

University of Nebraska - Lincoln

DigitalCommons@University of Nebraska - Lincoln

---

Theses, Student Research, and Creative Activity:  
Department of Teaching, Learning and Teacher  
Education

Department of Teaching, Learning and Teacher  
Education

---


4-2015

# The Disabled Teacher: A Memoir of an Interrupted Pedagogical Career, a Life with a Chronic Illness, and an Encounter with Real Barriers to Inclusive Education

Dorothy M. Bossman

University of Nebraska-Lincoln, [dottiebossman@gmail.com](mailto:dottiebossman@gmail.com)

Follow this and additional works at: <http://digitalcommons.unl.edu/teachlearnstudent>

 Part of the [Curriculum and Instruction Commons](#), [Disability and Equity in Education Commons](#), [Educational Methods Commons](#), and the [Secondary Education and Teaching Commons](#)

---

Bossman, Dorothy M., "The Disabled Teacher: A Memoir of an Interrupted Pedagogical Career, a Life with a Chronic Illness, and an Encounter with Real Barriers to Inclusive Education" (2015). *Theses, Student Research, and Creative Activity: Department of Teaching, Learning and Teacher Education*. 53.  
<http://digitalcommons.unl.edu/teachlearnstudent/53>

This Article is brought to you for free and open access by the Department of Teaching, Learning and Teacher Education at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Theses, Student Research, and Creative Activity: Department of Teaching, Learning and Teacher Education by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.

THE DISABLED TEACHER: A MEMOIR OF AN INTERRUPTED PEDAGOGICAL  
CAREER, A LIFE WITH A CHRONIC ILLNESS, AND AN ENCOUNTER WITH REAL  
BARRIERS TO INCLUSIVE EDUCATION

by

Dorothy M. Bossman

A DISSERTATION

Presented to the Faculty of  
The Graduate College of the University of Nebraska  
In Partial Fulfillment of Requirements  
For the Degree of Doctor of Philosophy

Major: Educational Studies  
(Teaching, Curriculum, & Learning)

Under the Supervision of Professor Edmund T. Hamann

Lincoln, Nebraska

April 6, 2015

THE DISABLED TEACHER: A MEMOIR OF AN INTERRUPTED PEDAGOGICAL CAREER, A LIFE  
WITH A CHRONIC ILLNESS, AND AN ENCOUNTER WITH REAL BARRIERS TO INCLUSIVE  
EDUCATION

Dorothy Marie Bossman, Ph. D.  
University of Nebraska, 2015

Advisor: Edmund T. Hamann

This dissertation is a narrative exploration of multiple themes relevant to education research: the relationship between the university and school, epistemology, teacher identity, disability studies, researcher subjectivity, and the retention of quality educators. This work of “autoethnography” (Ellis, Bochner, & Adams, 2011) approaches these topics through the tellings of a teaching career, the awakening of an education scholar, and the development of a chronic illness. While the focus of this inquiry often returns to the researcher’s pedagogical identity, the three storylines interact in myriad ways that relate to the larger field. Removal of one of these narrative threads would, metaphorically, unravel this effort and render the work into something less powerful. As a teacher, I struggled to maintain my pedagogical values during my time in secondary schools. As someone who remained a teacher while pursuing a Ph.D., I became a double outsider whose presence in two spheres of education exposed the divide between them. At the same time as these developments, I developed multiple sclerosis, which progressed over my ten years in the classroom. The profound experiences of adjusting to life with a disease and learning to cope with physical disability impacted my practice, research interests, and identity. For some readers, this work stands as an example of a memoir within the genre of “literature of the personal catastrophe” (Mairs, 1994), but for others the writing will be interpreted as “a love letter to teachers” (Ayers, 1993). Ultimately, the

project is a criticism of the mechanism of public education, “to challenge traditional educational ideology” (Giroux, 1988, p. xxx), with particular focus on the systematic edging out of committed teachers and the disrespect for the wisdom most relevant for constructing curriculum and preparing young people for their lives.

## ACKNOWLEDGEMENTS

This project would not have been completed without the devotion and indefatigable support of my partner in everything that truly matters, David Bossman. It would not have been completed as well without the direction and trenchant editing of my advisor, Ted Hamann. I am grateful to my daughters and my extended family for their patience and enduring faith in my ability to finish a PhD and to complete this dissertation. I dedicate this work to all of the young people who gave me the honor of being their teacher and to the many educators whose lessons enriched my life. It is my hope that the finished product is worthy of the individuals who made its creation possible.

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	1
CHAPTER 1: INTRODUCTION (WORTH THE FIGHT) .....	1
CHAPTER 2: THE DIVIDE.....	13
CHAPTER 3: MY LIFE AS A READER.....	19
CHAPTER 4: SEPTEMBER EPIPHANY .....	25
CHAPTER 5: METHOD (MY EPISTEMOLOGICAL STANCE).....	31
CHAPTER 6: LITERATURE REVIEW 1 .....	39
(EPISTEMOLOGY AND THE RADICAL TEACHER).....	39
CHAPTER 7: CORRECT TRAINING .....	53
CHAPTER 8: LITERATURE REVIEW 2 (DECEIT AND DISENCHANTMENT).....	59
CHAPTER 9: THE RESEARCH PROCESS, INTERRUPTED AND REIMAGINED.....	70
CHAPTER 10: MEMENTOS .....	96
CHAPTER ELEVEN: LITERATURE REVIEW 3(LITERATURE FOR A PERSONAL CRISIS) .....	102
CHAPTER 12: A DISABLED WOMAN .....	120
CHAPTER 13: ON BECOMING A NUMBER.....	128
CHAPTER 14: ULTIMA .....	139
CHAPTER 15: WHAT MY KIND HAS TO OFFER .....	148
CHAPTER. 16: WHAT IF THIS COULD HAVE HAPPENED? .....	158
CHAPTER 17: FROM HERE (AN EPILOGUE).....	167
 <u>WORKS CITED</u> .....	 171

## CHAPTER 1: INTRODUCTION (WORTH THE FIGHT)

This document is a memoir from the life of a teacher and scholar, as well as a work of research. As the narrative aspects of the piece will demonstrate, I hold that the process of inquiry begins with a human interest in something and those engaged in research cannot disassociate their work from their lived experiences. Although some perspectives on scientific research continue to claim that good research should be unbiased, “researchers (like anyone else) have been influenced by the particular understandings about, and interpretations of, the world to which they have been exposed” (Sikes & Goodson, 2003, p. 34). I do not believe, however, that this assertion lessens the value of such endeavors; rather, examining closely those who are involved in the process adds another dimension from which we can gain insight:

As part of the research situation, the researcher himself or herself is worth studying. To fully account for the texture of everyday life, it is not sufficient to relegate to a methodological appendix or later memoirs, “What this experience meant to the investigators.” Rather, we must look to the experience and see the anxieties, fears, delights, and repulsions as part of the very situation we are trying to understand.

(Zola, 1983, p. 194)

In addition to its candid portrayals of an interrupted secondary school teaching career and a particular process of inquiry, this writing is also the story of an experience with a chronic illness. For years, I attempted to hide my multiple sclerosis and its disabling effects so I could *pass* as healthy. But “both passing and overcoming take their

toll” (Linton, 1998, p. 21), and my illness refused to stay hidden; ultimately, its development became part of the research situation. This rendering honors my physical condition as relevant and powerful, even if parts of the narrative are unpleasant as a result. In the words of sociologist Arthur Frank, “The [illness] stories are uncomfortable, and their uncomfortable quality is all the more reason they have to be told. Otherwise, the interrupted voice remains silenced” (1995, p. 58). It is my hope that readers will be willing to brook a certain amount of discomfort in order to gain a clear picture of this “hopelessly human” (Wolcott, 1992, p. 7) story of inquiry and personal transformation.

Beyond tolerating the portrayals of adversity because they are necessary to further my narrative, I also hope that readers see that in difficult moments there can also be delight. Some of the most trying situations drew me into the intellectual worlds of poets, scholars, and scientists, allowing me to form significant connections across space and time. As I teach, as I learn, as I grasp more deeply the meaning of a life with multiple sclerosis, and as I become someone new in these ventures, I am indebted to the insights of many writers. Throughout the narrative, I weave in diverse texts that have enabled me to better understand my experiences in light of a larger story of human beings involved in quests like mine. Through the creation of a “thick description” (Geertz, 1973) of my experiences, including what I have gained as well as what I have lost, my writing furthers the agenda of disability studies, which “aims to dislodge the medical model of disability, replacing the narrow and deficit-based understandings of disability with alternative knowledge claims grounded in disabled people’s subjective and situated experience” (Ferri, 2011, p. 2271). Like an ethnographer who seeks to foster an understanding of a person’s culture by “[exposing] their normalness without reducing their peculiarity”



(Geertz, 1973, p. 14), the intention of my candid narration is to draw readers into a clear understanding of a human reaction to a series of unique situations, profound crises, and broader dilemmas.

My audience for this writing is, by necessity, the members of a committee whom I hope will see in this work sufficient evidence that I have earned the honor of a PhD; however, my intended readership is comprised of four large and important groups of people. First, it speaks to teachers—a class of humans in which I am pleased to name myself—because this audience will understand most keenly the love that has embodied every teaching opportunity I have had and they will likely empathize with the pain that accompanied my loss of a classroom. Second, it speaks to researchers of education who seek a deeper understanding of the mysterious power of pedagogical relationships and those who are concerned with the policies and institutional factors of schools that most affect these arrangements. Third, this work speaks to those who prepare teachers for careers; they will witness in my narrative an example of the real struggles—intellectual, moral, and emotional—that await new members of our profession. Fourth, I speak to the group I joined as a result of this journey, disabled men and women, particularly those who refuse to be cast aside and those who do not stay in the marginalized shadows allotted to our kind. For these readers, it is my hope that the narrative honors their stories and that the work I will continue to do as a scholar, a teacher, and a researcher furthers their efforts and illuminates continually the importance of our struggle for inclusion.

A theme that pervades this document is my identification as a teacher, an important aspect of myself that I have fought to retain. The profound nature of this crisis can be best understood if I describe the beginning of my life as a pedagogue, a passion

that began unexpectedly. I remain proud that when I know material well—and particularly if I love it—I can always find the confidence to teach it. Although this capability is an important piece of my identity, I was not always aware of it. Based on myriad experiences dealing with varying levels of social anxiety growing up and since, I was genuinely stunned and delighted by my ability to overcome introversion for the sake of a lesson. In most social settings, I am reticent and uncomfortable interacting with others, but when a class begins, I can find myself situated comfortably in the role of teacher. Caught up in a pedagogical mission, my singular focus on conveying the potential of the material allows me to eschew any other concerns until a lesson has ended. In the act of teaching, to quote from a favorite Emily Dickinson poem, I get a glimpse of a “brittle heaven” that keeps me persevering to bring it closer (Dickinson, 1960, p. 337).

The first time I had this experience was July 2001, when I was training for the Peace Corps in Vladivostok, an industrial port city in the Russian Far East, just north of both Japan and North Korea. My job title was “language instructor,” despite my lack of pedagogical training, and I was unsure what to expect. My first assignment was to teach summer school for a group of Russian high school students who were advanced at English and wanted to learn more about American literature. Excitedly and nervously, I prepared a detailed lecture on my favorite poet.

The classroom was a large and ancient space, too full of wooden school furniture, piles of books, and cardboard boxes, lit by large windows that offered expansive city views. Facing a bedraggled chalkboard, six young people sat expectantly and silently as I nervously walked up to face them. I remember the eyes of these Russian students as I started talking about Emily Dickinson; they were so eager to listen that my fears

dissipated and my enthusiasm took control. I recall that I felt strong in that bright space as I delivered that lesson. I relied on my love of the subject, naturally sharing my personal connections with many of her poems. Teaching with passion and personal knowledge (rather than reading my lecture, as I had practiced) was thrilling.

The next day, a few students asked if the class could memorize one of the poems we had discussed. I selected “I’m nobody, who are you,”<sup>1</sup> which they eagerly learned, practiced, and performed during our class a few days later. When I think back to my first induction into teaching, I can still hear a group of lovely, accented Slavic voices saying, “How dreary to be somebody, how public like a frog” (Dickinson, 1960, p. 133). It was beautiful.

Once I discovered this transformative power of teaching—especially its ability to transform me—I never stopped seeking chances to express and improve that part of myself. I returned to school for teaching credentials, began working as a secondary teacher, and then chose to pursue a PhD in education. My pedagogical self, or “inner teacher” (Palmer, 1998), is an integral part of my identity that survives and sustains me still.

I was not ready to leave teaching when I resigned. I had not stopped loving it nor had I stopped delighting in its ability to bring out the best in me, regardless of events in other areas of my life. Quitting was never my idea, and I am still not willing to look on the job as something I *used to* do or teacher as something I *used to be*. Based on a conviction that “the teacher is what he or she teaches” (Manen, 1991, p. 77), I hold that

---

<sup>1</sup> Dickinson did not title her poems, most of which she had no intention of publishing. This one is actually called “288” and the previous one I mentioned is “680.”

my choice to teach English was personal. My practice was an essential expression of my identity. When I first became aware of learning as an activity, I fell in love with the possibilities for personal transformation that each domain of knowledge revealed. When learning something new, I delight in “the prospect that I will find another way to see into the world, glimpse its beauty, reconstruct it in a way not yet known to me” (Liston, 2004, p. 469). Teaching provided daily chances to express my love for learning, my appreciation for a subject and, through the next generation, my hope for the future. I intended to use my time with students to illustrate what had been a profound revelation for me; learning new domains can enhance our ability to respond to the world. Knowledge can improve “who we are as persons” and I wanted young people to “stretch beyond [their] capacity to respond” (Stengel, 2004, p. 152). I felt deeply rewarded whenever those moments of greatness revealed themselves in my students.

I also felt honored by the chance to influence education, something that I believe “has the power to modify the social order” (Dewey, 1909, p. 7). My choice of this profession, and my decision on the most difficult days to keep trying, was supported by the optimism inherent in the existence of public education. As I watched students and colleagues at work, I saw an “infinite capacity for reinventing the future, imagining things otherwise” (Meier, 2002, p. 184). Each spring, when my time with students drew to its end, I felt an urgency to do as much as possible in every moment that remained. As tired as each year leaves those of us involved in “the drama of education,” we return with vigor, spurred on by the knowledge “there is always more to do, more to learn and know, more to experience and to accomplish” (Ayers, 2010, p. 5). I never stopped feeling that drive.

Nonetheless, my life changed when I developed multiple sclerosis. As a result of its progression, I no longer have a classroom (or a title) at a school; my deteriorating health monopolizes much of my energy; and I am often marooned at home. These are logistic factors, external to me, and they do not change who I am, the teacher I still am. My position in a school did not make me a teacher; access to a classroom and the expectation that I would guide what happened within it did not make me a teacher. Rather, the job provided me with opportunities to articulate and enrich a part of me that was always there, my “inner teacher” (Palmer, 1998). Since I began my relationship with education, the questions have kept me enamored; the chance to unearth or foster a passion for inquiry in my students “[made] teaching worth all the struggle and exhaustion” (Martusewicz, 1997, p. 110). It was not always easy on my health to work in a school, but the rewards of the job made its physical costs a viable exchange for the many years between my first diagnosis and my eventual resignation.

I have not lost the piece of myself that remains a teacher, but now I must seek a different outlet to express it. As I endeavor to cultivate a new pedagogical self, I must remember that being a teacher has always been difficult. When I worked in buildings that literally had signs out front declaring that they were ‘schools,’ I regularly faced failure, conflict, loss, anger, tedium, isolation, disrespect, and exhaustion, but I also knew joy that outweighed these trials. It is not a platitude to say that I learned from adversity; when I had to adjust to certain constraints (including my loss of mobility and energy); my creativity grew from “tensions that cannot be resolved in terms of ordinary solutions” (Csikszentmihaly, 1996, p. 87). I simply had to act.

In some of the most challenging moments of my life, my teaching skills were actually improving in exciting ways. Many artists (teaching *is* an art) have experienced that “resistance that calls out thought generates curiosity and solicitous care, and when it is overcome and utilized, eventuates in elation” (Dewey, 1934, p. 62). I had many such moments. The hours I spent instructing young people were a welcome respite when other aspects of my life were fraught with pain. My students, all those young people who came into my life serendipitously, frequently amazed me. I am grateful that I had the chance to be their teacher, to love them so deeply, and to gain wisdom from them. The job was a privilege.

