing, studying, or interrogating.

Autoethnographic inquiry is beneficial to readers and scholars. Communication does not exist in a vacuum. Scholars, especially in communication studies, have the power to help others around us in everyday interactions. Autoethnography not only allows us to see how culture and theory influence us but it also allows readers to understand ways in which they can help others around us. It is the practical application of theory and the encouragement to make better situations for our students, colleagues, and strangers we interact with everyday.

* * *

Just words

“Ha!” A burst of laughter into my right ear startles me. My partner sits on the couch next to me. We are watching a Dane Cook stand-up special on TV. I miss the context of the joke; I only retain the punch line.

“They’re just words; they don’t control us. ” I repeat the words, if only to hear myself say them.

“That’s going into my thesis!” I smirk and whisper to myself as if I am letting him in on a stroke of genius.

Funny. I realize how they have. My attention drifts from the flickering blue light at the end of the room. “Disabled,” “dyslexic,” “special needs,” “accommodation,”

“special assistance software” – all of these words apply to me and my situation. It dawns on me how disempowering they are, and I wonder to myself how many times these words have fallen upon my ears, or worse, been spoken from my very own mouth. I use the oppressor’s language and I enslave myself. I am oppressor and oppressed all at once. I not only used these words, but I needed them. I used them to cue others into my lack of ability and legitimacy all at once. I latched onto them and formed my identity around them. I could not be a “student” without being “accommodated.” Yet this identity has stifled me too. It has limited me and forced people to judge my work on the legality of equality, and not the merit of my work as it stands alone.

These small, seemingly everyday experiences are low-hanging fruit, ready for picking. They surround us, though at times we may not realize it, and once picked they are ready for examination.

Limitations to autoethnography

There are limits to autoethnography. Perhaps the most concerning is that the author is using anecdotal evidence, often an experience the author has personally had, as the subject for analysis. Moreover, the same author is conducting the very analysis on his or her own experiences. This thesis does just that, conducts an interrogation into my own experiences for the sake of analysis. Objectivity is greatly valued in research using scientific methods. Subjectivity has been viewed as dangerous in scholarly research since it can cloud situations with emotion. This can lead to data mining, where the researcher only reports what he or she wishes to see. There is great concern about the

blatant embrace of subjectivity in research. However, all research is reported through the eyes and experiences of imperfect human beings; therefore, all research (in some form) is subjective, despite attempts to strive for objectivity especially when it comes to language. As we know, language is constitutive (Fassett & Warren, 2007; Stewart, 1995; Lakoff and Johnson, 1980), and words we choose and omit create and negate power.

Yet this does not address the controversial use of emotion in research. Emotion has traditionally been prohibited in academic research as it was feared emotion would dictate findings and contaminate data, yet is emotion that easy to separate from research? Positivist and post-positivist scholars argue not that we shouldn't care about research, but that emotion shouldn't affect our biases and findings in research. Yet biases are present even before the research is begun. Emotion is not often as explicitly stated in many forms of research as it is in autoethnography, but it is implicitly enmeshed with all researchers and their research. Furthermore, emotion does not mean that the researcher is unable to acknowledge, interpret, or respond to opposing perspectives. Authors often respond to one another in published journals and even conduct new research studies in response to criticism or critique. Does this not involve emotion? When researchers read anonymous peer responses, is there not a visceral reaction to criticism of ones work? Yet this does not stop scholars from publishing. Goodall (2000) likens research to sports but also notes that in research (unlike in sports) authors are given a second, third, and sometimes even fourth or fifth chance to make the point. Emotion is still attached to these narratives and the interpretation of these narratives, the opportunity to edit and

revise helps the author place emotional accents where they are most appropriate. As when two lovers argue, with time they are learn to consider the other's point of view, even though their feelings about the initial situation may not have changed; so, too, autoethnographers are able to incorporate multiple vantage points and circumstances.

I am angry! Hear me roar!

Anger does not negate me. It does not make me less intelligent, less thoughtful, less caring, less disabled. I am an intersection of all these things, and much, much more. Anger is often interchangeable with rage or abuse, yet these things also do not define me. Anger has gotten a bad wrap from society, it is the least respected emotion, the easiest to fake, the first to be dismissed or invalidated, and yet, we have all been angry.

Anger is the most transformative of all the emotions. It can be scary, yes, but change is scary too. We must learn to have both anger and reason and not to let one overpower the other. If we let reason overtake emotion, we are susceptible to propaganda, unethical rhetoric, and malicious methods of persuasion. If we let anger overtake reason we never reach compromise and never better our positions. Anger is what anchors us to our causes and give us the courage to rise out of our comfortable lives and create our own change.

It is complicated to negotiate both and further pulls me in my double bind. Often anger and reason are portrayed elegantly in different people. John Adams and Ben Franklin and Scarlet O'Hara and Melanie Watkins are excellent examples. Anger is euphemized as passion, but it is much more than that. Passionate people have anger, but

anger is passion for the unlikely or unpopular. Anger has long been a great divider, but it has much more depth and complication to that. Anger is the great uniter. It is not anger that makes a person dangerous; it is the inability to forgive.

In Freire's notion of praxis, anger is what gets us from reflection to action. Action is not simply meaningless movement but intention to change the world. Anger in these kinds of situations is a motivative force to help, not only ourselves, but others who we never meet. If I can change the status quo one iota for someone I will never meet, my action up on the world will have been meaningful.

This leads us into a situation where the author must be critically attentive of details; in other words, not only does the author need to be careful of what s/he says, but the author also needs to heavily weigh what s/he omits (Lindlof & Taylor, 2002). This means not only calling out what is not said but people's perspectives that are glossed over for the sake of making a point. Because ethnographic narratives can be emotional, the emotion is often blamed for "bad" judgments in writing for example the use of curse words. Often bad writing is taken as bad thinking, and bad thinking is considered bad research (Goodall, 2000).

However, some readers take generalizability for granted. It is not my job as an autoethnographer to answer more questions than I pose. It is the autoethnographer's responsibility to create editorial controversy by displaying the cultural phenomena or communication patterns that are problematic for the context of the writing (Goodall, 2000). This is not to say that autoethnography does not answer questions; however there

are some questions autoethnography is better suited to answer. For example, “So what? So you had a bad experience, why is that important?” and “Since you had an issue, does that mean it’s a problem for other people?” and “Didn’t you contribute to the problem?” Though autoethnography is not generalizable as far as research and sample groups, it does problematize ideas and situations that are swept under the proverbial rug by scholars and generalize the problems we encounter from isolated incidents to social injustices. Intersubjectivity (i. e. , the examination of, stories of participants at given moments in time) is at the heart of autoethnography. We can see the cultural flaws and strengths that are often overlooked and taken for granted by autoethnographers when viewed through the lenses of autoethnography. Concepts that are created and reified by culture can rapidly lose and change meaning. Since intersubjectivity is so vast when it comes to cultural norms, people who fall outside of these norms are quickly marginalized and silenced; moreover, not only do these people learn to accept their silence, they want it, and feel as if the silent margin is their rightful place. Autoethnography challenges them to begin to break out of this place (Fassett and Morella, 2008; Fassett and Warren, 2007; Goodall, 2000).

Out of this examination of silences comes new ways to formulate the nexuses between data and theory. Narratives are easier to read and more appealing than theory: The exotic turns readers on (Goodall, 2000). In this way, autoethnographic narratives considered to be exotic are vulnerable to the fallacy of exoticism. “Qualitative reports typically interest these readers when they downplay theory, instead emphasizing problem-specific or site-specific descriptions and options for action” (Lindlof & Taylor,

2002, p. 287). Though autoethnographic narratives do not often call out theory directly, theory is there nonetheless. It is the analysis of these same narratives by the autoethnographer that bring theory and metacommunication back into the research. In this way, autoethnography balances the undeniable appeal of the exotic with the intrinsic value of theory.

A desirable side effect of this new theory-data nexus is a shift in normality. Through the eyes of the autoethnographer we can see the mainstream become marginalized and the marginalized become the norm. (Fassett & Morella, 2008; Turner, 2002; Tillman-Healy, 1997). We can more completely engage perspectives that we normally do not consider such as the disabled perspective, the English language learner perspective, and homonormativity.

The point in these shifts in the norms we are accustomed to is to create “scholarly talk and editorial controversy” (Goodall, 2000, p. 196). It is the launching pad from which new theories, research, and perspectives will (one hopes) emerge. Yet even before that comes to pass, it makes readers, scholars, and learners alike stop and think. Small steps towards understanding and compassion are achieved. It is the smaller ways in which this effects academia and life in general. Now perhaps a young man will not use the word “fag” to tease his friend in front of an openly gay classmate. Perhaps a homeowner will consider for the first time racism that exists in his or her neighborhood. Perhaps a teacher will not call out a student’s learning disability in front of the entire class. Perhaps that same teacher will stop and listen to his or her students struggle with depression before refusing an extension on class assignments. Perhaps a reader will be

more sympathetic to his or her sibling's plight with chronic pain and their requests for help in everyday activities. In any case, these autoethnographies stand to make positive changes in people's lives.

Self-reflexivity

Readers of autoethnography also can be concerned that the author does not exercise self-reflexivity, meaning the author may be reflective of the situation but does not examine how theory, culture, and communication shapes them and moves through their actions and their words. In other words how theory, culture, and communication influence the experiences they write about. Yet in order to fully illuminate both power and privilege in research, we must work toward self-reflexivity. It is not as though researchers submit entries from their personal diaries as evidence. As with any research writing, there is considerable time for incubation, examination into existing research, and revision of the final product. Self-reflexivity is ideally present in all stages of this research, yet in the final stage of revision, bad writing is hard to escape without self-reflexivity (though good writing is not).

Yet for all this discussion about the high-standards autoethnographers should be but are not held to, it is true that self-reflexivity must take place within the researcher's own mind, and it is impossible to externally regulate. The idea of intersubjectivity is key here, as through sharing autoethnography it is possible to examine this phenomenon.

A further implication of this inability to regulate autoethnography is that the readers learn nothing from the autoethnographic narratives, or perhaps that other studies

exist that better examine ideas and theories used in a given autoethnography. Narratives are, after all, stories, and stories are fallible. Experiences written in narrative may not have transpired exactly the way they were written. Furthermore, narratives can be published without the consent of others involved in the story. Though their identities are concealed, readers may feel implicitly named while reading an autoethnographic narrative. Now, the same challenge is posed to the readers, as was to the author when authoring it; work through your emotions and examine the situation to see what you and others learned from it.