Tone matters, and an important goal for this text is to celebrate some of the wonderful aspects of my time in the classroom and also to recount the most influential experiences I had with young people. I do want not to diminish my students’ profound impact on my practice, but the cultivation of a capable teaching self is only part of this account. As my passion for the teaching endeavor deepened, I approached graduate study with similar aplomb. Initially, I benefitted from concurrently acting as a student and a teacher; I delighted in improving my repertoire and I appreciated the chances I had to apply what I was learning to creating materials and lessons. Over time, and particularly once I began work on a PhD, my eagerness to live as a researcher and a teacher (and to talk about it) led to my status as an outsider among colleagues at school (Wilhelm, 2008; White, 2011). My studies offered me a rich understanding of education research, history, theory, method, and policy; at the same time, my perception of the larger system of education in which I was working became one of disenchantment. As a burgeoning scholar and as teacher made increasingly aware of the “irreducible complexity” (Labaree,

2010) of the job, the tightening confines of public education made it harder to flourish. The story of this gradual awakening and my related “intellectual crisis” (Ravitch, 2010) also comprises an important part of this memoir.

The narrative of my teaching career will include moments that are difficult to revisit, but that story remains much easier to tell than the one about the progression of a disease. Looming above this account, and casting its shadow onto every positive and negative memory of teaching, is a health condition that is still a constant (and unfriendly) companion. I was diagnosed with multiple sclerosis during my second semester as a middle-level English teacher, when I was twenty-seven years old. It was the insidious progression of this disease that ultimately ended my tenure in the classroom, rather than disillusionment about education or a failure to succeed within the system. Despite its powerful impact on my life, a chronic illness is just another part of this narrative, which is not designed “to complain or call attention to the specialness of my personal disaster” (Ellis, 1995, p. 334). This is not meant to be a tragic tale.

Instead, I believe that the complex interweaving of these threads of experience into my development as a teacher and thinker are interesting; considered as one cloth, they form a new curriculum that I am compelled to share. In this effort, I get to remain a teacher. Parts of my story *are* rife with pain, but only through recounting the vicissitudes of experiences can I clarify what I really learned from them. Through this instructive memoir, I hope to illustrate that the trials I have endured rewarded me with insight. As I share my story, my goal is for readers to look within their own experiences, even those that caused pain, for wisdom. In the words of memoirist Nancy Mairs (1994), “I invite you into the house of my past, and the threshold you cross leads you into your own” (p. 120).

I hope to inspire others to pursue and continue their teaching careers, regardless of the costs, because their work matters. As William Ayers (2010) reminds us at the end of his own memoir of teaching, “There are still worlds to change—including specific, individual worlds, one by one—and classrooms can be places of possibility and transformation for youngsters, certainly, but also for teachers” (p. 20). I write as someone who remains an educator, a scholar, *and* someone with a disease; it is my hope that this writing will evince my certainty that it is worth the fight to keep doing this work, to remain part of this particular “exhilarating and playful adventure” (Csikszentmihaly, 1996).

The document that lies ahead follows (often, but not exclusively chronologically) a teaching career, an awakening of a scholar of education, and the development of a disease. These three stories interact with each other, overlapping in interesting, complex ways. The introduction describes the genesis of my love of teaching and offers my unique perspective on this profession. Chapter two, “The Divide,” and four, “September Epiphany,” describe two key intellectual developments that were the result of my doctoral work. I step back to tell my history of literacy in chapter three, “My Life as a Reader,” in order to clarify the perspective on texts that I brought to graduate work and teaching. Chapter five, “Method” describes my approach to research and scholarly thinking about education, with references to works that most influenced me. Next is a literature review, “Epistemology and the Radical Teacher,” chapter six, which describes my evolving research interests and outlines the line of inquiry I originally planned to follow for my doctoral research. In relationship to these intellectual developments and my experiences as a doctoral student, flourishing as a public school teacher became



increasingly difficult, as depicted in chapter seven, “Correct Training” and eight, “Deceit and Disillusionment,” a second literature review.

In the middle of the document, my experience with multiple sclerosis occupies a more prominent place, just as it demanded more from me in reality. Chapters nine, “Research Interrupted,” ten, “Mementos,” eleven, “Literature Review for a Personal Crisis,” and fourteen, “Ultima” discuss the revisions in my career and my identification as a teacher and a researcher that developed as a result of my worsening health and loss of a classroom. Chapter twelve, “A Disabled Woman,” chapter thirteen, “Becoming a Number,” and chapter fifteen, “What My Kind Can Offer” consider ways that my voice and lived experience—in particular, as a scholar who is also disabled—can contribute to the areas of education policy, teacher preparation, and curriculum development.

Chapter sixteen, “What If This Could Have Happened?” adds to the discussion of what my perspective can offer with a fictional account of what might have been different if those who had the power to act in my situation had shared my conception of disability and believed, as I do, that the teacher is the most important resource in education. The last chapter of the document, “From Here,” is an epilogue that considers what steps will follow this project for me, both idealistically and realistically, and sums up—at least partially—what I have learned about research, education, and disability. In every chapter, this dissertation vividly depicts a particular research situation, with close attention to the role of the researcher herself. This choice places my work among other thinkers who “reject the tradition of hiding ourselves by using discourse, which attempts to neutralize, minimize, standardize, contain, control, distance or disengage our subjective or personal experiences” (Sikes & Goodson, 2003, p. 35). As

the candid narrative you are about to read will demonstrate, I offer my personal journey as data from which both I and the educational community can gain insight, wisdom, and direction.

For some audiences, my work is primarily memoir, within the genre of “literature of the personal catastrophe” (Mairs, 1994), including depictions of a developing a chronic illness, living with disability, and fighting barriers to remain functional in the world of the fit. But for others, my writing will look like “a love letter to teachers” (Ayers, 1993) from one who found a deep passion for the craft and, from this love, honed a pedagogical identity and philosophy of teaching. From another angle, my writing is also a radical criticism of the mechanism of public education, “to challenge traditional educational ideology” (Giroux, 1988, p. xxx), with particular focus on the systematic edging out of committed teachers and the disrespect for the wisdom most relevant for creating curriculum and preparing young people for their lives. For all readers, I can offer writing and thinking—wisdom purchased at a high price—extrapolated from concrete events of my life as teacher, a sufferer, and a scholar, to be useful for all those involved in the work of schools and those who happen to share my faith in education and the value of a pedagogical life.

## CHAPTER 2: THE DIVIDE

“The severest critics of qualitative research sometimes appear oblivious to the fact that *all* research begins with a totally subjective, hopelessly human decision about what to study.”

(Wolcott, 1992, p. 7)

It was my first class as a doctoral student and a group of tired-looking adult students were busy piling up provisions on their desks for the evening: bags of crunchy snacks, mugs of coffee, giant plastic cups of soda, and large boxes candy intended for movie attendees. I looked down at my outfit, wishing I had made myself look less like a middle school teacher, and I made a mental note to put a pair of jeans in my car. Nervously, I unpacked my bag that I had made quite heavy by bringing all of the texts for the class and a thick notebook. I should have brought something to eat. A woman I guessed was our professor walked in and, without fanfare or words, began to move our desks into a large circle, pulling and pushing them noisily across the waxed floor with surprising strength. We stood up and helped to create a lopsided oval (while trying to keep all of our items from falling) and then found ourselves facing each other, straining to make eye contact seem normal over our ridiculous accoutrements. Our professor introduced herself using only her first name, and indicated that we would start with a discussion. I flipped through my textbooks, wondering what preparation I was supposed to have done prior to this class.

Smiling, she wrote in large script on a white board, “What is your epistemological stance?” I glanced furtively at the others and was glad that none of them looked ready to

answer either. I attempted to think about the question. I knew what the word “epistemology” meant, but it was not part of any recent or memorable conversations. I had a fleeting recollection of an undergraduate philosophy teacher using the word frequently in his lectures, but that was more than a decade before. Also, my most vivid memory of that class was how ancient the teacher seemed, an observation enhanced by the wistful tone he used when talking about Athens at the time of Socrates. The group was silent and we averted our eyes, waiting for someone to make a gambit. Finally, a confident woman (dressed exactly how I imagined a doctoral student should dress, with a billowing blouse, large earrings and faded jeans) said that she always thought that knowledge was inside us, but that we had to work to discover it. That did not seem completely wrong, but I wanted to ask why I bothered to drive to another city for class, if I could have just found what I wanted to learn inside myself.

I did not ask my sarcastic question. I have forgotten most of our conversation, but I remember the realization that I had never tried to construct a theory of knowledge, despite my status as a teacher, my love for books, and a history of decent academic achievement. How could it be that I had never paused to reflect on the nature of learning itself in the midst of all that learning? After a few people said something more or less related to epistemology, we introduced ourselves, a part of entering new groups I have always loathed. After several students indicated how far they had progressed in their programs and which classes they taught at the university, I nervously said only that I had only been a doctoral student “for a few hours.” When the confident doctoral student described herself, she noted that she was conducting research at a high school and working on her dissertation. She indicated that she was finding it difficult to talk to the

teachers with whom she worked because, “You know, they don’t read research.” I tried to come up with a brilliant rebuttal, but lost the impetus when I noticed others nodding in agreement. As a teacher who could not even adumbrate a personal epistemological stance, I felt an urgent need to catch up on reading, thinking, and living like my graduate school peers.

There were many moments at the university and at work when I became aware of my status as a double outsider. In my doctoral courses, I frequently heard complaints about teachers who ignore educational research and teachers who resist innovation. My peers in the education department expressed wonder (among other emotions) at my desire to work full time as a secondary teacher while I pursued a PhD. My teaching colleagues questioned the benefits of studying education, since the researchers at universities do not know what schools are really like. I had heard many times that experts from college campuses, textbook companies, or government offices could not be trusted to know our classrooms or comprehend our actual teaching lives.

In our district, the disconnect between research about teaching and the experience of teaching was aptly supported by training activities during in-service days. Generally, the district would bring in authors of books or educational programs that prescribed solutions to educational dilemmas: How should we teach students who live in poverty? How can students do better on standardized tests? How can teachers mitigate hostilities with tough students? How do we motivate young people to stay in school? How can students do better on standardized tests? What are the best methods for teaching children with autism? How do you differentiate instruction for many levels? How can students do better on standardized tests? How can teachers address school violence and bullying?

How can teachers help ELL students in mainstream classes? How can students do better on standardized tests?<sup>2</sup>

Their sessions would be interesting, sometimes, and they occasionally shared relevant data and information about certain students, education legislation, and trending pedagogical approaches. I used to look through the materials, reading some of it closely enough to glean ideas for teaching. But then school would start again. The book, the brochure, or the pile of handouts from that event would get buried under the more timely paperwork and demands of my daily work with young people. Occasionally, administrators would refer back to the topics of these sessions, but without asking for our understanding or indicating how we should be implementing the ideas therein. If those presentations of facile solutions disconnected from the daily reality of teaching were the research to which my doctoral classmate referred, of course I did not read that, at least not with any faith.

In my first year living concurrently as a doctoral student and working in a public school, I soon learned that “research,” as it was presented by my district leadership during events of staff development and training, was not the same as the research I was learning to conduct and analyze as a doctoral student. I realized that my inability to formulate anything close to an epistemological stance illuminated a divide between the two worlds of education I inhabited. My role as a teacher and the expectations imbedded in the context in which I worked did not include opportunities for philosophical reflection on the nature of knowledge. It was not relevant what I *thought* about the information or its author; my job was to accept the truth—or at least not to argue with it—or the person

---

<sup>2</sup> The reader will notice the repetition of this question, which hints at its ubiquity during such sessions.

presenting it. Even though imparting knowledge was my business, I was not given the freedom to think about it critically. Of course I had never felt the need to create or to state my epistemological stance. Philosophical thinking about the source of knowledge was simply not relevant to my work and it had never come up in any of my professional activities.

It was that innocuous sounding question posed that night, years ago, that ultimately became *the* research topic for my professional life<sup>3</sup>. The creation of my own epistemological perspective (with the nuanced ways of thinking that accompany such a goal) excited me, but also marked the beginning of my alienation as a teacher. Adopting a critical stance on the paradigm in which I had been operating as an educator was an act of noetic freedom I had not experienced prior to doctoral work. In my experience, criticizing knowledge (or its source) is not a common activity for teachers, who are given frequently an abundance of informative items to digest: textbooks, curriculum guides, individual student plans, binders of teaching strategies, guidelines for classroom management, grading protocols, codes of conduct, legal responsibilities, testing procedures, and so on. There is often research (at least cited) in these materials, but its inclusion is not meant to invite criticism, dialogue, experimentation, or further reading.

When research was explicitly discussed where I worked, its function had actually been to silence discussions. During training sessions, if someone asked whether a practice that was being promoted or required would really work, the answer was generally akin to “the research says so.” And this answer was never an invitation for questions or

---

<sup>3</sup> I am forever indebted to my former professor, Dr. Margaret McIntyre Latta, for asking me that question and for showing to me that the mode of thinking it nurtured had the power to enrich my intellectual and professional life.

alternative perspectives (I know from experience), unlike the research I encountered in graduate classes. As a teacher, subordinate to administrators, policy makers, and the school district, my responsibility was to accept graciously the knowledge offered by those in power. As an experienced educator emboldened by my professors, my graduate school peers, and my training in research, I could not remain complicit in the passive reception of received knowledge. I lost the tact (and the stomach) to acquiesce and my pedagogical identity shifted: I was evolving into a “teacher as an intellectual” (Giroux, 1988) who found it increasingly difficult to function as I had before. In response, I sought an epistemological stance that would satisfy my passion for inquiry and bolster my ability to confront (and say out loud) difficult questions.



## CHAPTER 3: MY LIFE AS A READER

“Pearls!” He repeated, agape.

“I would keep them—I would not wear them,” she said, “only keep them.”

And she dropped her eyes and fell to twisting a bit of bedding where a thread was loosened, and she waited patiently as one who scarcely expects an answer.

Then Wang Lung, without comprehending it, looked for an instant into the heart of this dull and faithful creature, who had labored all her life at some task at which she won no reward and who in the great house had seen others wearing jewels which she had never even felt in her hands once.

“I could hold them in my hand sometimes,” she added, as if she thought to herself.

From *The Good Earth* (Buck, 1931, p. 149)

I remember when I could not read, but my older brother, Erik, could. He had started school and, like most younger siblings, I did not want to be excluded from his activities. Also, I longed to prove myself better than him at something, a task that seemed to be impossible. First, my brother was, and still is, good at making friends. He can enter almost any social realm and quickly find someone with whom he can connect. Second, he has always been an entertaining musician, quick to learn dances, and able to play most instruments by ear. In contrast, I flounder in interpersonal situations and often suffer from debilitating stage fright. Because I find it difficult to imagine a place for myself in most groups, I have little to say after introductions. As for musical talent, I took piano lessons, but my renditions of songs were painfully mechanical and I have never had the desire or

the necessary rhythm to dance. Thus, I devoted myself wholeheartedly to the endeavor of achieving literacy and I planned to be an outstanding student as soon as I had the chance to prove it. Before I started kindergarten, I was a proficient reader.

Contrary to what I had imagined, school was not enjoyable; I was not engaged by lessons, I was terrible at games other kids enjoyed, and I struggled to talk. In addition to these social deficits, I frequently slept in class, a problem that both my kindergarten and first grade teachers tried to solve by placing my desk next to theirs. Thus, I was an easy target for bullies and I spent many hours in the school health office, inventing ailments. At home, I skipped chances to spend time with neighborhood children, some of whom were the same antagonists I avoided at school, in favor of reading. In these hours—hiding away in trees or in the corners of our house—I was never lonely; I learned that a book can serve as a happy break from isolation. Wayne Booth, a literary critic who has explored the ways that the books we select are *The Company We Keep* (1988), points to the power of reading to “carry us away from all awareness of our “actual” world into a world of the imagination, and thus to free us, for a few moments or hours, from thinking about the evils of the day” (Booth, 1988, p. 191). I could interact with people (despite the reality that my companions were generally fictional characters created by authors long dead); as I read, I was invited into the worlds of others who did not expect me to change or to speak up to participate. I was riveted.

My ability to read most texts—with only occasional assistance from a dictionary—felt like a treasure. I tried to keep the activity from others, concealing paperbacks beneath classroom desks, piling books under my bed, and, on some late nights, reading with a flashlight in my room with the door closed. For years, I was an

avid reader who simply soaked up as much as possible. For me, there was “no frigate like a book” (Dickinson, 1960) to whisk me off to faraway, inviting places and I availed myself of this opportunity as frequently as I could. It took longer for me to transform my stance from that of a (very enthusiastic) sponge to a partner in dialogue. I remember feeling that there are already so many powerful voices, intriguing stories, and fascinating ideas that contributing anything to this panoply of thought just seemed unnecessary. What could *I* possibly add?

But there is an intimate conversation that transpires in the process of reading, particularly when it is done with an exclusive focus on a text (even if that focus is achieved at the expense of algebra homework or opportunities to socialize). Becoming a reader allowed me to find, in literature, the potential for a rewarding kind of friendship. The authors and the characters “are like the would-be friends we meet in what we call real life—that part of life that we ought to call less real, since its friendships are often less concentrated, less intense, and less enduring than those offered by story-tellers” (Booth, 1988, p. 177). There is also magic in the ability books give readers to bend back time and to take a glimpse at say, a family’s life in China under the reign of its last emperor (Buck, 1931) or the experiences of a shunned woman in a seventeenth century Puritan settlement (Hawthorne, 1850).

I was working through *The Good Earth* and *The Scarlet Letter* in tandem when my junior high English teacher asked me what I was reading independently. I was timid about such a disclosure, sensing that others would find in my most beloved activity another reason to alienate me. My English teacher was excited to hear my thoughts on both books, however, and her interest (as the first teacher who asked) woke something in

me. I struggled to explain why I loved these novels, but our conversations that year about my reading helped me begin to develop a voice and a unique perspective on texts. I did not hide my reading from future English teachers.

When I went to college, I became an English major, a decision based on my obsession with books and genuine gratitude for everything I had gained from reading. I am sure I also hoped to find other students who were as strange as I felt in high school, but I did not admit to it. Through my courses and because of my diligence as a student, I learned to love many kinds of texts. I did not consider that I had the talent to create any kind of literature, but I began developing a decent ability to write and talk about it. I met professors and other students who enjoyed reading as much as I did, but the hours I spent alone with texts were still the most delightful. This time became even more fruitful once I picked up a pen to respond. Beginning then (and still as a force of habit), I read with the intention of responding. Although I have progressed toward modernity enough to use a computer for composition, I still often read books and an old-fashioned writing implement dangling from my mouth and a pile of paper nearby.

It was this love of reading and the possibilities for intellectual communion that drew me into and kept me dedicated to teaching literature. My first formal teaching experiences in the U.S. were at a middle school and I saw in the faces of many students the estrangement I had felt as an adolescent. My desire to share the value of texts with young people defeated my introversion and fueled my ambition to teach. In these first years, I found myself passionately engaged. I began compiling a library of used novels, which I would pass out to students eagerly. I recall that I began with a system by which students would check out books, an activity that quickly devolved into an honor system

of book borrowing that meant I had to refill my collection often. I am still generous and forgetful when it comes to loaning reading materials. I often struggle to find my copy of a favorite volume, which I *might* have loaned to someone.

Now that I am a parent, I seek to make reading and talking about texts something we do openly. Sometimes I feel that I must keep my excitement in check now that my oldest daughter can read; I do not want my endorsement of books to turn her away from them (knowing that she has inherited a contrary nature). It could be dangerous, sharing this treasure. Will she experience the intimacy I have felt with authors while reading? Will she know the kind of gratitude I have for texts that shape my thinking? Will a book ever give her the rush they still give me, when words on a page transform the world? Will an author ever win her friendship (like they have mine) “by offering a distinctive, engaging way of being together” (Booth, 1988, p. 216)?

As much as my relationship to texts has always sustained me even when I read in isolation, I want others—my children and my students—to display their reading proudly. And I want them to know, as I do now, that part of becoming a reader is joining the grand “narrative adventure” of literacy during which “[we] told ourselves stories and those writers told themselves stories and gradually we started telling their stories and they started telling our stories and there we all were, caught forever in a tangle of language” (Mairs, 1994, p. 9). I love this mess of words and ideas, which should not be kept hidden or admired from a distance. Like a participant in any loving relationship, readers should open themselves to listen to the author. When we select a text written by someone, they “teach us, by the sheer activity of considering their gifts, a life larger than any specific doctrine we might accept or reject” (Booth, 1988, p. 222), but readers should also live in

the “real” world as people who have been changed, giving back to the author by displaying boldly that they have been transformed by reading.

## CHAPTER 4: SEPTEMBER EPIPHANY

“[A]ll education is political...there is no such thing as neutral education. Education stands *for* something or *against* something else.” (Ayers & Asch, 2008, p. 134)

It was the ninth anniversary of 9/11, but I had not taken note of the date when I filled my bag with materials to complete my homework that Saturday morning. As I settled down at a corner table in McDonald’s with a large coffee, I noticed that multiple televisions displayed a tribute to the heroes, victims, and survivors of that day. My experience had been very different from any that I had seen depicted in media. From certain perspectives, I missed it.

I was in the Russian Far East when it happened, asleep and unaware. We had an apartment, but no television, no internet access, and we shared a phone with our Korean neighbor. Our Russian language skills were very poor, so we may have heard something on the bus without comprehending it. When we arrived at the college where we taught English, our department chair frantically pulled us into her office and said in accented, halting English that “America has been attacked; I think Kamikaze planes!” The rest of the day was a hectic and frightening blur of misinformation that ended with a briefing from the regional Peace Corps office and house arrest for the rest of the week. My recollections of that period of time are not stories of falling buildings, brave firefighters, hectic airports, or bold exclamations of jingoism. Far from home, barely able to communicate, we were focused on gathering information and getting through to our families. As a very small group of Americans new to a distant place, we were

overwhelmed and scared. On this morning, I did not want to remember, nor did I want to celebrate this anniversary. I wanted to study.

The assigned article was “Why What Works Won’t Work” (Biesta, 2007), a critical title that appealed to me immediately. My responsibility was to create a one-page reaction (and no longer!); with the aid of headphones and a mix of music, I tried to focus. I read and highlighted, agreeing heartily with everything Biesta asserts about the so-called “evidence-based practice” that is promoted by many entities relating to education policy and practice. The article suggests that it is not well-advised to treat education like a science in the same vein as farming or medicine, since children are not crops needing to be protected from insects or patients seeking medical attention. I found myself smiling as I underlined “education is a thoroughly moral and political practice, one that needs to be subject to continuous democratic contestation and deliberation” (Biesta, 2007, p. 6). Then, Biesta indicates his concern about the simple concept that teaching is a series of interventions (causes) that can be linked to predictable reactions (effects). Rather, he proposes that the interventions of teachers are “opportunities for students to respond and, through their response, to learn something from them” (p. 9). I cheered silently.

Like other texts I had recently encountered as a new doctoral student (Dewey, 1938; Palmer, 1998; Ravitch, 2010; Meier, 2002; Wilhelm, 2008), the piece provided me with better ways of understanding, supporting, and expressing my pedagogical philosophies. As my isolation at work grew, I relied on such texts to be companions as I improved my teaching practice. Many of the scholars expressed a tension similar to what I experienced in daily battles to exercise my professional judgment. Biesta endorses Dewey’s portrayal of inquiry as something that “can only show us what *has been*



possible” and highlights his idea that research on interventions is simply evidence “for *what worked* but cannot tell us what works” (p. 16). I agreed immediately and thought about all the binders of reading strategies, test preparation materials, and scripted assignments that I ignored or reinvented. At that juncture of my career, I was frustrated with the current nature of education, but had not considered closely the relationship between my dilemmas as a teacher and anything as big as the state of democracy.

In truth, I was proud of my ability to take subversive action to function outside of the rules; I raced through required curricular materials to get to the “real” work, I made my own copies, I kept my real lesson plans to myself, and asked for forgiveness (rather than permission) only as needed. Perhaps it was a myopic focus on my agenda, or perhaps I was hoping that the hazards I encountered were limited to my sphere, but I did not connect my problems to a larger crisis. I knew that the most important decisions teachers make are “not about the effectiveness of their actions but about the educational value of what they do” (Biesta, 2007, p.10). Citing many uses of research in education policy, Biesta observes the following:

There seems to be an almost unanimous expectation that research can tell us “what works,” that it can provide “sound evidence” about the effects of policy and practice, and “sound evidence of effectiveness” more generally. Whether these expectations are warranted ultimately depends on the epistemological assumptions one brings to the understanding of what research can believe. (p. 12)

Taking off my headphones, I allowed myself to look at the televisions while consuming the entire cup of coffee, which I had neglected while reading. A giant flag

was draped on the back of a stage, behind a blond singer adorned with a tight red and blue dress. She was closing her eyes, preparing to sing as a band played a patriotic-sounding anthem. I found myself back in Russia, a few weeks after the attacks, walking through the market after we had spent the morning at an internet café, gleaning as much information as we could about what was happening back home. We represented America, so our training had instilled in us, so what did that mean, in light of the events unfolding after 9/11? There were so many horrible and bewildering pieces of news: terrorist cells, hidden weapons, anthrax mailings, threat levels, increased racism, and acts of obvious prejudice. We did not know how to sort it all out; we wondered how we should react to all of this, as young Americans living abroad, serving our country.

Already our experiences had begun to strip away our naiveté about what we had to offer as volunteers. We were a group of young people, fooled into thinking that our status as Americans gave us something the “third world” was yearning to attain. None of us had been trained formally as teachers and most of us spoke only a trace of Russian; we relied heavily on our local colleagues. Also, we were advised to hide anything that made our nationality obvious (in a crisis, you are from Canada) and to avoid critical discussions of our country’s policies. But after 9/11, when we could talk to our hosts or each other, all of our conversations were about the politics of the United States. At restaurants, on the bus, in the market, and in our classrooms, our opinions were demanded. What did we think of George W Bush? Bin Laden? Iraq? Muslims? Saudi Arabia? Terrorists? (Were we spies?) I remember one Russian colleague saying that it was “about time we had to deal with terrorism like everyone else.”

We were Americans, representing America. Emerging from our innocence and blinding hubris, we had to own up to our status and consider how our work fit into it all. It seemed that no one was having discussions like this at home; from across the world, the national reaction looked more like this singer, dreamily humming a patriotic tune, wearing patriotic clothing, waiting to return to an idyllic time when America was above the reproach of terrorism. We were learning that such a time never existed.

Turning back to the Biesta piece, I realized that teaching here could not be neutral either. Like we represented the United States under the auspices of the Peace Corps, a teacher represents an ideology that is larger than her personal agenda. As I stand in front of students and declare that “these are truths” and claim that the result of learning them is desirable, I endorse certain epistemological assumptions. For example, when I passed out the textbook for 9<sup>th</sup> grade English, *The Language of Literature* (McDougal Littell, 2006) I presented this anthology, which was compiled and edited by a corporate entity, as what they should read and understand over the course of our year together. The editors of this volume make choices, including who and what should be included (and who and what should not) and what aspects of the stories are most worthy of highlighting in questions, introductions, and the presentation of words on the page.

When I assigned material from this text and then tested over it, my actions said in essence that this entity—this book created by a company—is a valid source of knowledge about what 9<sup>th</sup> graders should learn (and not learn) in English class. I was not skeptical of the choices made by the editors, at least not in the reverent manner I treated the book. This text made most of the choices about our curriculum. I supplemented it from time to time with my knowledge and other small pieces, but ultimately I left the

biggest decisions about class materials to something else. In addition to the textbook, the district provided me with a teaching calendar, a detailed guide to each unit, and a list of learning objectives, which I was required to post. I wondered, if the ends of an educational endeavor come out of a binder, if goals are posted on the wall before we start, and a textbook is the ultimate authority in my subject matter, what message does that send about my role in all of it? Can students trust their teachers to enhance their knowledge or improve on their critical thinking, when the teacher cannot be relied upon to develop those things alone?

Biesta argues that in a democratic society, the purpose of school ought to be continually open for debate and negotiation, but unfortunately, “the current political climate in many Western countries has made it increasingly difficult to have a democratic discussion about the purposes of education” (2007, p. 18). If the climate of education research, as it is being applied to my profession, “should indeed be read as a threat to democracy itself” (Biesta, 2007, p. 21), the problem of clarifying my epistemological stance was something bigger, something more important than an attempt to fit in with fellow graduate students. Teachers find themselves caught in the crossroads of drastically different philosophies of knowledge, professional judgment, science, and the nature of education in a free society. Where did I stand? I refilled my coffee and got to work.

## CHAPTER 5: METHOD (AN INCHOATE EPISTEMOLOGICAL STANCE)

Intellectual method cannot promise genius, but it should at least forestall stupidity. (Inglis, 2003, p. 131)

The chapter describing my approach to research methods harmonizes with the interstitial nature of much of this dissertation. This “method”—which is in reality a description of a process of scholarly thinking based on my evolving epistemological understandings—conveyed herein is an intentional amalgam of academic traditions including memoir, ethnography, literature, philosophy of science, phenomenology, sociology, radical pedagogy, and narrative inquiry. Although certain schools of thought are dearer or more familiar, I define myself as a “self-styled researcher” (Wolcott, 1992, p. 39) who stays open to many perspectives and diverse methods of inquiry as far as they are relevant to my questions. I am enchanted by “the lure of learning” (Liston, 2004), but when I follow a new line of thinking, rather than enter a cavernous, unfamiliar space alone, I turn to others for guidance. In a sense, I enter a social realm and seek to learn “how to live in that world from those who already live there” (Longino, 1990, p. 67). In texts from thinkers of all stripes, I find knowledge that offers insight and cognitive direction. This writing is deliberately a “dialogue with other like-minded scholars” and I strive to “weave them into [my] discussions with informative context” (Wolcott, 1992, p. 15), irrespective of their academic origins or labels.

The decision to push against the boundaries that exist between schools of thought as I write and think is a conscious one. From holding a variety of statuses in the field, I have benefitted from opportunities to consider education from multiple perspectives and as different selves. My work in schools comprised of more than observation and

reflection, however; while occupying these positions, I played an authentic role as a participant taking action. Emboldened and burdened by the trust of students, I often found myself in moral dilemmas regarding the application of educational techniques and policies to specific, human situations. I had many, many hours of training and access to thick volumes of guidelines for action, but the knowledge I needed to teach was “not about the effectiveness of [my] actions, but about the potential educational value of what [I] do” (Biesta, 2007, p. 10). Education is a moral practice, not just a technical one; thus, as I developed expertise at teaching methods, that knowledge could not supplant “the need for ethical judgment” that accompanied every choice, “pressing [me] to take some stands, to sort through [my] ethical beliefs for the sake of beginning to make some discriminations about what is ethically desirable and what is not” (Hostetler, 1997, p. 9). There were times—situations involving real children—when the right thing to do or say could not be found in the formal guidelines for my job. I never entered into a pedagogical situation with the intention to break rules, to criticize policies, to undermine curricular goals, or to impede the progress of an administrative agenda, but they all occurred more than once.

As I grew in knowledge of the science of secondary public school teaching, I witnessed the accuracy of Kuhn’s classic observation that “[n]ormal science often suppresses fundamental novelties because they are necessarily subversive of its basic commitments. As a puzzle-solving activity, normal science does not aim at novelties of fact or theory and, when successful, finds none” (1962). As a person with an eye for exceptions and a commitment to speaking the truth, I have tasted the bitter response incited by my insistence on the existence—and relevance—of puzzles. In the science of

education, as it is applied by leaders in actual teaching and learning contexts, the practitioner is not expected to expose her expertise at navigating the “irreducible complexity” (Labaree, 2010) of teaching. Instead, as my experiences illuminated again and again, teachers are assigned the role of “simply carrying out predetermined content and instructional procedures” (Giroux, 1988, p. 124). In this (now) dominant paradigm, teachers are merely implementers of a “teacher-proof” curriculum, not creators of materials, inventors of methods, or advocates for students. The lesson of top-down, administrative control of classrooms is that “teachers cannot be trusted, as professionals, to effectively determine the best ways to educate and assess students” (Au, 2010, p. 6). Teachers who dare to do that, against the grain of a technocratic culture of education, pay a price. Their stories are an important source of wisdom.

My experiences illuminate the hazards awaiting practitioners who criticize the systems in which they work, an activity that can particularly make teachers vulnerable (White, 2011). It may be necessary for practitioners to be obedient or to follow the standard protocol most of the time, in order to protect their employment or to hold onto a particular teaching assignment. But there are certain moments, when interacting with human learners, when a decision a teacher must make is not illuminated (or supported) by existing policies. Good teachers must be able to “do philosophy” (Greene, 1973) in response to urgent quandaries and then they must act in the best interest of particular students, even when that judgment includes acting outside of the rules. Despite the danger, the most trenchant pedagogical thinkers should not confine themselves to facile solutions, narrow methodological approaches, or sanctioned problems or the discipline of education runs the risk of missing something vital.

If my approach seems, at times, wildly iconoclastic or too critical of the standard educational dissertation, readers should not confuse these moments with a lack of respect for tradition. As Csikzentmihaly (1996) asserts, “one must also be willing to take a stand against received wisdom, if the conditions warrant it. Otherwise, no advance is possible” (p. 103). This potential for lost advances in understanding is particularly relevant to those of us who are concerned with studying human affairs, which “do not break down in terms of scientific disciplines, which after all evolved for research and teaching convenience” (Nader, 1996, p. 264). It is my contention that research on education—as a discipline of human interaction—has a moral obligation to ascertain a deep understanding of phenomena prior to selecting the most appropriate methods with which to examine them. This quest for discernment could, and likely will, lead perceptive researchers to find methods outside of the traditional paradigm. Departures from a more formulaic approach—choices that break the rules, but do not defy their spirit—create a productive tension that can yield deep thinking.