The autoethnographic experience

Autoethnography, like any other method of research, has limitations and strengths. Bad examples of autoethnography exist just as bad examples of quantitative studies exist. I have read scholars' responses to self-indulgent and narcissistic autoethnographic work in the name of research, and they are quite right to challenge such authors. Yet do we need to use a cannon to kill the mosquito?

I first had to work through the ways I had been marginalized in order to begin processing the ways in which I had been privileged. Working through the marginalization was rough, and yet here was this outlet for my rage. I would call my committee chair in tears after my latest battle with the DRC, and she would tell me to do some writing. I eventually started writing before I left my sobbing voicemails on her cell phone, so that way she knew I was listening to her and maybe she would listen to me just a bit more. It was months, at times years, before I could go back and read these

experiences. Lots of F-bombs and incomplete sentences awaited me. My frustration had caused me to forget punctuation, my sorrow had caused me to use too many pronouns, and my rage had completely justified the absolute lack of quotations marks in dialogues I had relived on paper. Indeed, a literary mess of word documents was what I had to work with. Yet this was no scrap heap, but a gold mine. This is where data collection and procedures meet. I had captured these experiences, for better or worse. The best part is that I am able to reflect upon them now. I was wronged - I thought that at the time and I still believe that now – but now I have the coping skills to examine these situations and the presence of mind to see what I can learn from them. One day, I will have the wherewithal to understand how my own moments of heartbreak can help other non-visibly disabled people.

Crises

In order for communication studies to explore means to social change and justice, it is often necessary to examine situations of crisis. Crises are critical points of human existence; they are the situations where we grow most as learners and teachers. They are the situations where there is no right answer, the situations we find ourselves in where we require urgent action to ameliorate the pain (usually) of a social situation. Crises are not trials and tribulations, they are not set backs, detours, delays, nor nuisances. They are not flat tires on the way to work, cavities in our teeth, exposure to the common cold, or a jury duty summons. They are short periods of time where we face severe consequences. They are moments that shape us as scholars, as learners, and as people. They are moments where, for better or worse, our lives are changed forever.

The crisis of representation is perhaps one of the most useful crises to examine (Lindlof & Taylor, 2002; Goodall, 2000). The crisis of representation is the “...correspondence between language used to create the representation and the reality that gets represented” (Goodall, 2000, p. 12). Though this particular crisis exists in more abstract forms, it is a situation many people find themselves in nonetheless. Though authors are limited by the power of naming, autoethnography is an appropriate form to express this crisis as “we need all our words to tell the whole story” (Charmaz and Mitchell, 1996, p. 300; as cited in Lindlof & Taylor, 2002, p. 290). Typically in scholarly writing we see “the suppression of authorial experience in favor of objective reporting about “others” (Lindlof & Taylor, 2002, p. 288). These experiences may be passionate, messy, and sharp, yet they are none the less valid and significant (Lindlof & Taylor, 2002). Calmness comes from a place of privilege (Woodhouse, 2007) and so why should we dismiss writing that is not calm if we are to examine marginalized cultures and lived experiences? In times of crisis anger is a way to protect the self. Scholarly forms of writing condone mundane forms of violence in academic life: “how-to” discourses that commodify the product of writing without problematizing the conditions of its production (Bach, Blair, Nothstine, & Pym, 1996, as cited in Lindlof & Taylor, 2002, p. 292).

To this, autoethnography poses a fresh way to examine cultural and societal problems. Yet autoethnography is much more than fevered writings of the situationally oppressed. It is a complex compilation of reflexivity, voice, and rhetoric; “Reflexivity and voice produce the rhetorical character of the self as revealed in and through the

ongoing conversation with the world. Done well the manifestation of voice reflexivity and the construction of voice transform the reading of the narrative from... boring monologue to inspired dialogue” (Goodall, 2000, p. 140).

Autoethnographic data and analysis

The autoethnographic narrative serves as a new form of data. This data is deep, rich, and meaningful. This type of data is valuable because it is:

Data characterized by *enigma, paradox, and absurdity*... *Rich and varied data*... *Vivid and colorful data* indicate how social action is creatively crafted amid contextual... *Poignant data* "capture people humbled by transcending concerns that structure... persistent patterns in their lives. (Katz, 2001, as cited in Lindlof and Taylor, 2002, p. 447)

It is true that most autoethnographic narratives are easy to read. They are normally free from technical language (Lindlof & Taylor, 2002). They read like stories, complete with protagonist, antagonist, and plot. Stories are not normally the subject of empirical research, yet humans are storytellers by nature. Storytellers are the origin of articulation (Goodall, 2000, p. 194), and articulation is indeed a major component of the field of communication studies. These stories are normally not pretty or tame (Goodall, 2000, p. 193), but they are ways to break out of and study patterns of silence (Lindlof & Taylor, 2002).

Autoethnography in communication studies

Fassett and Morella (2008) have attempted to break the ice in the field of communication studies using autoethnography to discuss disability. Yet most of the autoethnographic works that exist in communication studies focus on the areas of performance studies and communication education (Fassett & Warren, 2007; Gingrich-Philbrook, 2005; Jones, 2005; Pelias, 2000; Shields, 2000; Ragan, 2000; Banks and Banks, 2000; Pelias, 1997). Many of these works (Shields, 2000; Ragan, 2000; Banks, and Banks, 2000) are responses to Pelias's (2000) autoethnography "The critical life." Though there are a handful of autoethnographic works in publication, they serve as a healthy starting point for other scholars to use. They are the beginning of a much larger scholarly conversation that has just begun and will continue well into the future.

I use autoethnography as well as in-depth interviews to complete my thesis and join this scholarly conversation with other people with non-visible disabilities. I invite participants using a purposive snowball sample. Since non-visible disability is still not a widely known term, I sought out those participants I know who are non-visibly disabled and asked them to "out" or similarly identify two or three people, and asked those people if they would be willing to participate in my study.

Interviews

Though self-report data is inherently and inadvertently shaped by participants' (mis)understandings and perceptions, in-depth interviews have intrinsic value as they invite participants to tell their own stories, as opposed to being confined and pigeonholed into categories as with Likert-type scales. There are many types of interviews that

are also their own distinct method: Focus group, narrative, respondent, ethnographic, informant, and so forth. Ideally I would be able to conduct interviews in all of the above mentioned formats to create a more comprehensive study and further understand the extent and implications of non-visible disability. However, my study will focus on in-depth or ethnographic interviews.

Ethnographic interviews (in-depth interviews) allow for a more informal conversation to happen while collecting data (Lindlof & Taylor, 2002, p. 176). This format has value as it makes research participants feel more comfortable during the interview. My interviews began and ended with general, open-ended and rapport-building questions. Conversational aspects to the interview made it possible for me to gain access to nuance and detail by validating participants' experiences and making them feel they are understood and respected.

My interview guide consisted of thirteen open-ended questions (see Appendix C). The interviews took approximately an hour. I asked participants to disclose information about their disabilities and about situations surrounding their disabilities, including frustrations, communication exchanges, and accommodations.

I strictly observed Human Subjects Institutional Review Board procedures. Confidentiality has been and will continue to be maintained at all times. Participants were asked to choose pseudonyms for themselves, and when they did not feel comfortable choosing their pseudonyms, I chose for them. Participants received copies of their informed consent letter.

Procedures

I sought research participants who were non-visibly disabled adults who have completed, are in process, or have attempted post-secondary education. I asked participants their opinion on the state of America's current post-secondary education system, as informed by their experiences an through university, community college, vocational schools, or other programs. I also asked participants to share the details of their disability, how it effects their daily lives (if at all), how they came to understand what their disability meant for them, how it effects their past, present, and future education as adults, educational success stories with their disability (as a child or adult), educational failure stories with their disability (as a child or adult), coping skills and methods, descriptions of their support system(s) if any, and advice for future generations who face the same educational challenges, set backs, and obstacles, as they did. All research participants had a form of non-visible disability including, but not limited to, neuroses including anxiety, bi-polar disorder, and depression; psychoses such as schizophrenia and personality disorders; learning disabilities, such as dyslexia, dyscalculia, ADD and ADHD; neurological disorders such as autism, epilepsy, developmental delay, and memory loss; chronic pain due to any number of bodily ailments or disorders such as traumatic injury, fibromyalgia, or lupus; speech disabilities such as aphasia or dysphasia; or vision difficulties not (yet) resulting in blindness such as retinitis pigmentosa or macular degeneration. Though research participants must have a non-visible disability, they may or may not also have visible disabilities such as cerebral palsy, blindness, Deafness, or mobility disabilities such as quadriplegia, hemiplegia,

paraplegia or any other disability that requires the use of an ambulatory aid such as a wheelchair or walker, or any other form of disability that gives visual cues to non-disabled peers that the participant is different or not part of the norm such as Down's Syndrome and other disorders (congenital or otherwise) that may effect development of bodily or facial features such as a cleft palate and fetal alcohol syndrome.

I had eleven participants. People who chose to participate in my research study will help me answer the following research questions:

1. How do non-visibly disabled students perceive discrimination or unfair treatment?
2. When and how do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated?

Though I could attempt to answer these questions through my own autoethnographies and interrogations of my own experiences, interview data allowed me to find themes within these questions and to draw initial conclusions about values, experiences, and the culture of non-visible disability. I asked interviewees to describe adverse conditions in their education, including social settings within education, and how their disability has affected them. Though the word "advocacy" does not appear in any of the questions on the interview guide, I was able to ascertain how each participant perceives advocacy, and how advocacy has failed them, along with ways in which they self-advocate. The idea of advocacy is central to my research as the focus remains not how people cope with non-visible disability, but how the non-visibly disabled cope with those who cannot cope with their non-visible disability.

I coded my data according to common themes in experiences from participants. Data is stories and recollections from participants. After reviewing the notes and tape recordings from the interviews I coded the data into categories with common themes. The three main categories the data was coded into were researchers, teachers and students, though there were many sub-categories. I found common themes in the way disability has shaped participants' identities.

My own voice intersects with the voices of the participants through these themes.

Data and theory nexus

The place where data and theory meet are the most useful to help us understand the phenomena we examine. It is a place where the micro meets the macro and we can see exactly how these ideas shape us and how they are perpetuated through our communication exchanges.

Discussing theory over chili

Thwap, bang, clang, thwap, whap... Smash, slam, ouch! I come into the kitchen from the garage to find my two dogs there to greet me, tails wagging, smashing into the trash can, the gate to their kennel, the door jam, and, finally, my knees as they step on my new heels.

"Hey babe, how was your day?" Joshua is there to greet me.

"Hi sweetheart, friggin long. I'm so beat. " He lets me put my things down and settle in as I slip into my jammies and re-heat the dinner he cooked while I was in class this evening.

“So you were going to tell me more about your thesis. Sorry I didn’t have time to listen to you when you were on your break today; I had to go to a meeting. ”

“Oh, that’s okay. ” I mean it in both senses. I only had a half hour break to talk to him and I find myself way more interested in my bowl of chili than my thesis at the moment. I secretly hope he drops the subject.

“You sounded excited about it on the phone. You told me something about the people you want to interview...?”

“Yeah, I think I’m going to use a snowball sample. ” I say casually with no intention of backing up my statement.

“What’s a snowball sample? Sounds dirty...”

“Gross Joshua...I’m eating. ” Ugh, he’s trying to lighten my spirits by making a joke, but the last thing I want to do is recount the details of my quantitative research class. “Basically it’s where I interview two dyslexics and they out two people who out two people... blah, blah, blah. ”

“That makes sense. ” He sits back in his chair and relaxes. He appears calm, but I know him better, even after only four months of dating. His eyes dart around the room indicating to me that he is searching for questions to ask to seem more interested than he really is.

“I’m not sure I’ll get the clearance to do it. ” I sigh, lift my glasses to the top of my head--where I will no doubt forget them--and rub my eyes.

“Why not?”

“Well, it’s not a very highly regarded form of research. ”

“Really? Interviews?”

“No, no. Sorry. I mean the way I’m going to select my interviewees. It really should be a random sample, but that’s impossible to do with people who have non-visible disabilities. ”

“Uh...um...why is that?” He knows I’m tired after a long day at school. He’s trying to answer the question himself.

“There’s not exactly a database of people who live with non-visible disabilities. Even if I conducted a random sample of the students at San José State with disabilities most of them would not qualify for my research... they just aren’t the people I am looking for. ”

“Ok, who are you looking for?” His eyes flicker and he leans forward again. I know this tone. He’s entered the boyfriend-problem-solving-mode. He thinks he can fix it.

“Anyone who is going to college, or has gone to college, with a disability that you can’t see...”

“So ... in other words other dyslexics?”

“Well partly, yes. But I’m also looking for people with other learning disabilities, ADD, ADHD, dyspraxia, dysgraphia, dyscalculia...”

“There are that many type of learning disabilities?!”

“Oh yeah, plus I want to talk to people who live with psychoses, neuroses...

“What?”

I take a deep breath. I hate being interrupted, but he's really trying to understand my research. "People who are bi-polar, live with depression, schizophrenia, anxiety... things like that"

"Gotcha. Anyone else?"

"Actually, I decided yesterday that I want to talk to people who deal with chronic pain. "

"You consider chronic pain a disability? Pain from what?"

"Anything really!" Now I'm getting pumped about the topic, I can feel myself mounting my proverbial soap box. "It doesn't matter what the source of the pain is, like my aunt who has pain on and off for years stemming from a bus accident when she was six, or a traumatic sports injury, or a disease like fibromyalgia. My guess is that they will want to talk to me about it since it prevents them from living their lives at times. They need extensions on assignments, extra help with many things people take for granted. "

He raises his eyebrows and nods. I am preaching to the choir, but it feels good to preach.

"So this is so these people... with invisible disa..."

"Non-visible," I correct him.

"Okay, non-visible disability, this is an opportunity for them to tell their stories? Get it all off their chests?"

"They tell their stories if they want to, but not for the sake of getting it off their chests. Scholars have written about the things that these people experience, but people

usually don't know it. There is theory in these stories, but we overlook it everyday! It's so important that people read their stories. That teachers and researchers like me, and other instructors at San José State can better understand what it means to live with a disability that people don't believe you have, or that people think is easily controlled when it's not! Society needs to be more accepting of all of us, not just the dyslexics!"

"Sounds like you're going to help a lot of people. That's great!"

"If I can manage to finish this bloody thesis..." I am drained and I part ways with my proverbial soap box, at least for tonight. Joshua has listened intently and diligently, almost hanging on every word. I am unable to match his conversational energy.

"You'll get there patootie. Baby steps. " He sees the defeat from the long day crawl back across my face. He shoots me a reassuring smile and kisses me on the forehead.

"Thanks for the chili babe. It's great. "

Though at times the explanation of the data theory nexus can be more than I am willing to take on, it is nonetheless the crux of my research. Through autoethnography and interviews, I can show how data meets theory and how they are reified through interactions with peers, students, and teachers. There are many sources of data that can be used when teasing apart given theories. Autoethnography is simply one more source of data that can be used to interrogate theory. As with all data, it has its strengths and limitations, but it is important to remember here that autoethnography is a method not just a genre.

Autoethnography is much more than the ethnographic turn in autobiographical writing. It is the initial tingle with the onset of a cold—the first sneeze that you know is more than just driving dust, though you may still be in denial of your soon to-be-illness. It is the fleeting and simple, yet unmistakable, twinge of pain that is indicative of larger problems to come, or as in the case of a cold, are already here and only going to get worse. Autoethnography is not the pot of gold at the end of our social justice rainbow. Autoethnography is the rain that will bring the rainbow, if you are patient and look for it, and you are not afraid to get wet.

CHAPTER FOUR:

FINDINGS

Telling the stories of others

Morning light rushes into my home office as I pull up the window shades. I settle into my oversized office chair to finally analyze my data from all the interviews I've conducted. I hear myself flip through the pages of notes and consent forms. I listen to the audio recordings, but no new data pops out at me. No novel and unconventional way to organize this information suddenly comes into focus. I had hoped it would. I had hoped that the main themes that had stuck in my head from all these interviews would be arranged in some new light, in a hopeful way. The morning light fades and the room darkens and I can see their faces, all eleven of them. I can see all eleven smiles fade as we rehash painful memories from their past.

They all settle in the same way: they smile, read the consent form, sign it, give it back to me and smirk as they think of clever pseudonyms. Many poorly attempt to conceal their real names or give me the name of a porn star or famous movie actor. The light mood has always faded by question three, when describing the frustrations with their disabilities. The mood turns from business to serious by question seven, when they list the people who have failed them in their educational careers. By question eleven, the mood is now dark when I ask them how they coped with their disability. Many of them hesitate to tell me about the violence they engaged in, others glance at the tape recorder and muffle their voices as they tell me about their abuse of prescription and illegal drugs.

None of them cry, none of them seem depressed or in need of consoling, but by the end of the interview, they all want better pseudonyms to conceal their identities.

I am caught off guard by their experiences. I want to commiserate with them by sharing my experiences, but I'm not sure if that's ethical, or even possible. How would I know what to say to them? My anger has gotten the better of me at times, but my experiences pale in comparison to those of my interviewees. I've never dropped out of school, in fact, I've always been too stubborn and determined to prove myself to entertain the thought for more than a fleeting moment. I've never given up on a dream. I've never been so distraught about school that I turn to drugs. What would my life be like if I had? Suddenly it comes into focus, I am the exception to the rule. I knew I wanted to tell others stories, but I had no idea, no clue, that they would be so different from my own. This presents me with a whole new challenge I had not anticipated. How do I take these people out from under the rug where they have been swept? So much pain, so many of them in crisis, how do I carry their voices?

I refocus on the morning light pouring through the window, and take a deep breath. I'm no longer with them, I'm alone trying to make all their stories known and important. I am more determined than ever to tell their stories. I am charged with the task of bringing to light the importance of these experiences and to do more than simply justify unruly behavior, attitude problems, and typical young person druggy behavior. It is my task to bring to light the true crisis of their situations. The very real danger they are in long before the back talk and self-medication become a pattern of behavior. I now must show how they have been shaped by their disabilities. Their disabilities are the

square peg and the education they seek is the round hole. Their methods of dealing with crisis are more than a way to escape, it is their whole hearted attempt to fix in themselves what they have been told for so many years is broken.

This chapter reports data collected from participant interviews conducted from March 20th 2008 to March 31st 2008. Eleven participants were interviewed. Participants' disabilities varied from chronic pain (for a variety of reasons) to depression and schizophrenia, but most of the participants had ADD and often at least one other learning disability. All participants were over age eighteen and had graduated from high school. Ten participants attempted to attend college or some type of post-secondary education. Three participants graduated from college. Seven participants are male and six are female. Their age ranged from eighteen to forty seven years old. All participants live in California and all attended local schools, though many also received parts of their educations in other states. Eleven participants work full time and one attends college on a full time basis.

This chapter reports the three main themes collected from the data shared by these participants. Though there were many more themes, notions, and concepts that surfaced in these interviews, I have selected the three themes that best address my research questions: RQ 1: How do non-visibly disabled students perceive discrimination or unfair treatment? RQ 2: How and when do non-visibly disabled students attempt advocacy when they find themselves discriminated against, under accommodated, or over accommodated? I expected to hear stories of angst and perseverance through high school

and college, of how participants (usually) eventually successfully completed their courses, or from time to time dropped out of the class. I expected also to have participants disclose a sense of both anger and catharsis during their interviews. What surprised me in these interviews was where participants reported discrimination or unfair treatment, they did so in terms of crisis and the bitterness many still harbor for their former teachers and advocates. These crisis situations led participants to disclose more details about how they coped with the situation rather than how they perceived the unfair treatment. It was clear through my interviews that many participants were very angry at the situation and focused on how to cope with their anger and survive in their educational settings. Crisis is a crucial theme in these findings. They survive persecution in the form of education and standardized testing. These crises forever shape the identities, cultures, and the very lives of these participants. Crisis becomes the catalyst for change. Not only are these participants forever altered by their experiences with these crises, but all those people whose lives are touched by these participants will be forever changed by the very same crises. Their children, parents, friends, lovers, and peers will be shaped by how these non-visibly disabled people cope with their individual crises. The effects may be too insignificant to notice at first glance, but these people are unmistakably and forever marked by the experiences of their loved ones and acquaintances.