My identification as a pedagogue is also an integral aspect of this pluralistic, exploratory approach to acquiring knowledge. Teaching is a job I happen to love, but it is more; on a deeper level, “a particular definition of pedagogy informs my teaching, and my learning but more generally, as much as I can make it do so, my living” (Martusewicz, 1997, p. 99). I want my research and writing to encourage others to find new questions, to enter domains of inquiry boldly. In my experiences with schools, it is a rare occasion when students are encouraged to “reach beyond the boundaries of [themselves]” (Liston, 2004, p. 460). Although educators generally believe the information they share is correct, “textbooks and teachers often fail to inform students



about the tentative nature of much that appears in the curriculum, and both are guilty of omissions and various biases in their presentations” (Noddings, 2012, p. 123). Materials used in schools (textbooks, films, assessments, reference books, websites, lectures etc.) often present information as if it were the last word on a topic; thus, neither students nor their teachers are inspired to conduct inquiry on their own.

What can an individual learner hope to contribute to an already complete educational program? When education is something that one receives, school becomes a place for “sitting quietly or practicing repetitive tasks until the mind aches, where the most worthwhile knowledge is presented as disconnected fragments of information” (Ayers, 2010, p. 103). In this dominant “banking model” of education, “knowledge is a gift bestowed by those who consider themselves knowledgeable upon those whom they consider to know nothing” (Freire, 1970, p. 72). The creators of curricular materials have expertise, but if education has been successful, students should not feel that they are *done* learning upon graduation. They should have acquired the ability to be shrewd students of the world they will encounter, one no educational program can predict with certainty. If credentials only mean that young people can “do school” (Labaree, 2010), the many hours they spend in this liminal space do not prepare them to leave it. We cannot predict the dilemmas young people will confront, but we do know that teaching them to be “docile bodies” (Foucault, 1977) will not empower them to approach problems as intellectuals. The same lesson should be applied to education research, which should not present knowledge or certain ways of gaining it as *the* answer to pedagogical concerns. Our field deserves research that begets deeper questions and even better research from its consumers.

At the center of my methodology is narrative inquiry, an approach to thinking and researching about education that has always suited me. As Bill Ayers (2013) explains in his memoir, thinking narratively “accommodated the noisy, idiosyncratic, complex, multilayered, dynamic reality of children themselves, as well as schools and classrooms” (p. 42). Rather than study children as abstractions formed from a conglomeration of facts, statistics, or probabilities, my thoughts on teaching have always centered on the living inhabitants of my classrooms. Of course there are commonalities one can learn about children—and teachers—and there are principles of teaching that have been *generally* effective. Some of these findings can be presented quantitatively or formulaically, but I could never imagine selecting a methodology that would involve “hammering the natural disarray everywhere into a convenient if choked-off and clotted frame called research” (Ayers, 2013, p. 42). Stories are less restrictive and they invite the reader to compare my observations with their own lived experiences.

Certain aspects of my work derive from two researchers who have developed and employed a narrative method extensively, D. Jean Clandinin and F. Michael Connelly. Building on Dewey’s conception of experience, these scholars “[think] of experience “beyond the black box,” that is beyond the notion of experience being irreducible so that one cannot peer into it” (2000, p. 50). In their research, they define four directions of inquiry: inward and outward, backward and forward. When my research explores narrative situations, I follow their thinking that “to experience an experience—that is, to do research into an experience—is to experience it simultaneously in these four ways and to ask questions pointing each way” (p. 50). Thus, the events that comprise the substance for my dissertation are explored through personal introspection and by theorizing their

connections to larger social forces. My thinking also takes into account the past, present, and future as they relate to the narratives, which are only part of myriad overlapping, fragmented, and unfinished stories from a life. As I render these events into foci for research, their accuracy is important since “every researcher should be honest about the status of his or her work as report, philosophical fiction, or speculation” *but* “narrative research, as part of the hermeneutic tradition, invites interpretation and reinterpretation” (Noddings, 2012, p. 143). Therefore, consumers of this kind of research ultimately bear the onus to consider exactly the wisdom they will gain from an inquiry.

As well as a source of knowledge, anecdotes are a useful communicative tool. In the way they are often used, such stories “let the recipient of the anecdote sense or perceive a certain truth that is otherwise difficult to put into clear language” (Manen, 1990, p. 116). But stories as research are more than clever ways to make a point. Using events of real life as testing ground, anecdotes offer generalizations with broad applications, and through the storytelling, they “are tested for their value in the contingent world of every day experience” (p. 116). Thus, a narrative approach to research is empirical; the specific events recalled serve as “a path pointing and leading back to something in primary experience” (Dewey, 1958, p. 6). My philosophical renderings of events reflect the importance of everyday life for understanding the world and invite readers to measure what I have come to understand against their own experiences.

In addition to revealing my thinking to be frequently pedagogical and narrative, my research reveals a devotion to writing as a method of knowing. At the beginning of my life as an intellectual, I fashioned myself as more of a reader than a writer. But in

private moments of reading, if I am truly engaged, a conversation is always happening. I have the ability to consort with thinkers across time and space, and writing is simply a necessary response. As I engage in dialogue, write, revise, and engage in dialogue again, I am orchestrating a thinking and learning process. For the sake of the reader, I remain committed to faithful descriptions of this activity, with a particular focus on disclosing the works and ideas of others that have contributed directly to my thinking. In this truth telling, my work is an expression of personal philosophy and empirical method; my way of writing “places before others a map of the road that has been travelled; they may accordingly, if they will, re-travel the road to inspect the landscape for themselves” (Dewey, 1958, p. 29). It is my hope that the metacognition I reveal will inspire others to devote themselves to reading and responding deeply, and to love, as I do, getting caught in the “tangle of language” (Mairs, 1994, p. 9) that results from this endless dialogue.

## 6: LITERATURE REVIEW 1

### (EPISTEMOLOGY AND THE RADICAL TEACHER)

My critical thinking and reading took me back repeatedly to epistemology as *the* central problem of education. Living as a budding scholar, an experienced teacher, and a burgeoning critical reader of research, my thinking repeatedly turned back to concerns about differing stances on the best sources of knowledge about my profession. I wanted to explore “how we can generate knowledge about ‘what works ‘and, more specifically, how we should understand the status of knowledge generated through experimental research” (Biesta, 2010, p. 494) .

I began looking critically at my own teaching site, considering the dominant perspective on epistemology that revealed itself through our training and use of research. According to what I knew of this job, what is presented as the best knowledge about teaching? Who has it? How can it be accessed? I had never considered this problem too closely, trusting naively that the leaders at my schools knew how to find, access, and evaluate research. The fact I learned is that most teachers and administrators “do not receive sufficient help in becoming critical consumers of research, and they too rarely learn to engage in research to foster their own professional development” (Lageman, 2000, p. 244). Once I began to acquire these skills, I realized how uncritical of research this job (and the professional development sessions in which I had participated) inculcated teachers to be.

A common phrase in my local environment and in the larger climate of education policy was “evidence-based practice.” It sounded so obvious. Why wouldn’t teachers want to use materials and actions that have been proven to work? I was skeptical, and I

remain so, to any guidelines that aim to make any aspect of teaching into something predictable or simple. No matter how much detail was contained in any set of rules or description of a method, situations in my actual practice had always asked for more from me. As quipped by Field and Latta (2001), “there are no rules for the application of the rules” (p. 891). For example, even if I scrutinized the state handbook on ethics for teachers, which I have done a few times, I would probably not find the right approach (nor would I have the time to look) to deal with the next ethical crisis I would encounter. In these moments of crucial decision making, I have simply improved over time at responding wisely. I heartily agree with Hostetler (2014) when he asserts that “it is a life experience that provides justification for teachers’ perceptions, building up a bank of stories, analogs, and metaphors to draw upon” (p. 10). Each year, I became a better, more flexible teacher because of exactly this process. Among teachers, it is common to assume that the veterans have amassed incredible troves of knowledge. This belief justifies the novice’s need for a mentor as well as the traditional system that rewards teachers for longevity.

Another problem with the reliance on “evidence-based practice” as the best practice is that in this way of thinking, the prescribed solutions and reactions would necessarily come from the past. If all choices must be made by considering only what has been shown through formal inquiry, this precludes the possibility of thinking of an unknown future and limits the ability of a practitioner to respond appropriately to her context. In a chapter in a tome that addresses the moral aspects of education research (2003), Jon Nixon, Melanie Walker and Peter Clough claim that the use of evidence to make decisions is a moral problem since “evidence itself is neither good nor bad.” These

scholars claim that the field must return to what they dub “thoughtful practice,” which conceptualizes education research “as integral to an inclusive tradition of thoughtful deliberation, which acknowledges the unpredictability of human action and the primacy of human agency; an insistence that is, on research as a common resource” (p. 87). They urge researchers to remember that the knowledge uncovered in educational settings relates to the larger social milieu and conversely, the setting must be considered when research is being applied in a particular school. Schools are part of a society and “the problems facing society are shared problems (litter, traffic congestion, terrorism, etc. ) that can only be addressed by our thinking together and acting together” (Nixon, Walker, & Clough, 2003, p. 102). Consumers of research, and those who want to apply its findings in particular situations must remember that educational research is a “politically driven and value-saturated” activity that exists “not only to provide policy makers and practitioners with evidence, but to provide as a public resource interpretations of that evidence that speak to the conditions pertaining at precise points and within specific public sectors” (p. 87). Looking closely at the way educational research is most often used, these scholars would suggest we consider what moral deliberation the choice to apply the results of a certain study reveals. They would also have us ask continuously what values and assumptions are embedded in how evidence is used.

In Biesta (2010), he explores the epistemological assumptions inherent in the perspective that education should be an “evidence-based practice,” in which evidence gained from experimental research (particularly the randomized trial) “is considered to be the only reliable way in which valid scientific knowledge about what works can be generated” (Biesta, 2010, p. 494). In this paradigm, researchers test certain methods and

then offer the results as knowledge for teachers and teaching. School leaders and teachers serve as technicians who carry out the action that the research has shown to be the most effective. Kincheloe (2003) calls this approach “methodological unitarianism,” a posture that assumes that “all research calling itself scientific must utilize the classical method of the natural sciences. Knowledge here is scientific knowledge” (p. 95). In this paradigm, teaching is portrayed as a rule-based system and “problems are reduced to the cause-effect rationality of empirical science” (p. 96). Use method x in situation y because it worked on student a, b, and c in situation z. The warrant behind such a claim is that certain kinds of students and certain educational situations are interchangeable. (Something like, “We used this method to help students of poverty in Chicago build connections to school, so it will work for students of poverty here” was generally invoked.)

I often had this experience with research when its results were presented as part of professional development. The new guidelines (and there were *always* new guidelines) told us something like how to grade papers, what to say to parents, how long to hold eye-contact, how to tell when a child is suicidal, how to observe other teachers, the best way to prepare students for final exams, how to talk about school shootings, or how to differentiate to diverse learners. There might have been a source or two included, but in general, teachers were expected to follow these rules because the district leaders had deemed them to be the best research results. It was not an environment that fostered what Nel Noddings calls “hard questions” like whether “the researchers claims correspond to what we regularly observe in schools” or if “their premises, methods, and conclusions hang together in a convincing way” or whether “there is an obvious ideological bias in



the work” (Noddings, 2012, pp. 124-125). The approach adopted by my district (and many, many others) assumes that the best, most reliable knowledge about how to teach comes from research conducted elsewhere. As an employee, subordinate to administrators and the district, it was not my place to question it.

Biesta (2010) points out several problems with this approach; first, the paradigm of causes and effects as absolutely connected assumes that social reality is a “closed deterministic system,” which is a “the exception not the norm, in the domain of human interaction” (Biesta, 2010, p. 497). Second, according to his critique, when these causes and effects do function as they did in the experimental setting, it is because schools have altered themselves to become closer to the laboratory conditions. This transformation of a classroom into a laboratory comes about through a social construction which “ [reduces] the number of available options for action for the ‘elements’ within in a system,” an act of complexity reduction Biesta describes as “a political act” (Biesta, 2010, p. 498). Third, the use of evidence-based practice does not leave room for consideration of what kind of conditions or actions are desirable, outside of their connections to certain results. Something might work to reach a particular goal, but its effectiveness alone does not prove its value. Evidence should be “filtered through decisions about what is educationally desirable” (Biesta, 2010, p. 501).

Teachers must base their decisions on something bigger than a particular guideline; they should do what they believe will be in the best interest of their students. Turning back to Hostetler (2014), if “we are to look for what is at the center of good teaching, we do not look for it in things such as evidence-based teaching, ‘best practices,’

and/or reflection. For those yield limited benefit if they are not located within the larger and essential project of helping people do well” (p. 11). The question this concern places at the heart of making pedagogical choices is not “does it work?” but, “does it improve the lives of my students?” This kind of thinking is not prized (nor is it relevant) in evidence-based practice. Research on education, like teaching, involves making choices about what the desirable ends of pedagogy ought to be. The pursuit of this sort of inquiry involves “a moral commitment to improvement of some kind, whether that be primarily in terms of adding to the sum of knowledge or, more immediately, by impacting on students’ and teachers’ experiences in some way to make them better (although there may be occasions when it is seen as justifiable to disadvantage some to benefit the common good)” (Sikes & Goodson, 2003, p. 37). When considering the epistemological validity of any research, its consumers should never separate the inquiry from the values revealed in the questions. For example, if a study takes for granted that classrooms can or should operate in a manner closer to a laboratory setting, its results are only relevant for those who agree that this reductive social construction (Biesta, 2010) is an appropriate ideal for a learning situation.

Scholars in other fields have also been skeptical about the hegemony of “evidence-based” practice as the highest form of knowledge. In the health sciences, Holmes et al (2006) describe this world view as “dangerously reductive insofar as it negates the personal and interpersonal significance of a world that is, first and foremost, a relational world, and not a fixed set of objects *partes extra partes*” (p. 181). Their article calls on thinkers to deconstruct this “regime of truth,” which the authors describe as scientific fascism that “relies on a process that is saturated by ideology and intolerance

regarding other ways of knowing” (p.184-185). The urgency of these authors to protect medicine from being inhumane is not different from those critics of the current trends in educational research. In medicine as well as in education, the model of evidence-based practice is promoted heavily and awarded with money, publication, and influence in the field. What is the danger in the status of this approach to knowledge?

Holmes et al (2006) compare the dominance of evidence-based practice, along with its corporate and government sponsorship, to the leaders in the book *1984* who want to control the thoughts of the populace. Biesta (2007) is concerned that the state of education research threatens democracy everywhere. Education and democracy are linked by the work of many others in education research. Linda Darling-Hammond (2010) claims that “strategic investments in education are essential to our long-term prosperity and to our success as a democracy” (p.3). Neil Postman (1995) stated that public schools create a public by “strengthening the spiritual basis for the American creed” (p. 18). In a preface for a volume on the topic, Bradley A.U. Levinson indicates that “only education can shape the values and cultures that turn governance into a more far-reaching and deeply rooted [democratic] form of life” (2008, p. ix). Au (2010) urges readers to fight against high-stakes testing because students “learn anti-democracy, as the curriculum of such policies work against diversity and deliberation and instead teach bureaucratic control and autocratic, centralized authority over education” (p.9). Maxine Greene (1993) reminds educators that “democracy is forever incomplete” but assert that “educators may begin by creating the kind of situations where, at the very least, students will begin telling the stories of what they are seeking, what they know, and might not yet know...” (1993,

p. 218). If education has the task of maintaining democracy, there is much at stake in this debate.

I have witnessed, on more than one occasion, that teachers who attempt to start a critical dialogue are not welcomed in schools, and I have wondered why questions were deemed so inappropriate by administrators. It seems that we have a different conception of where knowledge arises. If standards and knowledge are created in laboratories outside of schools, teachers are merely “deliverers of pre-packaged and homogenized information” (Kincheloe, 2003, p. 3), not inquirers. If that is a district’s epistemological stance, why would teachers need to ask questions? Why does evidence-based practice often suit teachers so poorly (despite heavy support from administration)? Behind the ideal that teaching can be perfected and isolated into best practices is a conceptualization of education as “an abstract system that can be applied everywhere” (Labaree, 2010, p. 156). Teachers engaged in real classrooms know that educating humans is just too complicated to be understood by even the most rigorous educational research. To succeed (or survive), teachers need a deep understanding a particular classroom. David Labaree (2010) describes this kind of knowledge:

An effective teacher is the expert ecologist of her classroom. This ecology is too complex and her goals for it are too broad to allow her to carry out her instructional role simply following the rules from her handbook of teaching. As astute students of the classroom have noted, teaching is not a matter of doing the right thing but of adeptly managing chronic educational dilemmas. (p. 157)

Most teachers, I would speculate, would agree with this characterization of what teachers actually do in classrooms. There is a certain set of skills, a certain way of being,

that cannot be learned from handbooks or dictated by top-down administrative control. Teachers do learn something from these entities, but the best results come down to improving technique, which “is insufficient in teaching, at least in *good teaching*, because we are simultaneously confronted with the demand not simply to know how, but to know when, and how much, and with whom” (Field & Latta, 2001, p. 891). Teachers need judgment *and* technical skill. They need to see their students in a particular way, and their looking should be a “mindful watching overflowing from the good in a situation that the good teacher sees. In this sense, teachers are more than they do. They are the teaching” (Aoki, 1992, p. 30).