The three themes I have found from my analysis are understanding, self-accommodation/coping, and crisis management. The theme of understanding drives more at the mutual understanding the participants deeply desired from their teachers, parents, or school administrators. A break down in this understanding was reported in

all eleven interviews and directly led to the other two themes of this chapter: self accommodation and crisis management. Participants' narratives are excerpts from interviews; these begin and end with their names as well as quotation marks. Some narratives have two names to identify the narrative. This occurs where similar themes and sentiments were echoed throughout more than one interview. If a narrative has two names on it, it belongs to both participants. Narratives also have a sub-theme. Sub-themes emerged from participant interviews and were illustrated by participant's narratives. For example, more than one participant described the issue of peer pressure, so naturally this became a sub-theme. These sub-themes also call out the commonalities I saw in interviews and are combine into narratives.

Understanding

Understanding is something many people crave at times, yet for those who live with non-visible disabilities, it is simply a necessity. In this case, perhaps understanding is best defined by negation through misunderstanding. When addressing the research questions for this study, it is clear that the concepts of coping and advocacy only come in when understanding has failed to happen between the non-visibly disabled individual and another party, normally a teacher or school administrator. All eleven participants expressed a desire to be better understood by their peers, superiors, and subordinates with whom they work or go to school.

As researchers and scholars, we know that mutual understanding is necessary to have free and open communication and communication fails when one party does not understand the other or has no desire to understand the other. Yet it does not stop with

simple message transmission. As scholars we demolish the drywall, the superficial faces of these messages, to reveal the bare structural framework of power and privilege. Communication scholars see not only the picture that hangs on the wall, but the nail that pierces the paint, dry wall, and the stud that holds up the wall behind the picture. We know it is upon this unseen stud of power that these messages of pain are hung. These structures of power and privilege are waiting to be decoded and analyzed. All participants who were able to find an advocate, teacher, mentor, or advisor who understood their disability and the position it put the participant in described very successful and happy learning experiences. When participants encountered someone who did not understand, or did not want to understand their non-visible disability, all described negative, hurtful, and unproductive learning experiences.

Nicholas and Preston

Attempting to improve work through peer pressure

“When are you going to stop making these stupid mistakes? Come up here and read this to the class. ”

“Why?”

“Because, Mister, if you have to display your half-baked attempt at this paper to your peers, maybe you will start trying...”

“Dude, I did try. That’s not fair. I’m not going up there and reading it. ”

“And why is that? Is it because your grammar is horrible? Your spelling incomprehensible? In fact, you didn’t even meet the parameters for the writing assignment! We spent a whole day talking about it in class!”

“It took me forever to do! I spent all night on it!”

“I highly doubt that. Clearly, by the quality of your writing, you didn’t. You just insist on goofing off. Did you even pay attention to the instructions in class?”

“Man, this is bullshit! How do you know how much time I put in?!”

“You’re outta here pal. Go see Coach Robinson in detention. ”

To many outsiders, this conversation between a high school student and a teacher may seem like just an unruly member of the popular clique with a bad case of senioritis. Yet this is the scenario described over and over again to me in the interviews I have conducted. In fact it is easy for teachers to get frustrated by students who are clearly intelligent but turn in low quality work.

These confrontations happen on a daily basis for participants. Often they are overwhelmed with the amount of conflict in their lives and often feel, “picked upon. ” These experiences transcend race, class, gender, and socioeconomic status. Learning disabilities are widely defined as a processing difficulty that has no bearing on intelligence. Often students with learning disabilities are very intelligent students (Kravets, 1997; Siminski, 2003; Laufer, 2000). The mistakes in non-visibly disabled student’s work often leads to misunderstanding. These kinds of misunderstandings can be very painful and detrimental to a student’s development as we see with Karen.

Karen

Questioning curriculum and loaded language

“Cause I said so...”

“Seriously? That’s the best you can come up with? Really, I want to know why I have to read Shakespeare. I mean, tell me when in real life I’ll have to know iambic pentameter?!”

“You know what your problem is Miss Smith, you’re just plain lazy! You have so much potential but you never try!”

“That’s bullshit!”

“That kind of talk will get you a one way ticket to the principal’s office. ”

“So that’s what you do with people who challenge the curriculum?! Insult them and send them away?!?”

“See you don’t listen either. I just told you that you have potential and you’re smart!”

“You called me lazy!”

“Well, what would you call someone who doesn’t try?”

“I do try! You’re full of shit! Fuck off!”

These situations are commonly described in my participant interviews: verbal violence, and at times physical violence, was manifested as a means of coping, especially when discussing experiences participants had in high school. It is difficult to get past the sheer anger of these situations, but in order to reach understanding, we must.

To dismiss these students as disorderly, or to say that they are dealing with anger issues, would only serve to further trivialize this situation. Ten out of the eleven interviewees described problems with teachers in high school and self-identified as

“trouble makers. ” All eleven participants identified some instance of “back talk” in academic settings when experiencing frustrations with the course, teacher, or their own disability.

Though these situations may not be a good or effective display of the attempt to reach understanding, these students are, in fact, using the coping skills they have at the time to reach out for understanding. Often this is taken as a threat to the instructor’s face or credibility, and the use of curse words is seen as an act of rebellion, when in fact it is a deliberate use of language to display frustration on the part of the student. In interviews when participants described these situations, nine of the eleven participants expressed empathy towards the teacher, but felt it was his/her job to make an attempt at understanding their position, and all eleven of the participants acknowledged that if the teacher had a better grasp of their non-visible disability, the situation would not have escalated.

Flipper and Fred

The mistake of appearing competent

“Really? You printed this report on colored paper? You know I can’t read it!”

“Well, that’s the only thing we had in the copy room. You’ll just have to make do. ”

“That’s what you said last week too. I just don’t understand why you don’t believe me when I tell you that my dyslexia prevents me from reading things on colored paper. ”

“You know you function just fine every time you don’t get what you need. You’ll be fine this time too. What’s the big deal?”

“This should have been valid for you the first time I told you I was dyslexic. You know children that are dyslexic and that’s real enough for you. Why isn’t dyslexia real for you when it comes from an educated adult?”

This conversation was described to me by an interviewee who works at a community college. Here we can see a different level of misunderstanding. It isn’t that the effects of the non-visible disability are unknown, it is the disbelief that the non-visible disability even exists. This is one way we continue to perpetuate a “culture of disbelief” with respect to non-visible disability (Fraser, 2007). This narrative provides just one example of the frustrations felt by non-visibly disabled people when their disability is questioned due to their sharp intellect or high degree of capability and competence. If a non-visibly disabled person is able to circumvent situations where his/her disability becomes problematic, either by self accommodating or seeking outside accommodation, the likelihood that his/her disability will be called into question increases.

Quest

Disbelief hurts

“It just hurts so bad when my back goes out! I’m a big dude, and people think I should be able to lift heavy things, but when I tell them that I can’t, they think I’m lazy. That’s not it at all. I mean I feel bad that I can’t help people, I really do! Sometimes people see me walking around without pain, but on the bad days, when the pain is really

bad, people have accused me of faking. They even have disability investigators! Those people are like the paparazzi! Always in your face making you justify what you are doing. ”

The above was described to me in an interview with one particular interviewee with chronic back pain from an injury. The culture of disbelief (Fraser, 2007) doesn't stop with learning disabilities. People who have chronic pain for a variety of reasons or people with chronic mental illness, such as depression, fall into this trap as well. Though we are all no strangers to physical pain, when it becomes chronic, or does not respond to medication it can interfere with not only everyday activities, but our learning processes as well. Since pain is not visible, and since our threshold for pain varies greatly for each of us it is truly impossible to measure or judge such a thing. Yet those who cope with chronic pain are held to others judgments of their own pain.

Lisa

Learning to accept your disability when others don't

There are so many stigmas. I feel like I can't tell anyone. They think I'm Britney Spears. People don't understand that even though I have a psychosis and I'm bipolar that I am just a regular person. It's not fair to label me as crazy, but it's also not fair to tell me that I don't struggle with this everyday. Even my own mom tells me that there's nothing wrong with me! She says it's all in my head! She doesn't listen to me tell

her what its like to deal with this. I just have to know that what I have is legit. It's up to me to validate myself sometimes.

This notion of understanding cuts across many non-visible disabilities. Participants with a variety of misunderstood medical conditions felt burdened by others' impatience with the extended amount of time it took to complete activities of daily living including standing up, completing homework, walking up stairs, and taking a shower. Those whose non-visible disabilities were classified as learning disabilities felt that a lack of understanding of their particular disability often led to a situation that directly threatened his/her education and many times resulted in a state of crisis.

Understanding is not a one way street. This too leads us into a double bind. Those with non-visible disabilities seek out trusting and understanding relationships, but their situation also calls them to be understanding of others. For example one participant with dyslexia who is enrolled in college was bothered by the behavior of another college student with ADD. Many participants were not able to extend the same understanding to others as they required for their own situations.

Self accommodation and coping

Often when understanding is reached and non-visibly disabled people feel they have reached a trusting relationship with those around them, self accommodation becomes much easier. Self-accommodation is when a non-visibly disabled person makes changes to his/her environment, behavior, or work/school patterns to ease the difficulty felt from a disability. It is what they are able to do to get by without asking for

formal accommodation. Self accommodation happens in two kinds of situations. The most common is when the non-visibly disabled feel that there is no accommodation the institution can provide and any attempt at formal accommodation would only put the spotlight on the student and draw unwanted attention and scrutiny. Often these formal accommodations require invasive or in-depth testing and thorough documentation. For example, accommodation for chronic pain may include simply bringing a cushion to sit on, or standing up every few minutes, or even teaching while sitting down, instead of a formal request and the required physical examination for an ergonomic chair. The other instance where self accommodation occurs is when the institution is unwilling or unable to provide accommodations. When this happens, many people seek the same accommodation they would have from their institution, but from outside resources. For example if a student has ADD and his/her school cannot provide a quiet place for the student to study, he or she may change his/her time to the middle of the night since there is less distraction. Or in the case of proofreading, students who have the monetary means may hire an outside proofreader to help them with their grammar and spelling.