I do not believe that most teachers would disagree with these assertions, but I have often been alone when raising critical questions of administration. For example, at a district department meeting when the curriculum director presented the decision that English teachers would not be permitted to edit the “summative” tests contained in the curriculum binders, I suggested that the tests could be improved by adapting their contents to reflect the materials and skills to which we had really devoted most of our energy. Also, I noted that adding essays that relate particularly to the progress of a class made the tests more relevant and interesting. I did not want to give an assessment simply because it was required (and required to be counted as seventy percent of a final grade, based on another recent policy decision); I wanted tests to reflect and augment my teaching, something my colleagues and I had discussed often. Not only was I alone in speaking, our curriculum director did not respond to my comments at all. After this meeting, I asked her directly if we could meet to discuss my concerns about the test policy and the answer she gave was, “No, sorry” stated with surprising finality.

Teachers are often reluctant to speak out against the way schools operate, including any critical discussion of their subordinate relationships to administrators. Why? Following the work of Lortie (1975) , one might suggest that teachers are not likely to question the status quo because they have been socialized for the roles they will play through their own school experiences. Thus, teachers behave roughly the way their teachers behaved. Also, the institution of school is robust (Eisner E. W., 1992) and already present as a fact long before a particular set of teachers and students enters a building with “school” on its sign. In the United States, the school developed “as a specialized institution dedicated to instruction by specifically authorized personnel” which brought with it

laws, regulations, certifications, teachers, classrooms, administrators, counselors, an industrial-academic testing complex—all tightly framed so that their presence echoes far beyond the areas one might expect to find them, in the everyday lives of all in the United States. (Varenne & McDermott, 1998, p. 155)

If schools are perceived as a social fact—along with the parts that people are supposed to play in them—it would not fit for teachers or anyone else to question the way they operate.

Still, there are teachers who continue to speak up despite the pressure to stay quiet, those who do not hide their desire to improve schools and make changes, but these individuals are less likely to last in teaching contexts than those who just carry on with the status quo. The best teachers are hindered by a system that “is organized with an eye on the incompetent rather than the competent. All are shackled, to “protect” students

from bad teachers” (Sizer T. , 2004, p. 196). Efforts to keep bad teachers in check often come in the form of top-down control of classroom activities and a lack of respect for teacher autonomy. Thus, the very individuals who have the most knowledgeable perspectives on education are either too cynical to speak up or too ready to quit teaching to engage in meaningful efforts at change.

Another reason for a lack of a critical teacher’s voice is that many educators who pursue graduate degrees and engage in research while still teaching have found their voices to be unwelcome in schools. Jeffrey Wilhelm, who became a researcher of literacy while still working as a middle school teacher describes such an experience when he criticized the use of standardized tests to measure reading skills. When he used the phrase “faceless tyranny of testing companies” he was shocked that “the atmosphere was getting pretty thick with tension” and after an impassioned speech on the lack of educational value of such tests, his “voice echoed in a silent room” (Wilhelm, 2008, p. 148). His passion and his expertise were ignored and, ultimately, became sources of professional isolation. Wilhelm cites hostility and remoteness from colleagues as the primary reasons he left his middle school job. If teachers who are deeply dedicated feel “punished by their school communities for wanting to study their own practice and for desiring to contribute to the professional conversation beyond the walls of their immediate communities” (White, 2011, p. 322), our field stands to lose valuable insights.

From my reading and thinking about the battles over epistemology, I wanted to study the teachers who dare to raise their voices, something I was doing much less frequently. These outliers fascinated and inspired me and I wanted to portray the experiences of teachers who become advocates or researchers while still teaching. I was

particularly troubled by the trend I had noticed, in my circles of educators, of teachers who receive training in conducting and assessing education research and then find it harder to continue teaching. If the job of being an educator becomes untenable for the individuals who are most dedicated to it, I worried about the future of my profession. Once I did find the right subjects, a group of dedicated teachers from across the country who had pursued graduate degrees in education and remained teaching, at least for a while afterward, I wanted to explore the following questions<sup>4</sup>:

1. How are teachers conditioned to approach research? What does the paradigm to which teachers are initiated teach about research? How does teacher preparation play a role? What approach to research is shared across many districts in the U.S.?
2. Why are teachers who speak up more likely to leave the profession? What kinds of issues generally get teachers involved in school policy? What positions of leadership do strong-willed teachers pursue? How have teachers been punished or praised for speaking up? What issues are “deal breakers” that finally push dedicated teachers to quit?
3. What defines the split between university researchers and teachers? How common is this division felt across the country? When teachers return to universities while still working, do they feel this division between the two circles? How are teachers treated as graduate students (particularly by non-teacher graduate students)?

---

<sup>4</sup> The questions as they are written here are too broad and complex for a research proposal, but they illustrate the depth and excitement of my thinking at the time. As the narrative will explain later, this research never happened.



4. What happens when teachers do not accept the dominant epistemological stance?

If a teacher disagrees with the manner in which knowledge is accessed in a school or district, how do they react? What are the most common epistemological stances of schools?

5. Why are teachers negative (or hostile) when other teachers engage in research?

How have teacher researchers been treated? Have other teachers been negative in the experiences of most teachers who conduct research or publish while still teaching?

6. What keeps great (outspoken, radical, critical) teachers teaching? This question gets to the heart of the issue: why stay? All administrators, policy makers, and researchers must, ultimately, make sure there are teachers in classrooms. If I come to understand the answer for at least a few teachers, they could offer useful wisdom for all of us.

I began making contacts with people I knew in education, seeking out participants I could interview and observe over the course of a year. I sought secondary, core subject teachers who fit the “type” that interested me.<sup>5</sup> I wanted to see the current teachers in action, but I also wanted to meet them at a neutral site, away from the potential conflicts inherent to meeting at a particular school to discuss topics that might not present this

---

<sup>5</sup> I am aware that it does not make sense to call “outlier” a type, but I wanted to find educators with a passion for continuing their education and improving their practice who may have had isolating or frustrating experiences like I had. My interest in this sort of dilemma was, of course, personal.

context in a positive light. I had found a few teachers who expressed interest, but this project was just a sketch when the changes to my health ended it abruptly.

## CHAPTER 7: CORRECT TRAINING

We must cease, once and for all to describe the effects of power in negative terms: it ‘excludes,’ it ‘represses,’ it ‘censors,’ it ‘abstracts,’ it ‘masks,’ it ‘conceals.’ In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production.

(Foucault, 1977, p. 194)

When I started my doctoral program, I was a middle school English teacher; however, after my revelations about the contested roles of research and pedagogical knowledge in education, I developed a more critical perspective toward the context in which I was working. Rather than taking pride in my ability to “sneak in” material that I found to be better for my students, I began to wonder what my doing that revealed about teaching. I questioned the orientation of a school in which the teacher of a given subject is not trusted to be the source of knowledge about that subject. I found that I was unable to function amiably within the confines of district policy in the form of items like curriculum guides, common assessments, disciplinary guidelines, test preparation, and district rules for assigning grades.

These concerns led me to request a move to a high school in the district. As a 9<sup>th</sup> grade English teacher, I would not have to prepare my students for standardized tests and I imagined that in a larger school, there would be a better chance to have autonomy. I would miss teaching middle school students, but I hoped that high school would offer

more chances to approach my subject passionately and with flexibility. I thought, naively, that in this new context, I might be able to step outside of the problems I was experiencing to play a role in “a democratic discussion about the aims of education” (Biesta, 2007) in the context of a new teaching job.

It was my first professional development day as a high school teacher, before classes had started. I had received a curriculum guide a few days before, but I was happy to note that it appeared to be flexible about how outcomes were met. I arrived too early that day, so I sat alone in the area reserved for my department, ate a donut, and sipped lukewarm coffee. The agenda said that the morning topic was “student failure and teacher interventions,” and I allowed myself to sigh a little. Would this day really help me develop? Would we have a chance for real discussion? I tried to hold onto my euphoria of leaving behind the challenges I had faced at the middle school and hoped for something good. Once everyone settled in, the principal called the meeting to order and an assistant gave every department a large pad of paper.

The principal told us to discuss the following question: “Why do kids fail?” Our department chair wrote, “They don’t care” and then several English teachers suggested answers including “bad parents,” “health problems,” “missing school” and so on. I wondered to whom each of those suggestions referred. Our chair furiously wrote down ideas until the paper was full. As we waited for her to share our ideas with the wider group, I reflected on the word *fail*. What did we mean by that word? Dropping out of school? Skipping class? Not graduating? Getting into fights? Getting pregnant? Getting arrested? Failing to play sports? In a climate of examination and competition, there are so

many ways to be labeled as failing. I felt cynical about this discussion, so I decided to stay quiet, lest I become an immediate outsider in my new school.

After each department presented similar reasons for failure, the deans each shared some advice on how we could reach “failing” kids. One said, “Building relationships is the key to help students feel connected to school.” I wondered again which children the speakers and listeners were picturing during the presentation. I thought about students I had cared for over the years, regardless of failures they might have had. Although I love English, the act of teaching is also a method to help kids feel connected to a school, to their classmates, and to the larger community. If so-called “failing” kids had been eavesdropping, would it make them feel good to hear us discussing them in this generic way? Next, someone turned on a projector and on a large screen; there appeared a list of names with corresponding numbers.

The principal announced that we would be looking at data for incoming freshmen, so we could see how each student scored on 8<sup>th</sup> grade reading assessment. Was this test result what we had meant by failing? I looked at the screen again and saw that I recognized the first name on the list. It was Ben Adkins<sup>6</sup>, whom I had taught. I remembered him fondly; he was a hard worker and an attentive listener. I always felt sorry for Ben, despite the fact that he smiled and laughed frequently, because it seemed like school was a time-consuming struggle for him. Ben had two resource periods, as well as a special reading class, which meant he had no chance to take electives. In English, he took modified, second-grade level reading tests (complete with embarrassingly large fonts and illustrations), but those were still difficult for him to pass.

---

<sup>6</sup> The student’s name has been changed.

Originally, I thought the list was organized alphabetically and then I realized that the students were ranked by their scores, beginning with the district's lowest performance on the state reading test. Immediately, I felt embarrassed for Ben that all of the teachers at his new school were seeing his name and score before they met him. I imagined how hard Ben probably tried on the test. I have only met a few adolescents like that, kids who could be so positive, even when school is a constant trial. Our discussion of failure was not over; English teachers were each assigned to a different group of non-English teachers, with whom we would discuss how their classes could improve reading scores. I sat down with my colleagues, whom I was meeting for the first time, planning to suggest generic reading strategies. The screen continued to show the list of students with their corresponding scores and my eyes were continuously drawn to it.

Half-heartedly, I talked about think-alouds, questioning, visualizing, and other ways to access texts in various content areas. One teacher asked me how he might relate the reading assignments for the ROTC curriculum to reading test preparation and I could not form a coherent answer. Honestly, I was thinking about Ben and reflecting on my years with middle school students. I loved to see their growth, regardless of where they might have ranked on the list of scores. I thought about this reading score and the label "failure" and I felt its *wrongness* acutely because I could picture the real person. This activity was as soulless as a curriculum calendar, which attempts to dictate how we should spend class time to maximize the success of students, without any mention that the students for whom it was designed are fictional. I struggled to find words to express my point of view, without coming off as self-righteous or livid. Timidly, I said to the group, "You know, I know the kid who got the lowest score. He did not fail. Ben is a

good kid.” The teachers stared at me and then, and after a moment of silence, they began talking about other things and I moved hastily back to my corner.

I did not hear my new principal’s final comments, but I was relieved when the projector was finally off. When lunchtime came, I did not eat with my new colleagues. I spent the hour alone in my new classroom, thinking about the events of the morning. I relived my unsuccessful defense of my student as a “good kid.” Where was my voice? What kind of power could my convictions about teaching hold if I could barely speak to colleagues about them? But there I was, with new colleagues in a new school, silenced. My knowledge about the students on that list, despite my unique status as someone who actually *taught* a few of them, was irrelevant in comparison with the received, absolute facts of their test scores and the need to improve them. Preparing to teach in this school did not feel like a genuine, democratic discussion. Also, even though my level of English did not include a state test, striving to master them would still dictate our practice. And my knowledge of this young man—and of the thousands of students I had taught—was disqualified and invalidated in our discussion.

Instead of a break from problems, this new context deepened my interest in the epistemological assumptions underlying teaching practices, administrative oversight, and educational policy. As I began to consider knowledge as it is presented in schools, my experiences justified this research as something bigger than my teaching method. It was a profound example of serendipity (or irony) that my reading assignment the week after this event was a chapter in *Discipline and Punish*, “The means of correct training,” (Foucault, 1977) which clarified what I had witnessed with regard to Ben, but also illuminated it in horrifying light:

The power of normalization imposes homogeneity; but it individualizes by making it possible to measure gaps, to determine levels, to fix specialties and to render the differences useful by fitting them one to another. It is easy to understand how the power of the norm functions within a system of formal equality, since without homogeneity that is the rule, the norm introduces, as a useful imperative and as a result of measurement, all the shading of individual differences. (p. 184)

As Foucault details the “visible brilliance” of the examination as a tool in the process of normalization, I found it easy to understand the power of measuring individuals based on one mechanism, testing, but I did not find it easy to escape the awakening that started that day. I began, at that moment, to edge toward a deeper understanding of the school as “an apparatus of uninterrupted examination” and “perpetual comparison.” (Foucault, 1977, p. 186). What, in reality, does testing teach young people and their teachers? I felt powerless to change my new school, but I longed to make it better for Ben and all of my students. How could my teaching fight against this reduction of knowledge? This reduction of people?



## CHAPTER 8: LITERATURE REVIEW 2 (DECEIT AND DISENCHANTMENT)

My review of literature evolved from its original focus on epistemology (shared as Part 1) out of personal necessity; the literary works included herein were helpful companions during a professional crisis. My development as a scholar created problems for my life as a teacher. Moments of isolation, indignation, and frustration became frequent parts of my experience at school, where my burgeoning critical stance was not welcome. When I dared to raise critical questions, I received explicit or tacit negative responses. As my isolation grew, I began to understand that my development as a critical thinker contradicted the role I was expected to play as a teacher (Au, 2010; White, 2011; Wilhelm, 2008). Apparently my job was supposed to be that of a technician, skilled in the delivery of a *received* curriculum using *sanctioned* methods that *experts* have proven to be effective. Inquiry was not an acceptable trait to display while at work, overt criticism was a dangerous activity, and I was presumed not to be an expert. Still, it was hard to keep it in.

Like Jeffrey Wilhelm recalled in *You Gotta Be the Book*, “I really hadn’t intended to be a gadfly, much less a full-fledged nuisance” (2008, p. 148), it just happened. And the negative reactions of colleagues worsened the more I wanted to talk about my graduate work or research interests at school. The negative treatment of teachers who engage in research, publication, or certain advanced degrees has not been studied deeply, but I resonated with Brian White, a researcher who has looked into this phenomenon, when he claims that “some teacher communities so strongly value sameness that anyone who appears to be setting herself or himself apart by engaging in research and publication

or by presenting at conferences is in great danger of being ostracized and perhaps even hounded from the building” (2011, p. 333). I did not want to call attention to myself or make others feel uncomfortable, but my graduate classes trained me to speak critically and “enabled me to traffic in the codes of power” (White, p. 335) that are often associated with university researchers and educational experts.

Once, I silenced a teacher training session with the sarcastic assertion that we did not need to worry about beating other schools at the state test, since the schools on the Indian reservations would always have to take them too. In another instance, when a principal announced that our school was improving because our minority student test scores increased, I suggested that we just needed to thank several young women (who happened to be African-American) I knew had aced every standardized test. I was not always so surly, but I was increasingly disenchanted with the activities that teachers were expected to do—and not do—at school, a feeling that was the catalyst for a profound professional crisis.

As might be made clear by the two brief examples above, my response to what was becoming an unwelcoming environment for me did not win me many friends among the teachers. When I was humorous, other teachers would laugh, but they would keep their distance when I appeared to be challenging the standard way of doing things. Another part of my crisis with regard to teaching was that I was beginning to love it less. As graduate study made it increasingly difficult to keep my questions to myself, I found it harder to brook a teaching culture that did not encourage—or allow—inquiry. Despite encountering celebrations of practitioner inquiry (Cochran-Smith & Lytle, 2009; Latta &

Wunder, 2012) in the academy, I was not negotiating the same celebration in my school building.