Mary

The accommodation of financial stability

“Thank God I have the funds to get what I need. If I didn’t I’d be up a creek. Not many students have a situation where they are not strapped for cash, but because I’m not I’m able to succeed more than if I was on student loans. Formal accommodations are lackluster and because I have the means to, I can buy all the books on tape that I want, I

can buy expensive technology to assist me, and I can seek answers from specialists in the field of disabilities. ”

Self accommodation often times overlaps with coping. Many participants found themselves in frustrating situations that no amount of formal accommodation could ameliorate such as physical pain that does not respond to medication, a required, but noisy lab classroom that frustrates a student with ADD, or the word searches that a writing teacher gives out as a “fun in-class assignment. ” Many of these situations were frustrating, short moments. Though these moments may or may not have resulted in a crisis for the participant, they were nonetheless discomfoting and painful to address. These types of coping methods become a self accommodation in that they are ways to level the field of play. They are ways in which the non-visibly disabled are able to better understand the situation and material being discussed. Often these are simple things like, cushions to sit on, regular bathroom breaks, or finding clever ways to link memory to course material (such as how the color of the shirt the instructor is wearing may remind them of a concept covered in class).

Nicholas

When self-acceptance makes others uncomfortable

“I used to suffer from insanity, now I enjoy it!”

“What do you mean Nicholas?”

“You gotta be happy with where you are. No matter what you do, you can’t change how you learn, what you need to learn, and how you process information. When people can’t deal with it, just revel in it!”

Once the non-visibly disabled person realizes that their disability makes others uncomfortable this poses a whole new set of challenges. He or she still needs to interact with others, yet his/her disability can threaten a positive exchange between them. At this point the non-visibly disabled person not only has to accommodate him/herself, but their non-disabled counterpart. One of the most common ways this happens is with the use of humor.

Fred

Using humor to cope

“I just make a joke out of it. Sometimes I compare my ADD to being like a cat. Dangle something in front of me and I’ll be obsessed with that instead of what I’m supposed to be focusing on. It lightens the situation and I’m able to deal with the subject better than if I feel I have to defend myself for how I think. ”

Some of these coping skills and self accommodations are happy. About half of the participants who disclosed methods of self accommodation talked about them in a positive way. Usually this involved an element of self acceptance, but many times it involved self advocacy and knowing when to become ornery. For example, as Flipper discovers, “Always know who the idiot is. I always know what is my bullshit and what

is theirs and I never hesitate to call them on it. ” None of the participants sought out confrontation; all reported having the confrontation brought to them in the form of educational threats. Though confrontation was not the desired outcome, participants rarely shied away from it.

Flipper clearly knows that in many of these situations she is not the idiot and chooses to point the blame squarely at the other party. Though this method of coping, this self accommodation, is not the most pleasant, it is the way in which she can best understand the situation. This may overlap with self advocacy, but many times this is merely a way for her to verbalize her understanding of the situation, which in turn helps her to cope and go on with her business. When the blame is exposed and spoken, for Flipper, it allows her to be calm about the situation, even if the situation is not resolved.

Nicholas

Coping with other people coping with you

“When people turn up the ‘mean,’ I turn up the ‘stupid. ’ I pretend they have a fake disability called *dimenguing pledmere*. I talk to them the same way they talk to me. Most people think I do this just to piss them off. I guess it might help them understand how to better address people, but mostly I do this to give me patience and to help me to know that we are on the same level, otherwise I might get pissed off. ”

All eleven participants expressed some notion that they may never have all their needs met, yet they all look for the silver lining. When asked who has been the most helpful to them in dealing with their disability, three participants listed themselves as the

most helpful person in their situation. This is not to say that no one has ever helped them, but to say that back talk is more than just trying to upset people, trying to mess with them, trying to be difficult for the sake of being difficult. It is because they have figured out a way to deal with a given situation to the best of their abilities. Since they were the ones who figured out what they truly need to cope with, understand, or succeed in a situation, the credit goes to themselves rather than teachers, parents, or formal accommodations. These participants found positive attributes that stem from their particular disability. Nine of the eleven participants say there is something advantageous to having their particular non-visible disability. They range from being a better computer programmer and technical writer, to being able to recall spoken messages better than most people, to over-studying for tests. No amount of accommodation or support can help the non-visibly disabled find the good in their situations and conditions. It is a matter of self-acceptance and reframing one's identity. As Nicholas observes, "It's like having super powers. Sometimes it's a pain to deal with, but you can do other things better than other people. "

Many non-visibly disabled students come to a place of optimism when reflecting upon their own disabilities. Sadly this optimism doesn't always translate to self acceptance. The last section of this chapter is where I feel the most common ground with my participants. This last section of this chapter contains sad and painful memories for participants as they recall crisis and the ways they cope with their crises.

Crisis and self medication

It is crucial to understand that situations described here by participants are more than situations of conflict and inconvenience, they are situations of crisis, a state of intense pressure and pain. The coping skills in this section are a direct result of the state of emergency in which the participants see themselves. The behaviors and actions described here are not a response to an inconvenience, but rather a description of the extremes people go to in order to alleviate their situations as a direct response to a perceived threat. It is a desperate situation, one that many know they cannot recover from without great difficulty—as Mary notes, “If you fall into the cracks it’s hard to advocate for yourself. ” The following are the stories of participants and the skills they had to cope.

Crisis is important on more than a thematic level, but a conceptual one as well. Crisis is the earthquake that chips paint on the drywall, but we need to examine the studs that structure the wall. Crisis is not what results, but it is what defines us as non-visibly disabled. It is part of our culture and shapes us as more than just individuals, it is the connective tissue, the very pulse of our diffuse but well connected culture.

The narratives in this section have been separated out to tell as many of the participants’ stories as possible. In the interview, they all expressed that the following stories were important to share. These crises cannot be shared or lumped together. Each crisis is as unique as a snowflake and must be displayed separately in order to accurately examine the circumstances and the coping skills.

Karen

“I used to cry a lot. Every time I heard that my learning disability was fake, I would cry. Every time I was told it’s all in my head, that I’m the problem, not any disability I might have, all the times I was called lazy, it hurt so bad, so bad! I used to cry hysterically in class, out of class, I couldn’t help it. My school counselor told me I was just complaining and that I should knock it off. But then after eighth grade, my sadness just turned to rudeness and anger. On a good day I would tell my teachers to fuck off then walk away. On a bad day, well, it got a lot worse. People started being afraid of me. At least the teasing stopped once I was violent. I don’t want to be feared, but people stopped being mean to me once I was aggressive and violent. ”

Flipper

“I called people on their bullshit. I knew I wasn’t faking. I guess that’s how I coped with it. People weren’t happy to see me coming because they knew I was going to put up a fight, that I wasn’t going to be punked around. I knew how to handle myself. I knew where to mind my manners, and where to insert backhanded insults. I knew who the moron was and it wasn’t me. I knew that I could handle myself in these situations, and I guess other people couldn’t. It felt like these situations escalated into a mob mentality. ‘There’s the dyslexic! Let’s get her!’”

Preston

“My school counselor made it clear to me more than once that I was dragging down the school’s test scores. He had no hope for me going to college and that would have pulled down the school’s average for graduating seniors going immediately to college, a number the school was very proud of. I was labeled as a trouble maker for that alone. The principal had my schedule taped to her wall so that she always knew where I was. I never wanted to cause trouble or hurt anyone, but people gave me such a hard time about the way I learned. I was quite, rarely mouthed off at first, but after all this persecution, I just said “fuck it!” I did what I wanted when I wanted, which was usually pot. I drank a lot too, and it killed the pain and made everything easier to deal with. If I was going to be treated like a fuck up, I was going to act like a fuck up. ”

Marc

“Yeah I used illegal drugs! The pain in my shoulders was so bad. The doctors didn’t give me anything for it, they couldn’t even diagnose the cause of the pain! I couldn’t concentrate in school. My teachers thought I was faking, and since I had no diagnosis, I had no recourse. I had nothing to come back to them with and say “look! This is real!” So, I repressed my feelings. I used alcohol, amphetamines, pot, speed, whatever to make the emotional pain better, nothing could help the physical pain. ”

Mary

“I guess ‘cope’ would be the key word. I’m still trying to figure that out. The joint pain from my genetic condition I’ve had for a while. I can deal I guess, but the panic attacks, well that’s new. I guess I never thought of that as a disability, just me being broken. I was like a fish out of water. There’s no handbook on how to deal with

this, no best practices, no standard operating procedure. I was in crisis, I had no choice. I broke away from school. I dropped out. It was the only thing I thought I could do and it broke my heart. ”

Quest

“I deal with it the best way I can. People don’t get that my back injury is a life long condition. Yeah, I have good days and bad days, but it doesn’t mean I’m faking it. My back pain is no reason for me to skirt my responsibilities. I developed a way to hide it from people and deny my own feelings. ”

Seymour

“I don’t tell anyone. I don’t want pity, I don’t even want help. I just want to be left alone. ADD is my condition and not anyone else’s problem. I want to be independent. Ritalin doesn’t help, it never did all the years I was on it. I have to smoke pot to cope. ”

Lisa

“The medication helps the psychotic effects, but I can’t concentrate. I’m so close to finishing my degree, but now I can’t focus long enough to finish papers or write anything. I’m supposed to know that things are hard and that in itself is supposedly helpful, but that doesn’t cut it. I’m going to have to drop out of school. I have no choice. ”

Nicholas

“For decades I self medicated with coffee and Sudafed. I also used a variety of amphetamines, which were surprisingly helpful, but dangerous too. At one point I had a

prescription for dyphenhydramine sulfate, but now that it's widely known that it's the main ingredient in speed, I can't get it anymore. I had no fear of my own mistakes but other people did. I had to use, there was no 'how to be angry' seminar I could attend. The amphetamines helped me learn to cope with other people who were learning to cope with me. ”

Larry

“How could I succeed in a place like that? Teachers were the enemy, and even the nice ones didn't do anything for me. They just babied me. I can't say I learned anything from them. About the time I started doing well in school was about the time I started smoking pot. ”

There is no transition between these stories of crisis for a reason. To weave in and out of these stories would only serve to weaken them. These people do not weave in and out of crisis. These stories are barbed, snagged, toothed, rough, serrated, and tangled. They are a series of broken windows through which one cannot easily move. Instead of seeing the mess of glass on the floor and wondering who will clean it up, we need to look at the shards that still cling to the window panes. Examine not the sharpness of the jagged points, but the beauty of the cracks and the intricate designs they make. There is no rhyme or reason why some shards cling to the pane and other shards fall and are scattered haphazardly on the sill. Each broken window is a story of crisis, full of painfully sharp edges that can cut people who had no hand in breaking the

window. Yet there is beauty and strength that lies within these windows, though they do not look and function as other windows might.

These stories answer both research questions, though not in the ways I had predicted. Though all interviewees attempted some form of post-secondary education they almost exclusively focused on experiences in high school that caused them to reach a state of crisis. Unfair treatment and discrimination led to the states of crisis the interviewees experienced. Rather than focusing on how they perceived the unfair treatment, they focused on the danger and trauma this treatment caused them. My second research question focused on advocacy, yet none of the participants used the word advocacy to describe their situations in any of the interviews. Many of them felt they themselves were their only advocate. Many of them were forced to advocate to teachers, parents, and administrators, without any outside help leading to a state of crisis and thus causing them to seek alternative coping methods. Their actions, though rebellious, are complicated since they are forms of resistance, advocacy, and coping all held within a single action.

The single act of getting high, or self medicating with a drug intended for other conditions, such as dyphenhydramine for sinus congestion, is a compilation of many sentiments and intentions. It is an act of resistance against parents and doctors who prescribe other forms of medication or treatment that the non-visibly disabled person finds less than useful or problematic in some way. It is a form of self-advocacy as teachers, parents and administrators will engage in more meaningful communication when the non-visibly disabled student has conformed to the societal norms of classroom

behavior, though that is not who they are in reality or how they learn. It is a coping method. Non-visibly disabled students with ADD, dyslexia, chronic pain and other issues are not opposed to learning. Self-medicating is an attempt to cope with the distracting sounds of the outside world rushing into a classroom through open windows and doors. It is the dulling of the constant sensation of someone, with athletic cleats standing on your shoulders so you can focus on the lecture that is zooming past your ears. It is a way to curb the frustration one feels when they watch words scramble around the page like ants. Though it may not make the words stay, it allows you to deal with frustration that would normally cause you to walk away and work at it longer than you normally would. All this meaning and intent; resistance, advocacy, and coping stems from the single act of self medication.

Luck as privilege

My eyes close. Deep breath. I am searching. My narratives normally start with quotes. I need a sentence, a saying, an experience... something! Nothing. Deep breath. Still searching. I open my eyes to see the word doc and blinking cursor on the screen in front of me. It's taunting me. The words preceding the cursor are the words of my people, my culture, yet I cannot enter their narratives. I cannot synthesize my voice with theirs. I have not had this experience. My privilege has made my story different from theirs. Now it's true that my privilege cuts many ways. I am white, raised in an upper middle class neighborhood, and went to an upper middle class school with a low incident

of crime. I am a Christian living in a Judeo-Christian society, and heterosexual in a world of heretonnormativity. Yet this is not where my real privilege is.

My real privilege, perhaps dumb luck, is two-fold. First and foremost is my auditory retention. I was able to escape high school without reading a thing! Regurgitation of key concepts from teachers lectures and class discussion provided me with the solid "C" average needed to escape my mandated secondary education and enter community college where I was formally diagnosed.

This leads me to my next set of privileges, because of my auditory retention I was able to progress in my education so far before I found my own personal crisis. I was in graduate school when my crisis hit. My participant's crisis hit in high school. I had more coping skills than they did, more language to express my rage so I didn't have to pick up my fists or a pipe when words failed me, they never did. I already had my B. A. so I was never going to be labeled a drop-out or part of the dredge of society.

This graduate program I found myself in when my crisis hit was another form of privilege. I had found a place where I could be angry and an advocate who listened to me. She is the single, solitary reason I was able to finish grad school. I tried to leave the program in the midst of my crisis. Her answer to me was not "If you leave you fail", or "You just not cut out for this type of work" or even "Fuck them! You're right and they don't know what the hell they are talking about!" It was simple and powerful. She said "Please trust me. " These three words circumvented the need for self-medication and coping. Though it did not resolve the crisis and conflict I was having, these words greatly diminished the threat to my face and my education and ameliorated the situation

so much that I was able to concentrate on the work I had in front of me rather than planning my advocacy and resistance. These three words are my privilege, and my saving grace.

These stories are powerful, and much more than just stories. They have meaning beyond that of their face value. In chapter five I will discuss the implications my research questions hold for students, teachers, and researchers. I will call out what this means for teachers, students and researchers, and how each of these audiences have very different needs and how this information is useful to each of them. I will also make suggestions for future research.

Self-medication is a tangled ball of twine that can only be unwound and fully understood through more research in this area. Rather than focusing on the inappropriate use of curse words in the classroom by students, we need to look at what drives them to use such curse words. It seems as though these words are the only way in which students know how to express the desperation of their situation. Yet these words are what further alienates them from their teachers who resent the use of these words. It is true that these words are spoken in anger towards the teacher and the teacher has every right to put a stop to verbal violence. Yet detention and punishment blocks any path to mutual understanding which is nothing less than necessary for success in the culture of non-visibly disabled students.

CHAPTER FIVE:

IMPLICATIONS

Revisiting revisions

It is easy to become entrenched in grammar and formatting, but once I step back and look at the larger picture, not of the document but how the process and the experience has forever changed me, my own metamorphosis becomes clearer, though not entirely focused. It is the slow change from angry undergrad, to angrier grad student, to educated and bitter, to a more secure and determined, less angry, scholar in search of enlightenment. It is the recognition of this metamorphosis, that I am still in, still a part of that is the real accomplishment. As I look forward into the future, I know this experience will continue to change me and I am unable to fully articulate the ways in which I have already been changed.

This thesis is an exploration into non-visible disability. Though we start out with only my story, we end with chorus of voices echoing the same sentiment: Be willing to listen, don't assume we are lazy, let us work hard, let us help create solutions for our own situations, and accept us and our disabilities for what they are. These are sentiments we find in research, for example, work by Cornett-DeVito and Worley (2005) and Stromer (1983).

As tempted as I am to let these stories and data stand on their own, it is my job as a researcher and writer to call out the importance of this data and what it means for my audiences. I have analyzed this data and called out the importance of it for researchers

and scholars, teachers, and students, particularly students who are coping with some non-visible disability of their own.

Implications for students

Life is rough, school is rougher. At least this is the case for many non-visibly disabled students. Though my message here is to the non-visibly disabled students, non-disabled students need to understand the importance of their roles in the classroom as well. Non-disabled students often serve as bench marks and role models for non-visibly disabled students. This role is, perhaps unfairly, thrust upon the non-disabled students in the class, but understand that the more accommodating you can be of the non-visibly disabled students' feelings and needs, the learning environment will improve for all students in the class. You are in no way the marked enemy. Non-disabled peers are often the strongest allies and advocates for non-visibly disabled students. Keep open hearts and open minds when a classmate or acquaintance discloses a disability to you. Your words carry more meaning and power than you know.

This research is meant to help others who are suffering. Though I have a wide range in audience, the most powerful and meaningful for me are my fellow non-visibly disabled students. The only way I can address this audience is with the following letter. Anything else just doesn't feel right.

A letter to my people

My dearest friends,

It is a long road to travel to come to the place of understanding I have finally reached about my own disability. I know now that people who I thought were trying to hurt me or didn't care about me were trying to help me. Though perhaps it wasn't the best way to help me, and at times their efforts bore no fruit, it was their sentiment that needed to be commended. People sometimes stand in our way, mess things up for us, but they mean well. They need to be educated in so subtle a way that they don't know they are being educated. Seek the help of allies and advocates to help you through, and when there is no way to get around them on your path to your education, start building outlet roads. Persevere, there are creative and meaningful ways to achieve your goals without sacrificing who you are or your education. Use honey to catch your flies. Education is politics at every level. We live it each time we set foot into a classroom. It is the power of what is possible, not probable. Know you are right in your heart, when you are publicly scorned for your disabilities and your accommodations.

Seek each other out. We have a stronger bond than many realize. We are a culture. Our culture is unconventional, diffuse, de-centralized, and at times oppressed, but we are unmistakably a culture. Though we are greatly diverse, we value the same things, communication, understanding, and patience. We know what it is to have our lives threatened through education. We know the persecution of curriculum and standardized testing. We are guilty of seeing the world very differently than those who make the rules and we suffer, often silently, and take punishments for the way we are. The person who sits next to you in class may be your strongest ally. The barista who serves you coffee everyday may have your non-visible disability. Your teacher may

have suffered through some of the same experiences as you. Be open about your disability, but allow yourself the protection your heart needs. Do not shut others out; there are more like you than you think, I promise.

Never give up. There is a torch that burns in all of us; don't allow bad experiences that happen in your academic career to extinguish your flames of knowledge. Bad experiences happen. Allow yourself to feel the depths of every emotion you have. Anger, betrayal, deceit, sadness, mourning, determination, outrage, despair, and all the others that come to you, but never allow them to diminish your wit. Wit is smarts that are employed at a faster pace than those around you. Many of us are given this gift, perhaps to make up for our other areas of diminished capacity. Don't be afraid to use it, but use it wisely. It must not become a vessel for your emotions. Do not allow your anger to become hate and blind you to alternative paths to success. The best revenge is to live a good life. Find a way to be happy that does not hurt yourself or other people. Drugs are not the answer; self medication is dangerous. Should you find you do need prescribed medication, don't feel bad. Medication can be helpful in allowing you to build a healthier life, but be careful not to let this become abuse of prescribed medication. Though you may see results you like at first, do not fall into the trap of thinking you need to be medicated to be normal.

Find allies where you find them. Do not turn on each other. It may be tempting to think our classmate in a wheelchair has an easier time in school because people can see his or her disability, but this is a trap. Stand not in judgment, but in solidarity with one another. Allow yourself to be an ally and an advocate to others as well. There have

been ties between both visibly and non-visibly disabled communities and other powerful communities as well like the GLBTQ community, English Language Learners, and other marginalized groups. Alliances cannot be forced or rushed, but should you find yourself in a position to support them, allow yourself to do so as we have gotten support from them in the past.

Do not stifle who you are. You don't have to look farther than your local bookstore to find printed words, words that will stay forever, that together form dangerous language about us. You'll see words like "cure, subjects, broken, problem child, alternative education," and perhaps even "eugenics. " Language is power so arm yourself. Know that it is acceptable to reject something that contradicts how you learn and who you are. Do not be afraid of inaccessible language. Never allow yourself to feel unworthy of information because of the use of big, long, complicated words with multiple syllables. The internet levels our playing field. Find out what you don't know. Do not make the mistake of thinking knowledge is only acquired in school.