Ironically (even as my satisfaction waned) I felt that I was becoming a better teacher because of my coursework and my interactions with talented pedagogues. At the same time, the curriculum I was expected to deliver became increasingly “teacher proof” (Russell, 1997) in nature. Our curriculum director, working above a team of writers, fitted teachers with calendars that included the order of units and which days should be devoted to which skill, story, or idea, common tests and quizzes, and premade projects and speeches (along with the rubrics to grade them) that accompanied each unit. Teachers who worked outside of these parameters were disciplined by district administration, as I was for my (excessive) teaching of poetry not included in our anthology, for altering or changing completely summative projects and tests, for creating and using my own rubrics to grade papers, for switching the order of units, and for failing to give all of the required practice tests. In each instance, I apologized and acquiesced quickly. Among colleagues, I began to feign an absent-mindedness that I hoped others would perceive as part of an “artistic” personality. I am not sure if this ruse was very convincing, but I began to hide most aspects of my work from other teachers and administrators.

In addition to chastisements and orders from superiors, teachers in my district criticized other teachers who rebelled. I can only assume that I was discussed in the same way I heard other teachers decried for breaking the rules. I remember one department meeting when our chair brought up, as negative gossip, the fact that a teacher at a different school had decided on his own volition to change the guidelines for the required research paper. The directions instructed students to research some aspect of the

Holocaust, with the teacher's guidance and the use of the district's extensive collection of materials on the topic. The class had just finished reading Anne Frank and several related pieces out of our anthology and this teacher was rumored to have said that they just needed a break from the topic. As I sat silently, I heard another teacher gasp in reaction to this story, and another ask whether he let the students research *anything* they wanted. I did not rise to his defense, nor did I mention that I had done the same thing.

I used ingenuity and deceit to get around much of this attempt to constrain what I could do—whiting out multiple choice answers on tests, editing common assignments, requiring students to annotate standardized tests, teaching my students to decipher the code of test writers, pretending to be forgetful when I did not follow the calendar, adding literature to the curriculum, and so on. Although these actions improved some aspects of what I was required to do, it was exhausting, alienating, and morally questionable to work outside of the parameters (and the rules) of my position. A friend who works in the medical field asked me at the time, “Doesn’t it bother you that you have to sneak around to do what’s good for students?”

It did bother me. Even when my students did well, it did. I began to wonder why my wisdom and teaching expertise did not carry weight in a real context in which I was positioned as the guide for instruction and learning. I had extensive knowledge of my subject area, but I was not given the freedom to exercise professional judgment, if I followed our curriculum guide to the letter. Much of the material I was slated to pass to young people was created as a result of research done by educational experts, but it frequently failed to fit my students' needs and lives. I used our anthology and required

novels, but I added many materials and activities that were based on interactions with specific students.

For example, our curriculum included the book *Bearstone* (Hobbs, 2004), which tells a coming of age story of a troubled Ute Indian boy. To provide the appropriate context for understanding the character's background, my classes and I engaged in a research unit on the history of the Ute Indians, and together we had begun to understand some aspects of their culture, like the significance of grizzly bears, and we learned about the struggles this diverse group of native people has encountered in their attempts to stay in the mountainous and desert regions they find to be sacred. Many of my students were very interested yet troubled by what they were learning, and our classes often included spirited discussions like our on-going debate on whether the name "Utah" honors or disrespects the Ute people. The project that was assigned—by the district—to culminate the reading of *Bearstone* was the creation of a three-dimensional totem pole that would represent each student's identity. By this time, my students and I were keenly aware that totem poles are not part of the Ute tradition. Rather than complete this unrelated and unwieldy craft as their final project, students researched and shared the myths of Ute people and interpreted them by creating art projects, poems, or their own myths. I was proud of this unit (and mortified by the district-assigned project), but I kept it to myself.

When I expressed my frustration and my nascent revelations to my advisor, he handed me chapter two of *Pedagogy of the Oppressed* (Freire, 1970) I knew of the text, which came up now and then in my graduate class discussions, but I was amazed (and alarmed) at how well Freire describes exactly the situations I found so troubling in education. First, I related to his metaphorical description of children depicted as

containers that the teacher must fill with knowledge (an image Freire then decries). I thought immediately of my experiences with teacher assessment when Friere states, “The more completely she fills the receptacles, the better a teacher she is. The more meekly the receptacles permit themselves to be filled, the better students they are” (Freire, 1970, p. 72). If standardized test scores illustrate teaching ability and the worth of students, this metaphor is too often appropriate. The humanness of teachers and students (i.e., their curiosities, interests, biographies) is not relevant in this kind of system, just the outcomes. Second, Freire explains the motivation of leaders to “react almost instinctively against any experiment in education which stimulates the critical faculties” (pp. 73-74). Ironically, it seems that just as we emphasize more and more that schools should teach critical thinking skills we concurrently impede the prospect at least as much.

I had not previously thought of educational leaders as oppressors, but Freire’s observation matched my experiences. In the banking model, there is little room for teachers and students to learn together or for students to construct their own curricula (two activities I promoted frequently). These efforts “to resolve the teacher-student contradiction, to exchange the role of depositor, prescriber, domesticator, for the role of student among students would be to undermine the power of oppression and serve the cause of liberation” (p. 75). Freire offered a new perspective on my daily battles.

I am not sure that I would have described my teaching at this time as liberating, but in Freire’s description of banking education, I saw many aspects of schooling that I do not like. Students are regularly treated simply as problems to be solved (like my former student Ben, whose low reading ability was presented as a problem before he began high school) often turning the enterprise into “a paternalistic social action

apparatus” (Freire, 1970, p. 74). Also, creativity is deemed as unimportant or irrelevant for students and teachers. The standard curriculum—particularly the current model that makes the claim that a good educational program can be pre-packaged—“attempts to control thinking and action, leads men and women to adjust to the world, and inhibits their creative power” (p. 77). Finally, I had experienced that the findings of research are often presented to teachers as absolute rules (see Hamann [2003] regarding interpretations of the National Reading Panel’s findings as an example), as if such “knowledge is a gift bestowed by those who consider themselves knowledgeable upon those who they consider to know nothing” (Freire, 1970, p. 72). My ability to translate what was happening to me and my students into oppression was enlightening, but it did little to reignite my love for teaching English. How could I stay optimistic, while operating in such a system?

In one of the readings for a graduate class I was taking at the time, I recognized what I needed to do if I did not want to become cynical about teaching my subject area:

As teachers we may need to relearn how to love our subjects, to invite our students to inquire with us in those subjects, to do so without harming ourselves or our students, and to demand that schools no longer constrain these efforts. We need to learn how to protect ourselves and demand that our society honors these loves, or at least create a place where these loves can exist. (Liston, 2004, p. 451)

I would have to stay focused on the love I discovered for teaching and if I did fight, it would be for the space I needed to share that feeling, that joy of inquiry, with my

students. To recapture my vision for that space, I reflected on my favorite memories of learning and remembered the joy of discovering “that I could ask a question and recognize the essential limitations of finding an answer while still experiencing the desire to know” (Martusewicz, 1997, p. 100). I needed to hold onto that passion for my work at school.

The words of education scholars offered me sustenance to stay professional, to keep teaching, and to keep fighting against the prevailing message that “teachers cannot be trusted, as professionals, to effectively determine the best ways to educate and assess students” (Au, 2010, p. 6). I found collegiality in the writing of Bill Ayers, whose love of teaching did not falter, even in “the contested space of schools” (Ayers, 1993, p. 7) and who did not lose his faith in the power of activism despite being painted as “the putative unrepentant terrorist” (Ayers, 2013, p. 95) with whom President Obama should never have associated. Reading his account of the “splendorous range of actions” that make up teaching, I thought of all the activities I still got to do daily including, “questioning, instructing, advising, counseling, organizing, assessing, guiding, goading, showing, managing, modeling, coaching, disciplining, prodding, preaching, persuading, proselytizing, listening, interacting, nursing, doing and making, discovering, and inspiring” (Ayers, 2010, p. 17). It reminded me that teaching is not boring, even when it is hard.

Ayers also echoes my love for individual students when he reminds his reader that everyone “has a unique and complex set of circumstances that makes his or her life understandable and sensible, bearable or unbearable.” Such an understanding “asks us to reject any action that treats anyone as an object, any gesture that *thingifies* human



beings”(2010, p. 164, italics added). I was reminded not to teach that way and to remember the humanness of my colleagues and administrators as well.

In her hopeful account of Central Park East public school in Harlem, Deborah Meier reminded me that “schools [still] embody the dreams we have for our children” (2002, p. 11). After years of frustration at how large schools treated individual children, she took charge of an alternative school and was offered a chance to work with a small group of teachers to “build a school just the way we wanted” (Meier, 2002, p. 19). She and her teachers wanted the school to be democratic, steered by common ideas of teachers, parents, and students. Following many of the ideals of Ted Sizer and the Coalition of Essential Schools (Sizer 1984, 1992, 2013), they created a progressive high school. Meier and her colleagues designed a small school in which “teachers [were] rarely responsible for more than 40 students a day and stick with the same students for two years” (p. 36). They also designed a highly personalized program in which students completed portfolios to demonstrate their learning. The staff of the school focused on creating a safe place where each child was known. The ultimate goal of the school was to help each student develop “close observation [skills], attention to detail, having information ready to use and the know-how to use it” (Meier, 2002, p. 167). Overall, the school (and fifty others that followed a similar model) was a success. They learned much from triumphs and missteps, but in the end Meier reminds us that school is “about our kids and our shared future with them. Worth arguing about” (p.185). I benefitted from revisiting this story, which reminded me that teachers should never stop fighting to improve that future.

Reading and reflecting on schooling and the role(s) of the teacher enabled me to listen, like I had when I started this career, to “the teacher within,” my sense of professional identity that “stands guard at the gate of selfhood, warding off whatever insults our integrity and welcoming whatever affirms it” (Palmer, 1998, p. 32). I turned away from the insults surrounding my work to linger on my pedagogical values. Fundamentally, I have always believed that teaching is an art. I turned to literature that elucidated what this designation means for the work we do in classrooms:

[I]t is a work of art because we reconfigure and decorate our spaces, make our marks, elevate ourselves and others above confinement, routine, and the mundane. We expand our capacity to see, hear, love, critique, and act on our possibilities in the world...The medium of teachers is the curriculum, not students. It is formed, co-created, enacted, and experienced with students in schools and classrooms. (May, 1993, p. 211)

My exasperation with my job and the context in which I was working made sense; from an artistic point of view, I needed space to work and “anger appears to be a reaction in protest against fixed limitation of movement” (Dewey, 1934, p. 217). It was good to know that my anger meant something, but it was even better to find ways to alleviate it and rededicate myself to my teaching tasks.

My context felt constrictive, but I also felt pressure to accept the notion that schools were factories, producing young people as products. If one holds an aesthetic view of education, “the studio is a better image” (Eisner E. , 1991, p. 47). I would still have to deal with conflict in order to do my work, but I was reminded that the challenges

of the job (and the risks I would continue to take) are part of its fragile potential.

Teaching as an artist would mean “the releasing or surrendering of self to the present, immersing self in immediacy” (Latta M. M., 2001, p. 50). The literature reminded me that I could love this job again, by allowing myself to close my classroom door. Then, turning my attention away from the cacophony of conflicting voices, I could embrace “the art of thus giving shape to human powers and adapting them to social service,” a job for which “no insight, sympathy, tact, executive power, is too great” (Dewey, 1897, p. 23). Teaching with such a liberating ideal in mind would be difficult, of course, but doing it well has always been.<sup>7</sup>

---

<sup>7</sup>In anticipation of my third literature review (later in this document) that returns to the theme of the influence of my health on my practice, it is worth acknowledging that the ideals that inspire me to teach did not change even when my means for realizing them have had to.

## CHAPTER 9: THE RESEARCH PROCESS, INTERRUPTED AND REIMAGINED

“The illness story begins in wreckage, having lost its map and destination. The story is both interrupted and about interruption. In the illness stories, what begins as a breakdown of the narrative—life’s interruption by illness—is transformed into *another kind of narrative*” (Frank, 1995, p. 164)

I did not want to write about myself. One of the reasons I loved teaching was the chance it afforded me to think about something and someone other than myself. In my time outside of the classroom, my physical setbacks were a constant source of frustration and I expended a great deal of energy hiding them from my students and colleagues. Teaching was a reprieve. Before I started constructing a dissertation, the last thing I wanted it to be about was myself, particularly my experiences as someone with a chronic illness. But then life interceded, my disease refused to be cast aside, and the related events changed the direction of my research and my life as a scholar. I like this new focus; in fact, looking back at my experiences it appears that it was always the goal of my intellectual life for me to write and research the way I do now.

Despite this positive resolution, the journey that brought me here was arduous and, at times, harrowing. The tale that demands to be told is *about* me, a topic I will approach boldly and honestly with the use of the first person. One of the lessons about writing that I have learned—one that was not easily wrought—is that “bad writing at every level is easier to bear, and to work with, if the writer is *in* it, not holding herself ten thousand light years away in the name of objectivity” (Mairs, 1994, p. 10). Since I have surrendered completely the possibility that I might narrate this story with the dry distance of an academic, I will commit myself to candor and tell what really happened.

In the fall of 2013, I had evolving research questions for my doctoral research, I had a classroom in which to teach, a teaching practice on which to reflect, and I had begun a graduate class on narrative inquiry, a topic I knew would be germane to my interests. In October, I had also just begun working on my comprehensive exams, a process that occupied my evenings and weekends. I had grown accustomed to a hectic schedule, but still delighted in my ability to wear many hats (teacher, researcher, student, mother), despite my lack of sleep and free time. On October 8th, I left school to meet my informant for a narrative research project, a college-bound English language learner whom I was tutoring in exchange for the chance to hear her story of coming to the United States from Mexico. I did not feel well, but we had cancelled our most recent meeting and I did not want to lose our nascent connection (she had promised to bring pictures of her family this time; last time she had regaled me with details about her quinceanera). Although I longed to go home, I drained a mug of coffee and swallowed four ibuprofen to fight off the urge to rest. This routine had worked for years and it allowed me to operate at the frenetic pace my life required, despite acute pain and fatigue.

When I arrived at our meeting spot, Burger King (she had chosen the location, in walking distance to her home), my legs were almost completely numb. When I got out of my car, they would not propel me forward and could barely hold my weight. I tried to slide along as if I were walking in skis, but I could not keep my balance. Grabbing onto my car, I managed to cram my legs back inside and decided that cancelling was the only option. As I drove, I had to push and pull my right leg with my hands to work the pedals. By the time I arrived at my house, I could not stand at all. I crawled inside, lay on the floor of the living room, and called my husband, David, who was picking up our children.

My next phone call was my neurologist's office, where I had not visited in a while. Actually, I had skipped my regular appointment, since I had continued to take my MS medicine without problems and I had been managing to live my life (fairly) normally. The receptionist was cavalier about my situation, offering only to leave a message for the doctor to call me. I hung up and called the hospital directly, which began a series of unhelpful conversations with individuals who did not seem to appreciate my desperation. By the time my family arrived, I could not move enough to make any more calls.

David took over talking to medical personnel, and finally I got permission to check myself into the hospital. My daughters were scared, but I told them that "mommy is sick and I need medicine," something they had heard before. When a babysitter arrived, we drove to the hospital. From then on, the evening was crowded with paperwork, questions, more questions, and needles, until I was in a bed in a room on the neurology floor with IV steroids infusing into a vein. A team of neurologists came to see me when I was still unable to move; I was embarrassed to meet this group of doctors for the first time in such a vulnerable position. No! I did not want to be a patient. I had been resisting that reality for almost a decade, passing for healthy enough to live the existence I enjoyed, delighting in my ability to do so much concurrently. It was working.

But it was not working to my benefit. The goals of my professional existence were outweighing the importance of my physical health and suddenly I was forced to pay dearly. I had a disease, but I was invested in *this* story instead: a plan to research and work, to complete my degree, and to move onto another level of teaching when I was ready. But my health crisis forced me to reconsider the validity of this plot, and I found myself starting anew from a painful state sociologist Arthur Frank (1995) has called

“narrative wreckage.” In this story of research, the intersection—the crashing---of illness into the events forced me to alter its focus considerably. Eventually, I had to leave my teaching position, put my course work on hold, and step outside of the educational circles I planned to study. There would be no more passing as healthy.

From my hospital bed, I tried to continue my activities. As soon as the steroids gave me enough strength to use a phone and computer, I put together lesson plans for a substitute teacher, I continued to revise my comprehensive exam answers, I wrote to my informant in an effort to keep progressing on that project, and I also worked on my homework. Meanwhile, I could not walk without an incredible amount of assistance and sitting up was often a challenge. One of the physical therapists (who had just carried me in and out of the bathroom) expressed concern that I was not getting enough rest, when she noticed the pile of textbooks I had on the table next to my bed. It *was* ridiculous, seeing the accoutrements of my hectic teaching and studying life crowding the space that also held bottles of medicine and piles of hospital paperwork. “What should I do?” I asked stupidly. I had no idea how to change the way I functioned.