Most of all friends, focus on hope. It would be ideal if you were able to kick down doors so that others may walk through them, but sometimes that is not the case. Though we want others to succeed in our wake, at times we leave behind a path of destruction. This is the exception, not the norm. Do not allow the one person who explicitly oppresses you to set the standard for your advocacy plan of action. You may have to burn bridges to reach your goals, but don't let it jade you. The law often holds no protection for us and skepticism is something that is here to stay, at least for a while, but this should not stop us from taking strides to create a better future for our culture.

Many of our specific disabilities are hereditary. It is likely that our own children will form the next generation of our culture of non-visible disabilities. Let us work together to not only build a better situation for us, but for our children, and our children's children.

Implications for teachers

Recognizing disability in my own classroom

“White people are kinda lame, but they aight. ”

I am writing on the board and have to stop myself from turning around and giving this student a scathing look. I finish my sentence on the board and slowly turn to face the class that is still in an uproar of laughter. I wait for silence and it soon comes, I pause until I know all eyes are on me and the anticipatory tension is just right. I look at my student in the back of the room and say simply “Dude. ”

He nods and slumps in his chair. I know this statement was not said with malice, nor was it meant to evoke my reaction as a white teacher. It was said because he didn't know how to meaningfully participate in the class discussion on racism without being shocking, disruptive or talking out of turn. We finish the discussion and he manages to stay engaged without any further outbursts. I see him shift in his chair when he hears something that strikes a chord with him. I see him fight back the comments he has and put his head down on his desk when he attempts to mentally check out of the conversation.

There are two ways I can see him. I can see him as problem student. Disruptive and borderline racist. He is a firm believer in all things loud and obnoxious and a solid

supporter of the hyphy movement as indicated by his clothing and backpack. He is often late and rarely comes in without making some sort of scene. He frequently talks to the students sitting next to him during lectures and rarely goes ten minutes without flipping his pen around or checking his phone.

However true all this information is, I see this person as someone who I suspect has a mild to moderate case of ADD. He high fives his friends when he comes in, because he sees them and is drawn in by their presence. Social rules dictate that we acknowledge and greet our friends when we see them. He is never mean or purposely disruptive. When he talks to students next to him, they are often not from his inner circle of friends, and when he speaks with them, it is about a topic from my lecture or the book. When he put his head down in the class discussion, I saw that he was trying to reduce the amount of information he was taking in and not that he was checking out. He leg bounced furiously to work off extra energy that served only to distract him from the class rules and code of conduct that the students agreed upon at the beginning of the semester.

As the class is shuffling out the door after the discussion, I ask him to hang back. He agrees. I say nothing about the inappropriateness of his judgment of the lameness of white people and instead ask him how he is doing.

“I’m aight. ” He looks at the floor and his voice drops.

“What’s up?” I say.

“I’m trying really hard in this class, I dunno, I guess it’s not paying off. I have ADD and I’m really strugglin’.”

Perfect; though I'm not happy that he is frustrated, I am happy that he has "taken the bait. " He had not disclosed his disability to me before this conversation, but now that he has, we have so many more possibilities to work with how he learns. This is the conversation I wanted to have. I wanted to talk about what we can do to make him feel better about his participation in class. We discuss ways he can help control his ADD and ways in which he can meaningfully participate without compromising his thoughts, feelings, and integrities.

The most common adversaries in the stories of the participants were the teachers. Yet this does not mean that teachers are, in fact, the adversaries to the non-visibly disabled. Teachers, you are our most powerful allies! Many teachers will tell you that they teach much more than the subject matter of their curriculum. We model (we hope) healthy behavior for our students in post-secondary education, responsibility and caring for those who teach high school, and basic societal rules such how to raise one's hand or stand in a line for those in primary education.

Teachers have perhaps the most challenging role in this examination of non-visible disability. They easily become the "bad guy" and often are placed in very vulnerable positions. Teachers are charged with teaching the very curriculum non-visibly disabled students find (at the least) problematic and, more commonly, very threatening and dangerous. Teachers are the bearers of bad news, and with limited coping skills and the lack of privilege to stay calm, many non-visibly disabled students

release their frustration, fear, rage, and anger on their teachers. In essence, we shoot the messenger, when really we should be finding ways around the messenger's message.

In fairness, it is difficult for anyone to overcome a threat to his or her face. When students react adversely, it is common for teachers to want to turn away and withdraw offers for outside help. I implore you teachers, please see through their anger. Know that though you are bearing the brunt of the frustration, you are the first line of hope for the non-visibly disabled. Allow them to be angry; everyone has a past and most likely there is something in theirs that gives them the right to be angry. This is in no way a call to tolerate abuse from students. Be keenly aware of anger the student possesses from their situation and anger that is directed at you. Acting out in class is often a cry for help. A check in after class is dismissed often cues the non-visibly disabled that you are an ally and not one to stand in their way.

Dealing with issues where behavior is the tell-tale symptom is perhaps the most frustrating. The behavior adds a layer to the problem, and only after the face threat is resolved can we address the core problem directly. It is near impossible to arrange accommodations for students who are unwilling to be helped. If the non-visibly disabled person is unable to ask for help or unwilling to receive help, then the situation becomes more complicated, especially in situations like high school where the student is mandated by law to attend and the parents are involved.

These situations possess hope for both student and teacher. De-escalation is possible as is mutual understanding. If teachers can see through the direct disobedience, the curse words, and the disruptive behavior and communicate with students in a place

that is not a threat to their face, not calling them out in front of class, it is likely that the students will engage in this conversation. If a student is approached with a non-threatening check-in kind of meeting, the lines for communication are wide open. Teachers must realize that as much as we would like to think of our classrooms as safe environments, they often times are not. Threats of failure and humiliation still loom in the shadows of the classroom, and the frustration the student feels never really disappears, no matter the location. It is important for teachers to keep this in mind when addressing non-visibly disabled students.

The other extreme is to treat these students as though they are less intelligent, to pity them, or to pull your academic punches and refuse to challenge non-visibly disabled students. As with other non-visible disabilities, learning disabilities are a matter of processing, not a matter of intelligence. Non-visibly disabled people are no less intelligent than their non-disabled peers. All eleven participants in my study were of average or above average intelligence, yet they all struggle with learning new material.

$2 + 2 = \textit{Diploma}$

“There is no way I’m going to put you in a geometry class Dana. ”

“But I need 2 years of math to graduate. ”

“Yes, but I can tell by your grade in algebra that you won’t do well in geometry.

”

“If you’re bad at algebra, isn’t there a good chance you will do well in geometry?”

“I can tell by your grades that you won’t. ”

“So what am I supposed to do so I can graduate from high school?”

“I’m going to put you in a special section of math. It’s math having to do with money, like counting change and so on. ”

“Oh, I guess that’s okay...”

I remember this meeting with my high school counselor. Like it was yesterday, I can see her powder pink suit and blond curly hair. She promised me a meaningful math class, but what I wound up in was an after school class for “special” math students. I was mortified when I discovered that this class was only held after regular school hours, hindering my chance to work, and freeing up a whole class period during my day that I had to account for to my friends who wondered why I wasn’t going with them to their twelfth grade math classes.

There was no mention of dyscalculia, no offer for tutors or accommodation. I was persuaded that this miraculous class was the answer to my math woes. I remember the utter blow to my ego when on the first day when I walked in, sat down and opened up the reader (we weren’t allowed to have books). Page 1, question 1, $2 + 2 =$

What an insult. I suffered through this class all year doing arithmetic and long division just so I could get my high school diploma.

Though I have stories and a voice as both teacher and student, I am keenly aware that I tread on sacred ground. Teachers are people too and to that end fallible. They are the heroes of our society, yet they are often underpaid and overworked; it is impossible

for them to reach out to all their students. Yet this does not mean that there is no room for improvement in how teachers communicate with non-visibly disabled students. It is tempting to assign blame and fault, to either a teacher or a student, when a communication misunderstanding happens. I believe that we will not serve to help or support teachers by condemning their classroom communication skills but rather we need to frame the emotions and behaviors of the non-visibly disabled in a way that allows the teachers to save face and retain their academic integrity when accommodating a non-visibly disabled student.

Teachers, please understand that no matter what the grade level or subject, non-visibly disabled students are likely to find their way onto your roster. It is possible to maintain the strictest academic integrity and challenging course material and invite the non-visibly disabled students to have their accommodations. There is a difference between lazy and disabled. Mutual understanding between student and teacher allow for better communication paths and ultimately result in better odds of success for both people. While students, particularly high school students, may be likely to challenge the curriculum, I encourage teachers to rise to that challenge. Use the freedom you have within your own govern classrooms to make course material relevant. Allow yourselves to laugh with your students, indulge them in five minutes of rapport-building at the beginning or end of each class. Encourage them to teach you about pop culture or things that are relevant in their lives and make an effort to relate that material to your lesson plans. Above all, keep the lines of communication open with you and your students. Do not allow stereotypes to define your relationship with students. Though stereotypes

may play out to be true in some cases, they hinder the trust the student puts in you. It may be easy to dismiss their concerns as lazy, too much partying, irrelevant, naive or ignorant. These students, particularly college students, are diligent workers and want to succeed. Their fear of being held to impossible standards can be ameliorated by connecting with them and maintaining communication.

Implications for scholars and researchers

What I am supposed to be and what I actually am

My mother and father had no idea I was dyslexic until I was in my late twenties, far too late if you ask me. They did all the things they were supposed to do. Mom listened to my teachers who told her I was intelligent, but lazy. She and my father took away TV and phone privileges for bad grades. I'm pretty sure I was grounded for the better part of high school. When nothing else worked, they made me sit at the kitchen table for hours on end to do my homework because they were afraid I was just too distracted when I tried to do homework in my room. They never compared me to my younger, but much smarter, sister. I always felt she should have been the oldest since she is so much better a role model than me. She transitioned between grades flawlessly, recalling information she had read in the previous years to build on that knowledge. She was the easiest to raise of the three of us and would have been more of a help to my parents had she been in a position to guide and mentor me. She should be the leader of our generation of this family, not me.

After I escaped high school by the skin of my teeth, I was diagnosed with my learning disabilities in community college. Even after the diagnosis, mom didn't want to

say I was dyslexic, she preferred the term “reading disorder” for the first year. I think there was a certain amount of guilt that went along with the label “dyslexic. ” All the fights, all the times I screamed at her, all the times she screamed at me, I’m sure that weighed heavily on her mind. We can never get those times back. Maybe I wouldn’t have gone to live in the group home if I had better communication skills, maybe if we understood each other, maybe if she understood how I see words, there would not be a dark and tumultuous past for us. Maybe we would be closer. It’s too late for “what if”s and “maybe”s. The past is exactly that and there it stays. Yet when looking at how this disability has shaped me, I cannot help but see how it shaped my relationships and it is just impossible for me to separate the two.

I cannot state it more simply than this: More research is needed. Non-visibly disabled people suffer in front of our eyes everyday, yet without knowledge of it, scholars are helpless to reach them. Make no mistake, this is not an issue best left to psychology, psychiatry, neurosciences, marriage and family counseling, or behavioral medicine. This is squarely at the feet of communication studies scholars and researchers. These are issues of identity, power, privilege, and most of all, the communication skills of the culture of non-visible disability. Scholars such as Cornett-DeVito and Worley (2005), Braithwaite and Eckstein (2003), Wilson (2000) and Stromer (1983) have started us on this journey, but now we need further exploration. We need to examine the power and privilege of the teachers, parents, and non-disabled peers of non-visibly disabled students. Disabled identity is a deep subject which has yet to be probed by cultural communication

scholars. Intercultural communication scholars can become instrumental in the solidification of the disabled culture as it is so diffuse now. The labels these non-visibly disabled students are given divide them from parts of society, peers, and even family members. These labels drastically shape identity well into adulthood. The label of “disability” is just as powerful as an ethnic, racial, or socioeconomic label identifier. Further studies in this area are pertinent to further understand the complexity of these issues and necessary to help those, both the non-visibly disabled and their non-disabled counterparts, who struggle with finding meaningful, healthy, and successful ways of coping and advocating.

It may be tempting to be dismissive of data collected from angry students. However, these outbursts are not temper tantrums, but rather pieces of their stories—stories which demand an audience and in-depth analysis. These stories are very real and meaningful and are exactly the kinds of stories that communication studies scholars would benefit greatly by examining.

These reactions from the participants are reactions to situations of perceived crisis. These non-visibly disabled people are reacting not to the compliment of his or her intelligence. The statement “It’s all in your head. You have so much potential, you just don’t apply yourself” might not seem explicitly threatening or even problematic, yet this is, in fact, an extremely dangerous statement to hear. Moreover, these statements usually come from teachers, school administrators, and parents. All people who are charged with setting standards for student’s academic success. It is indicative of the standard of

achievement the non-visibly disabled are held to, and the culture of disbelief (Fraser, 2007) to which they belong.

The people who find themselves in these situations, the non-visibly disabled who are trying to not only survive but thrive in the culture of disbelief that has set the standard for their achievements, are forced to become masters of innovation, thinking up new, creative, and perhaps unorthodox solutions to the problems posed to them in their daily lives. Whether this entails keeping odd study hours to pass a high school exit exam or writing term papers in front of the television, these non-visibly disabled students cannot reach this standard without augmentation of and alteration to the methods others use to reach these standards. Since the focus of this curriculum is outcome-based, as with the high school exit exam, the non-visibly disabled tend to focus on the level of accomplishment they need in order to be considered successful and not the measures they need to take to reach such levels. This often leads to a breakdown in communication as the parents, teachers, and school officials who are not disabled see only the defeatist attitude and the unwillingness to attempt to succeed. Perhaps in these situations the accommodation itself is the focus on the smaller, more manageable goals, rather than the larger, more daunting tasks.

Reactions of anger and angst may seem disproportionate to the situations in which these participants find themselves. Let us not fall into the trap of labeling one party as unreasonable and therefore incapable of rational discussion. These people are in crisis, they are scared and anger is a manifestation of fear. Perhaps the non-visibly disabled person is incapable of articulating this fear and anger, but, as communication studies

scholars, the onus is on us to deescalate the situation. Here the most important information we have is the communication patterns and styles of the non-visibly disabled. It is easy to dismiss angry writing as bad writing, and angry behavior as bad behavior, but we deny them the attempt at mutual understanding that is a solid pillar of our field of study. We as scholars and researchers must not turn away from these people but seek them out. They are not angry, malicious, or threatening people, yet they maybe perceived that way because of the only skills they have to cope. Many of these people are learning to advocate for themselves in high school when their tools of communication seem more vast than they actually are. Their means to cope is very limited and without the very education they are advocating for, it is impossible for them to expand their knowledge and communication skill set as a means to cope.

Here we can see that calmness truly does come from a place of privilege (Woodhouse, 2007). Calmness implies the lack of crisis, and the less critical the situation, the easier it becomes to omit emotion from our dealings with it. Students are held to the same standard in primary and secondary education, yet students who perceive, induce or deduce, or know that they will have problems reaching the same goals as other students without augmentation and accommodation are less likely to be calm about their situation.

Ribbons, bows, and autoethnographers

If a thesis is a present the conclusion is the ribbon. The nice little bow that adds just the right accent to the package. The problem is that this autoethnographic thesis is no package, there is no bow that neatly ties it all together. It is the intention of this thesis

to pose more questions than it answers. It is through autoethnography that this happens. I have used autoethnography to bring to light this problem, the oppression of the non-visibly disabled through education, this social injustice that so desperately needs further analysis and research.

My story, and the stories of my participants, my people, have no bows, no ending, no neat little conclusion to tie up all loose ends and package up our lives for the easy consumption of our readers. I do not have enough distance on this project to weave in a healthy dose of self-reflexivity, yet this does not negate the validity of my thesis, my story, my people. Though I lack distance, the metamorphosis that has happened over the past three years is easy to see. I have gone from angry student, punk rocker jockette with boarder line anger issues to advocate, scholar, and writer. It is a change that many of my non-visibly disabled peers will never go through and it is my calling to help these people, my people, find ways to better their situations through self-advocacy, and the education of those who hold the reigns of power. As I strive to gain self-reflexivity in my own life I make the same call to you, the reader, to explore the ways in which you participate in the oppression, misunderstanding, and crisis of the non-visibly disabled people around you. I ask this not to evoke guilt, but hope. Perhaps a shift in communication, the recognition of problematic discourse, or simply a friendly check-in with a student or peer is all that is needed to better the immediate situation for the non-visibly disabled. These things may not fix the oppression and struggle that non-visibly disabled people face, but it will help them in their day-to-day lives. We suffer, often in silence, around you. All of my readers, including the non-visibly disabled ourselves, have the power to reach out

to those around us and alleviate the suffering of someone who struggles with a non-visible disability.

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APPENDIX A:
HS-IRB APPROVAL



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UNIVERSITY

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To: Dana Morella
5195 Calicowood Pl
San Jose, CA 95111

From: Pamela Stacks, Ph.D. *Pamela C Stacks*
Associate Vice President
Graduate Studies and Research

Date: March 20, 2008

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Disability, advocacy, and copying: understanding the intersection of non-visible disability, disclosure, and expectancy violation"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to all data that may be collected from the subjects. The approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Pamela Stacks, Ph.D. immediately. Injury includes but is not limited to bodily harm, psychological trauma, and release of potentially damaging personal information. This approval for the human subject's portion of your project is in effect for one year, and data collection beyond March 20, 2009 requires an extension request.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services that the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

Protocol # S0802052

cc. Deanna Fassett, 0120

The California State University:
Chancellor's Office
Bakersfield, Channel Islands, Chico,
Dominguez Hills, East Bay, Fresno,
Fullerton, Humboldt, Long Beach,
Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San José, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

APPENDIX B: AGREEMENT TO PARTICIPATE IN RESEARCH

Agreement to Participate in Research

Responsible Investigator: Dana Morella

Title of Protocol: Disability, advocacy and coping: Understanding the intersection of non-visible disability, disclosure and expectancy violation

You have been asked to participate in a research study investigating the experiences—the successes and the struggles—of college students with non-visible disabilities. You will be asked participate in 1 or 2 interviews (each approximately one hour long) with Ms. Morella, a graduate student, at times, dates and locations that are mutually convenient; these discussions will be audiotape.

While you are participating in this study, you may choose to reflect on personal experiences that are challenging or uncomfortable. You may enjoy having the opportunity to share your experiences with advocacy and coping as a college student who has a disability.

Although the results of this study may be published, no information that could identify you will be included. You will receive no monetary compensation for participation in this research study.

Questions about this research may be addressed to Dana Morella, (408) 924-5360, <danalu63@hotmail. com>. Complaints about the research may be presented to Dr. Deanna L. Fassett, Graduate Coordinator, Department of Communication Studies, (408) 924-5511. Questions about research participants' rights, or a research-related injury, may be presented to Dr. Pamela Stacks, Associate Vice President, Graduate Admissions and Program Evaluations, (408) 924-2480.

No service of any kind, to which you are otherwise entitled, will be lost or jeopardized if you choose to not participate in this study.

Your consent is being given voluntarily. You may refuse to participate in the entire study or in any part of the study. If you decide to participate in the study, you are free to withdraw at any time without any negative effect on your relations with San José State University or with any other participating institutions or agencies.

At the time that you sign this consent form, you will receive a copy of it for your records, signed and dated by the investigator.

- **The signature of a participant on this document indicates agreement to participate in the study.**
- **The signature of a researcher on this document indicates agreement to include the above named participant in the research and attestation that the participant has been fully informed of her or his rights.**

Participant's Signature

Date

Investigator's Signature

Date

APPENDIX C:
INTERVIEW GUIDE

Guide for Participant Interviews

1. Please describe your disability.
2. Describe some frustrations you encounter with your disability.
3. What sorts of accommodations or special education have you received for your disability during your college career? Can you describe your accommodations?
4. In what ways have your accommodations/education addressed your needs? What needs do you have that are still unmet?
5. If yes, do you encounter resistance getting these accommodations in your classes?
6. Have you ever felt failed by someone that was supposed to help you (teacher, counselor, and advisor)? What did you do?
7. What do people not understand about your disability?
8. Do you hesitate to disclose your disability at times? Where and when do you feel safe disclosing your disability? Where and when do you feel unsafe disclosing your disability?
9. Have you ever encountered anyone who does not believe you are disabled? What was that like for you?
10. How have you coped with your disability?
11. What advice would you give to other college students who struggle with non-visible disability?
12. In what ways has your disability been an advantage to you?
13. Who has been the most helpful to you? How so?