My tenure at the hospital did not afford me much free time to reflect on this problem. Teams of doctors, nurses, occupational therapists, and other pleasant professionals visited me. Some would offer me business cards and fliers of information. Others would check my reflexes, adjust my IV medications, read over my chart, or measure how well I could stand on my own. I did not know how much longer I was going to be stuck there, but I longed for normalcy and I worried about the state in which I was leaving all of my projects. “Six weeks,” one of the neurologists advised me when I asked how soon I could get back to work. Six weeks was impossible. But when my regular

doctor visited me, he said the same, adding to it that I should also stop working on my graduate classes. "Work appears to be a trigger," he noted calmly. My reaction was not so impassive; I felt lost even imagining what I would do if I stopped.

Before I left the hospital, I had agreed to take a medical leave. My "job" was rest and to attend physical therapy three times a week, my husband and doctors insisted. I still could not walk without help, but I held out hope that I would recover quickly once I returned to my house and my normal routine. It turned out to be much harder. On my first day of leave, I had my initial meeting with a physical therapist who, I had been assured, was an expert at helping people like me get better after a relapse. With confidence, I wheeled into her office, prepared to work hard and overcome this recent adversity. I had done it before, right? Our first test sounded ludicrously simple. I was to rise from the chair on my own and take one step forward, which I would hold as long as possible. I had been getting around my house and feeling better, so I was unprepared for my complete failure. I could not get up. The therapist had to pull my frame from the wheelchair and set me upright. She managed to get me balanced enough to stand in place. Then, the step. As I tried to do what I had at once done thoughtlessly, the weight of my foot prevented it. I tried again, this time managing, with excruciating pain, to raise my foot slightly off the floor for a second until I lost my balance. I collapsed back into the wheelchair and began to cry for the first time since this had all begun.

The physical therapist pulled up a stool and sat next to me while I attempted to pull myself together. While I sobbed and wiped my eyes with a tissue, she smiled and waited patiently. We managed to get through several other tests, although each proved to be impossible and painful. After feeling more like myself, I joked that I felt ashamed



because I had never failed a test before. We both laughed, but the shame was real. When I left the appointment, I was exhausted and relieved to be done for the day, but I also felt empty. After my brother-in-law drove me home and went back to the restaurant where he worked, I lay on the floor of our living room. Considering the soft brown carpet, which we had recently installed, was a source of comfort while I reflected on my body and my life at this moment.

I had been dealing with multiple sclerosis for a decade. It was a source of pride for me that I did not let it get in the way of my plans, regardless of its progression and disabling effects. My health was simply not relevant to my identity. Just as I had wanted to do before getting sick, I had two children, I did well in my career, and I still pursued a Ph.D. True, it had not been easy, but I believed that if I kept striving I could overcome my health problems and achieve my dreams. But what if I couldn't? What if overcoming was not an option? I realized, during that afternoon's tragic epiphany, that I had never considered honestly what I would do if my body refused to be complicit in my effort to do everything as if I were healthy. I had never considered what I would become, if I failed to be the hero who overcame MS.

I had promised not to work during my leave, but I decided that day to begin keeping a journal. I had never written about my disease (choosing instead to deny the reality), but at this time I had so many strong emotions to sort out that it made sense to record them. It was hard, but as I lay in bed I could type on our laptop computer. The writing was meant to be for no other purpose than personal catharsis. I turned off the grammar and spell check, so I would not think about getting those things right. I described the PT examination as "weird, surreal, tragic, impossible how I could not DO

anything with my body. Definitely one of the worst and strangest hours of my life. A macabre situation (Day 1),” and it felt better to get it down. I could also feel more in touch with my literate self, even if I could not teach or work on my graduate courses.

I began a routine of daily journal writing, sleeping, and physical therapy. I did get better, not completely better, but by the time it was over I could walk a little distance on my own and I felt like I could work again soon. Looking back on the pages of my journal, I am saddened by the amount of painful questioning that accompanied the reflections during my medical leave.

- What do I do with all the anger? (Day 4)
- What is this hope thing? What does it actually feel like to possess it? (Day 6)
- What if I have to go on disability? How will I ever show my face again? (Day 9)
- What good could I do? I try to be perfect. And it is killing me. (Day 11)
- I do not feel like myself, but more and more I question what that means. (Day 12)
- I am the one not working. How can I not feel responsible somehow? (Day 14)
- How does being isolated and trapped by your own body become acceptable? (Day 19)
- Do I have something worth sharing? (Day 22)
- How much have I punished myself for this disease? (Day 24)
- How will I get back to normal life? What is the new normal? (Day 29)

This artifact of my medical hiatus contains hope as well, “What if I have worth? What if it is good? What if I am actually pretty strong?” (Day 32), but much of that hope

hung on the belief that I would be able to return to work. I had managed to create a new literature unit and I was anxious to return to my students and begin it.<sup>8</sup> I leaned on my teaching ability as a source of pride. I also had faith that my principal and others at the high school would help me ease back into the classroom. I was certain my employer would appreciate my resolve to keep teaching. “My job is waiting for me. I have a successful track record with teaching. My boss is understanding of my absences” (Day 29). That is not what happened.

I tried to merge back into my normal routine as gradually as possible. I returned to full-time teaching, during which I used a wheelchair for part of the day. My students and I had a happy reunion and my return was not nearly as awkward as I thought it would be. In many ways, it was better to be able to ask for help, to explain my health conditions, and to use a wheelchair when I needed to. Returning to my old habits, I again relied on caffeine and pain medication to make my normal activities feasible. After just a few weeks, I realized that coming back full-time was not going to be tenable, and I worked out a way to share my job with the woman who had been my substitute teacher. In order to make this arrangement work, I had to count the half days I was gone as an extension of my medical leave. I knew I had used all of my leave and sick days by March, but I was still surprised when my school district forced me first to take another leave—unpaid—and then to quit teaching there entirely. My contract included insurance for this kind of event, but I had to retire and apply for disability to access the money. Thus, with that ignominious choice, forced on me by economic necessity, my teaching career was over only ten years after it began.

---

<sup>8</sup> See “Ultima” for the full story related to this unit.

Multiple sclerosis had finally won. I would not be passing for well, nor would I be able to overcome this illness with willpower. I did not have a job. I had to take an incomplete in my last doctoral class. I had to go on disability. Just as I did the day after my first physical therapy appointment, I found myself reflecting on the state of my life, my health, and my future since so much had happened. It was too painful to write it down this time, so I began reading instead. Always a student, I returned to my narrative inquiry class materials and I reread our focal text, *Narrative Inquiry* (Clandinin & Connelly, 2000), searching for inspiration. This text offers advice for education researchers who, like me, “are interested in learning and teaching and how it takes place; they are interested in the leading out of different lives, the values, attitudes, beliefs, social systems, institutions and structures, and how they are all linked to learning and teaching” (p. xxii). I still longed to be in the field, conducting education research. I wanted to collect stories too.

When I said this to my professor a few days later, she suggested I research what I had been through during the medical leave to finish my incomplete in her class. Reluctantly, I began to re-imagine narrative research as something about myself. In my quest to understand this approach to research, I found the writing of Carolyn Ellis, a sociologist who creates and teaches her students how to write “auto-ethnography” an experimental method designed “to open a space for detailed, lived experience within orthodox social science” (Ellis, 1995, p. 307). By using her own life as data, she is “the author/ researcher and the subject” (p. 311). Using Ellis’s textbook on the topic (Ellis, 2004) as well as her book *Final Negotiations* (1995), I begin to imagine my own story as fodder for research.

My crises and those described by Ellis were not identical, but our response to life events was similar. She had one direction for her academic life, but then her lover got sick and her brother died in a plane crash. A new focus was introduced by fiat, rather than from intellectual musings or from reading influential literature. Ellis explains that “these two events were the most profound and unsettling experiences of my life. I felt compelled to share this part of the human condition—loss and illness” (Ellis, 2004, p. 33). Like me, her academic pursuits had always been personal and she could not just bracket these life-altering events to get back to work. I connected immediately to Ellis who says she writes “when my world falls apart or the meaning I have constructed for myself is in danger of doing so” (p.33). I continued to work through *The Ethnographic I*, a fictionalized version of a class on autoethnography, complete with lectures, class discussions, course readings, and her personal reflections on what it is like to teach this style of research and writing.

My angst as a result of my job loss and the progression of my illness qualified as profound events, I concluded, and also longed to reconcile these events with the meaning I had ascribed to my life. Ellis’s work led me to another source that would help me begin turning my own experiences into data for research. *Researching Lived Experience* (Manen, 1990) offers advice, examples, and methods to assist researchers in their efforts “to construct an animating, evocative description (text) of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld” (p. 19). Although the author does not suggest that these texts should come from the researcher’s own life, the book includes specific directions regarding how someone might produce the kind of text that would describe a lived experience in a vivid manner. I took these instructions into

consideration as I aimed to describe my struggle to complete my doctoral comps. I liked their clarity and I imagined myself as a participant, responding to them.

(1) You need to describe the experience as you live(d) through it. Avoid as much as possible causal explanations, generalizations, or abstract interpretations.

(2) Describe the experience from the inside, as it were; almost like a state of mind: the feelings, the mood, the emotions, etc.

(3) Focus on a particular example or incident of the object of experience: describe specific events, an adventure, a happening, a particular experience.

(4) Try to focus on an example of an experience which stands out for its vividness, or as it was the first time.

(5) Attend to how the body feels, how things smell, how they sound etc.

(6) Avoid trying to beautify your account with fancy phrases or flowery terminology (Manen, 1990, pp. 64-65)

What follows is the first account I wrote following this advice, describing a private moment, something I might have just written into a journal earlier, if I had wanted to remember it.

## **A Finish Line**

I am sitting at the kitchen table, sifting through the pile of papers and books surrounding my lap top, reflecting on what else I need to do to complete my last question for the doctoral comps. It is Thursday before Easter and I want to get the answers to my committee before the weekend. This one has been difficult. No, they have all been difficult. I first started this test in October and it is April; it will be a relief to complete it and I am driven to finish today.

Earlier this morning, I helped my daughters get ready for day care and kindergarten. My role is to feed them, check that they look presentable, and to make coffee for my morning-groggy husband. It was hard to get out of bed; it usually is, because of excruciating pain in my feet. The narcotic pain pills are the only effective way to make that pain forgettable, but they hinder my ability to think clearly, so I took four ibuprofen tablets and hoped they would help. Today I have a lingering headache too, which has had a grasp on me since I had an infection that sent my disease into attack mode again. (I really do have a strong immune system; it just attacks all the wrong places with misdirected fervor whenever it senses that something is wrong.) I managed to stay out of the hospital for this relapse, but walking was very difficult and I am still a fall risk. As I got out breakfast items from the cupboards today, I struggled not to slip on the tile. After three trips across the room, I was exhausted and decided we would just eat what was on the table. My older daughter can read my fatigue, so she brought me what I needed to do her hair and she helped herself to food. My toddler was not eating well, but she made me smile by playing peekaboo with a napkin and saying “naughty” over and over. My husband came into the kitchen and began drinking coffee, packing his

materials, and making sure the girls were ready to leave, without sitting or stopping his quick movements.

When I hear the garage door shut, I feel a pinching in my gut. I feel marooned at home, weighted here with the nebulous goal of getting better and resting full-time, not helping with the kids, not working, not riding with my husband, and not cleaning the house, or even whittling away at our list of springtime chores. I am supposed to take care of myself, which is not easily done when my ambulation and mood are this bad. After they leave, I normally fall asleep again, fatigued from the exertion of morning preparations. Today I need to stay awake and finish this answer. This one is about educational ethics, a topic that I love, even though I find that explaining why teaching is ethical is an intimidating task. So instead of trudging back to my bed, I slide down to the end of the kitchen table, where my ad hoc office is located, and start thinking about what I have already written. I am hoping I used Nel Noddings (1988), Bill Ayers (1993), and Jon Dewey (1909) well in this section, without oversimplifying or misusing their ideas on ethics, but I am not sure. I realize that I need to add a few citations for some paraphrasing I had done, when the pressure behind my ear starts again.

These latest waves of migraines, which apparently entered my body through the attack I just had, are new to me. I had hoped they were gone, since they had kept me in bed earlier this week, staying powerful even with my better pills. These headaches come in a flash and feel as if something very sharp is inserted behind my right ear, which causes me to jolt my head and shut my eyes. Instinctively, I place my right hand on the spot of the pain, which makes it feel a little bit controlled as it throbs. Then, along with that weird pulsing under my right hand, a shock of pain runs through my left arm,



paralyzing my fingers into something like a claw, with really just the forefinger having the ability to do what I want it to do. Stubbornly, I don't stop this time. I just cannot allow the migraines to win today. I keep my right hand behind my ear, a pressure which somehow enables me to keep my left eye open, and then use my left pointer finger to type in the authors and dates, one key at a time. N... o... d... d... i... n... g... s.

I am not a good typist in general, but I am so slow this way that my pace strikes me as ridiculous. It is funny, that *this* is the manner in which I am finishing my comps. I think of a scene at the end of an inspirational movie in which someone has gone through hell trying to finish a race, but now is sliding across a finish line many hours after everyone else. This weary, beaten hero is cheered by a stragglers in the stands, which makes the protagonist cry with joy and say something like, "I did it!" while dramatic music swells. Even before I had this disease, I did not find this kind of scene inspirational. I do not fault the hero for wanting to finish something, but I have never wanted to be like that person. I want to be a regular participant who finishes the race on time, along with other normal racers, and then feels the satisfaction of exertion used well. As someone at the end of a race of sorts, I am not thrilled to compare myself to a racer who is elated, but perhaps near death. It is inspirational when a person does something that is difficult because they love it so much, like an amputee competing on *Dancing with the Stars* using prosthetic legs or a hiker who lost his sight but climbed Everest anyway. Do I love this? I don't know anymore. But I sure want to finish. I manage to put the citations in that I think I need. Then, I save the paper and lumber my way back to bed, where I spend the rest of the day.

That afternoon, before the kids and David return, I get out of bed and try to look like I feel better by brushing my teeth and putting on day clothes. Then, I sit down at the table and send my answer to my doctoral committee without reading it again. I prepare a smile and think of questions for my family, whom I know will have had a more interesting day to share.

\*\*\*

But what should I make of this piece? It was certainly a powerful moment for me to recall, but what benefit does retelling it have? Turning back to Ellis (1995), she describes how she began the book that narrates the illness and death of her lover. She started by “writing the details of what has occurred so far, an exercise that helps sort out what I know from what I guess and distances me from the experience” (Ellis, 1995, p. 153). Manen makes a similar point when he describes writing as method: “As we stare at the paper, and stare at what we have written, our objectified thinking now stares back at us.” (1990, p. 125). The act of writing this kind of account certainly has potential to offer new insight in understanding my own experience. Creating something offers me a different vantage point from which to reflect on how this illness is affecting my outlook and daily existence. In this light, I can focus on what I gain.

Concha Delgado Gaitan (2009) writes about the lessons she has learned while suffering from systemic lupus erythematosus in her memoir *Prickly Cactus*. Early in the course of her illness, Delgado Gaitan comes to a conclusion that relates to my piece:

While I reaped many coveted rewards and awards from working excessively, I noticed that I could no longer control the illness as I was accustomed to controlling the rest of my life. It was becoming clear that no matter how hard I

worked, my body had limits. Physical endurance was central in obtaining the external rewards and achievements I craved. Without it, I faced the unknown.

(p. 57)

I also faced the unknown as I learned how to live, work, research, and think in new ways. In the account about my finishing my comps answer, I had to confront the reality of a body that was not going to obey my wishes anymore. It is interesting that I felt the need to “prepare a smile” for my returning family members, rather than letting one develop naturally after completing something as daunting as doctoral comprehensive exams. Although I lament my connection to so-called inspirational stories, there is something stunning about my tenacity in the face of pain and disability. The self displayed in the written account is sad, but still pragmatic, thoughtful, stubborn, devoted to her family, and loving as I have always been. These important attributes are not in any way lessened by my illness. In the writing of this piece, I was able to see that, perhaps because of the distance writing and reading granted me.

But what value does such writing have for others? As Nancy Mairs, who has written extensively about her life with MS, pointedly asks in *Voice Lessons*, “Why do I, and others like me, write this stuff? Why does anybody read it?” (1994, p. 125). Before I could commit myself to writing more about my illness experience—particularly if it was going to become a dissertation—I needed a good answer. One came from Arthur Frank (1995) who describes illness itself as “a call for stories” and extends to those who are sick the invitation to act as a “wounded storyteller” who can be a “moral witness, reenchanting a disenchanted world” (p. 185). One type of story he describes is the

*testimony*. Such stories, according to Frank, “are openings to their more fundamental testimony, which is the presence of the embodied teller. Illness stories require an interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony that is the suffering body of the teller” (p. 144). Thus, there is a longing for human connection implied by the stories of a body confronting an illness and the act of reading them brings that possibility closer.

It is true that if someone were to read the account I created, he or she might empathize with my frustration as I try to manage my illness, act as a mother, and still complete work that is important to me. All readers know, at some level, that our bodies will eventually limit (and stop) what we want to do and my work illustrates vividly how it feels when this abstract fact suddenly becomes real. I am not sure if this testimony can “reenchant” anyone, but it could remind readers of the frailty of the human body and demonstrate how one might keep on striving, and have success anyway. To quote the end of *Prickly Cactus*, “[r]ealizing that my body was destructible opened my heart to the indestructible” (2009, p. 175). What indestructible wisdom might my account reveal? I could admit, on reflection, that it could respond to the ethical dilemma Arthur Frank describes as “how to live a good life while being ill” (Frank, 1995, p. 156). I am trying hard to do that, but I want my writing to speak to a larger audience than those who are suffering or those who care about someone who is ill. It will have to become something more to satisfy me intellectually as well. Ellis and Mairs and Gaitan do more than tell their stories; they place themselves among a network of ideas, theories, and experiences that are common.

Taking an analytical perspective, what can I make of the account I created?

Researchers do not simply find data and let it speak for itself (even if it is fascinating).

They analyze it; that was the deeper piece I was missing in my writing. Ellis describes the act of autoethnography as more than looking within, a description that would alter the manner by which I had been approaching my data:

First they look through an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretation. As they zoom backward and forward, inward and outward, distinctions between the personal and cultural become blurred, sometimes beyond distinct recognition. (Ellis, 2004, pp. 37-38)

My writing expressed vulnerability, but how does my experience fit with those of others? What do my reactions to illness and disability reveal about these events and my cultural milieu? Just like I would have treated the data I had been planning to elicit from others, my telling “demanded interpretive analysis by the researcher in order to produce a human science description of the experience of illness” (Manen, 1990, p. 164). I needed a researcher’s stance. But even as I tried to distance myself to gain that perspective, I knew that “I could not talk about loss without showing attachment” (Ellis, 1995, p. 9). But rather than hide my emotions and inner conflicts, they would add to, not delude this inquiry.

My reluctance to treat my own experiences as data is ironic, coming from someone who has been trained to think as a human science researcher, but it also reveals

something important about the experiences of the disabled and the chronically ill. Most people see such conditions as something that rests solely within a person. Disability, as it is presented by the academic curriculum of education and in popular media “is the individual’s or at most the family’s problem” (Linton, 1998, p. 134). But my illness and my related disability are cultural as well as physical facts. My increasing marginality was not derived just from my health status; the cultural world I inhabit revealed itself to be even more “healthist, capitalist, and hierarchical” (Zola, 1983, p. 235) than I had known it to be. When I was able to pass for healthy, I was part of the ruse that says that “disability is an individual thing, a matter of personal fortitude and courage” (Linton, 2006, p. 183). When I am unable to overcome it, it often feels more like a personal failure than a concept ripe for analysis.

Like most people, I have been conditioned to keep these things to myself. After all, talking about health problems “seems like a litany of complaints. And no one, at least in our society, likes a complainer!” (Zola, 1983, p. 208). Thus, restraint and this shame reveal themselves in my account. When I have tried to discuss my illness and disability in the past, I have been the primary source of my own silencing. Although my shame (and the shame felt by everyone who is marginalized by illness or disability) is socially constructed, I am “in a way, censored once and for all, through the forms of perception and expression that [I] have internalized and which impose their form on all of [my] expressions” (Bourdieu, 1991, p. 138).

I was hesitant to write my memory in the first place, as much as I have been reticent to talk about my illness in other contexts. I describe “a pinching in my gut” when my husband and daughters leave for the world of work and school and I immediately list

all of the things I am not doing, “not helping with the kids, not working, not riding with my husband, and not cleaning the house, or even whittling away at our list of springtime chores,” without acknowledging my devotion to my family and to my work that is evident. I also admit that I am exhausted from the morning and ailing with a headache, but I do not allow myself to rest or take the medicine my body requests. I do not want to let my illness “win” this time, hinting that in other circumstances I have “lost” this battle with a personified adversary. At the end of the narrative, the tone is shameful when I describe heading to bed as “lumbering” and then again through my attempts to look better than I feel to greet my family “whom I know will have a more interesting day to share.” My negativity and my assumption that I do not have anything to share reveal the stigma I feel about my disease. The account reveals, at that time at least, I saw succumbing to my illness as a moral failure; being left behind, being unproductive, and needing so much rest to function are sources of shame rather than side effects of adversity that was happening to me.

There is something in my identity that has been shattered irreparably by having this disease, regardless of my knowledge (and that of others) that I did not do anything agentive to get it. Still, it marks me. Erving Goffman (1963) defined stigma as “an attribute that is deeply discrediting” (p. 3) . It does not make sense, rationally, that a health crisis should somehow make me a less creditable person but this is a common experience for many people who are chronically ill or disabled. My health condition sets me apart from others that I perceive as non-stigmatized, those Goffman calls “normals,” and when I encounter them (even within my family), my preoccupation “is not that of managing tension generated during social contacts, but rather that of managing

information about [my] failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where” (Goffman, 1963, p. 42). I am familiar with this kind of calculation.

Why do the sick carry such shame? Susan Sontag theorizes that individuals with cancer and other life-threatening diseases often find themselves shunned by others, particularly because the genesis of the sickness is unknown. A “disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious” (Sontag, 1978, p. 6). So others stay away. Irving Zola also offers a cultural explanation for such aversion. Because the United States is “a nation built on the premise that there is no mountain that cannot be leveled, no river that cannot be tamed, no force of nature that cannot be harnessed,” we also “claim that there is no disease that cannot be cured.” Therefore those of us who remain noticeably sick or disabled “become objects, permanent reminders of a lost and losing struggle, symbols of a past and continuing failure” (Zola, 1983, pp. 200-201). Thus, just seeing us is hard, unless we can hide our ailments or handicaps. My approach to disease and disability reveals how deeply I have internalized that truth. No effort is too herculean and no lie is too much of a stretch, if they allow me to hide my failure to overcome this disease.

There is also something important to consider in my connecting myself to the trope of the beleaguered hero crossing the finish line. Like many people, I was not born with my sickness and disability and I do not know anyone personally who has had troubles like mine. So to find models for action, I have had to rely on the dominant myths of disability and sickness that get passed around the world of the fit. One is that serious sickness somehow makes one wise, like the professor in *Tuesdays with Morrie* (Albom,



2002). In these romantic portrayals, “illness exacerbates consciousness” (Sontag, 1978, p. 36), and those lucky enough to be around the sick person will benefit from their insight in profound ways. In another popular myth, a person who is ill, disabled, or handicapped overcomes adversity to do something amazing, like becoming president of the United States or winning a gold medal in the Olympics despite having serious physical setbacks. Even though my account expresses a similar complaint as historian/activist Paul Longmore who says that “those of us with disabilities hate the word “inspiring” (2003, p. 129), I have no other image to which I can compare myself as I finish my doctoral exams.

As I think of myself—albeit begrudgingly—playing the role of the hero, I realize that these stories do not usually focus on how it *feels* to be that hero, but more on the good lesson the ending provides for everyone else. My work as well as the writing of others who become (or remain) sick or disabled can respond to this lack by “revealing not illness as metaphor, but illness as illness, in order to persuade the skeptical reader, through the very writing, that survival (at least till the last page) is possible” (Mairs, 1994, p. 129). If I had known more than myths and unrealistic stereotypes, if I had known real stories of individuals living with disease and disability who did not do something incredible like climb Everest despite their setbacks, adjusting to my illness would have been less isolating. If I had known stories of disability that “talk back to the dominant scripts and point to a more embodied form of social critique” (Ferri, 2011, p. 2279), I might not have deemed my inability to embody an ideal as a personal failure.

As my work develops larger social concerns like these, the writing begins to do work that rises beyond my particular experience. It becomes more. The act of writing personal narrative is important work when the story becomes “more compelling, more

moving, more physically and emotionally stirring than lived-life itself,” a quality that “can bring an otherwise sober-minded person (the reader but also the author) to tears and to a more deeply understood worldly engagement” (Manen, 1990, p. 129). It seemed that my ability to tell and analyze my story had the potential to alleviate some of the “symbolic violence” (Bourdieu, 1991) that is done to many disabled people who are marginalized, pitied, labeled with derogative terms, ignored, or used as object lessons for the fit. This possibility enchanted me, but I did not want to leave behind my interest in education research completely. I wondered how to stay part of that world. In terms of audience, who would benefit from my research on education once I was bereft of my teaching context and access to participants? How might my thinking about epistemology and other pedagogical topics still be useful? Could I still write about education with authority?

The answers to these new questions came from re-evaluating and recommitting to the “pedagogic creed” (Dewey, 1897) I had followed as a teacher. Following Dewey’s model, I had written such a statement for a class a few years prior. Turning back to it, I was gladdened by my delight in students<sup>9</sup> and the passion conveyed in my words.

I do not have one illustrative event from this school year for this point, but a multitude of beautiful images. I see Johns’s face twisted in thought as he types, Caleb’s pencil finally moving roughly across a page, Aaron illustrating his book of poems, Bobby stopping in my room between classes to ask if I had read his story yet, Sherri and Tamara silently exchanging papers without my prompting, and Trevor, eagerly handing me a very late, very wrinkled essay. Most

---

<sup>9</sup> All of the student names have been changed.

importantly, I see *words* on reams of lined paper; some are messy, others are in neon ink, a few have hearts over each of the 'i's, a handful look like text messages, and many are misspelled. I cannot share the significance of the words my students gave me; I will lock away these gifts selfishly and take them out when I need renewal. If teaching is an invitation, these powerful memories are an affirmation of its acceptance and every word is sustenance for the pedagogical life.

My interest in qualitative education research was not quashed by these adverse events, even if they removed me from a school. My desire to live pedagogically was not diminished by the alterations in my plans, nor did the weakened status of my body erase the yearning to remain a teacher. In fact, the dramatic turn of events in my life brought these aspects of my character into clearer focus. Intellectually, philosophically, and emotionally, my health condition could serve as a boon, when approached through the gaze of a researcher. My concrete existence is what I would study empirically, gathering and refining insights for the benefit of those who have devoted their lives to education, and others who are committed to the concept that learning is “a constant unveiling of reality” (Freire, 1970, p. 81) that is available to all who are willing to participate in it.

I could still follow a line of inquiry to create a dissertation on education, but without the traditional cast of participants or a live research site. My research questions<sup>10</sup> needed to be revised based on the wreckage that had become of my original plan to focus on the politics of epistemology as they relate to teacher satisfaction and longevity through narrative research. To meet with teachers and to find participants seemed impossible

---

<sup>10</sup> The original set of research questions can be found in Chapter 6 of this document.

without my former mobility or access to schools. Despite a desire to separate my physical self from intellectual pursuits, I would not be able to conduct research without accepting that the knowledge I might unearth would be filtered through the reality of an ill body that refuses to be elided. Although my work is not just about a life with a disease, its personal nature “locates subjectivity in the body and positions bodily experience as a site of epistemological and ontological insight, rather than impediment.” (Ferri, 2011, p. 2269). I serve as the researcher and the participant; the stories entail learning to live with sickness and engaging in an intellectual, pedagogical journey.

To quote Carolyn Ellis as she describes the writing and analyzing of her own narrative, “In both stories I was passionate about the undertaking, yet frustrated by the complexity of the task, sometimes unsure and scared, other times spellbound by the mystery, relishing the unknown and challenge of figuring it all out” (1995, p. 331). My life would have to be the data by which I would consider new research questions in my attempts to “figure it all out.” Like any good researcher, I would need to take a step back from gathering to analyze my data, to consider it in light of extant literature, and then to reflect deeply on my findings as they relate to my fields of interest. I wrote new questions to shape my work, ones that enabled me to approach my life, including my disease and my related losses, as data for research.

#### Revised Questions

1. What wisdom have I gained from my (good and bad) teaching experiences?
2. How did being sick affect my teaching practice? How was it helpful?

3. What new learning has come from my status as an outsider from a teaching context?
4. How can I still remain a teacher, without a classroom or students assigned to me?
5. What can I teach current educators through my writing and research?
6. What barriers have my disease and resulting disability made visible or more apparent?
7. How does a chronic illness affect identity? How can I remain myself? What changed?
8. What lessons has my life in schools and in hospitals illustrated about both spheres?

## CHAPTER 10: MEMENTOS

“Without learning to ‘let go’ a hand cannot grasp what is extended to it from beyond itself as the possibility of a new beginning” (Smith, 2006, p. 80).

It was the fall of 2014. My husband had returned to his job as a high school English teacher in the district where we both once worked. I did not return to work, for the first August in a decade. I had followed David to this district; his tenure there preceded and outlasted mine. A few weeks into the year, he brought from his school several large boxes full of items I had left in my classroom when I was forced to leave it last spring. I say “forced,” but that word choice should not elicit images of guards walking me out the door. Really, I was alone when I left, but I did have to leave my key and I would not receive more paychecks or benefits. Months later, someone in my building had sent some of my personal items; I wondered what had become of all I had left behind. I hoped that a new teacher did not have to work around things I should have at least thrown away.

When I closed my classroom on the last day, I did not take stock of what I left. The act of going was hard enough. My principal said an awkward goodbye, a few friends at work said a little bit between classes, but mostly my co-workers did not know what to say. One group of students did throw me a goodbye party, which included a Star Wars cake decorated with the words “We will miss you!” but none of my students knew quite how to handle the farewell. Why should they have known? It was unprecedented. I could not hide my bitterness and sadness, so I hid myself most of the day. I skipped lunch, just to avoid any conversations with my English colleagues. I showed a movie in class, a plan selected more to avoid interacting with students than to reward them. Our department

chair brought a cake in my honor, but she had to come and ask me to have some in the afternoon. I sat at the end of the table in our lounge and ate my piece silently. There was never really a time for me to say something formal, other than to thank them for the cake. For my colleagues, it was a normal busy day in spring and there was not usually much time for conversation during breaks.

I knew that I was leaving things I had compiled over ten years of teaching, but it was an act partially of defiance and partially of self-protection. My room was full of random accoutrements that related to the teaching I had done there: posters, games, books, decorations, lesson plans, tests, legal pads, construction paper, highlighters, pencils, stickers, name tags, markers, photographs, pencils, crayons, glitter, and many student items. I chose to abandon them, despite having purchased, saved, or carried these items from classroom to classroom. I left an ancient stool I had brought with me from my earlier job, which I loved for its ugliness, its comfort, and the fact that someone had spray-painted “Doug” on it, which was the name my students and I had called it for years. I left a bookshelf full of young adult novels I had collected or purchased from various sources along the way. I could not carry them on my own, even if I had wanted to. Frankly, the day I left I just needed to get away from the school before I got emotional. I just did not want to give my enemies (the district, my disease, my isolation) the chance to hurt me anymore. Somehow looking through the stacks of items I had lovingly yet haphazardly carried with me was more than I could handle.

That afternoon, I did not open the closet that I knew was full to the brim. I did not clean out my desk or even sort through the piles of papers sitting on it. I tried to force my internal monologue to be something like, “Good riddance to all of this,” but really my

mind was full of melancholy, frustration, and memories I did not want to revisit. I also had shame, which has always been a companion when my health problems have become obvious to others. When the final bell of school buzzed, I rushed out of my room (as much as one can rush in a wheelchair through a hallway of children), with just my purse and the electric pencil sharpener that I had recently bought. When I got to the back door, I parked myself between the outer doors and inner doors and took out my phone. I had a long time to wait for my husband to pick me up, but I did not go back into the building. Instead, I read a Sherlock Holmes story that I had downloaded earlier, although I am not sure any of the words actually registered with my brain. I tried to block out the cacophony of thoughts clashing inside my mind, and waited impatiently.

Now I am at home, facing mementos that I did not confront on that last day. Looking at the assortment of boxes, I wonder if this is really what I have to show for all of it. Of course, what a teacher might physically save is a tiny fraction of what each year, each student, each trial offers. I have memories of so many faces, incredible moments to which I can return, but also painful crises I wish did not still bother me. Still, it is hard to sort through these items, these formal and haphazard artifacts. Suddenly they remind me of the bizarre collection of household things my grandparents had left in their tiny apartment when they died.

Like my boxes now, their things were randomly piled in laundry hampers, shoe boxes, and crates, all of which my father had made into a mountain on our old pool table in the basement. Like me and my classroom, my mother could not bring herself to look through all of it, to choose what should be saved. It was all trash and yet it was all precious. My brother and I sorted through some of it, but it seemed trivial and reductive



to imagine which of the items we should keep to honor our grandparents. I took a few things over the years, just some practical items: an old trash can they had in their living room, a recipe file, a box of pencils, and a lamp. Carrying these things out of my mother's house has only been a fraction of the work of mourning for the loss of two people who had been an integral part of our lives.

The work of confronting loss and change directly is much more than sorting through some boxes, but the sorting can occasion some of that confronting. I did not want to sort either time, and I put it off as much as possible, but the task could not do itself. My mother had shut my grandparents' items in the basement, out of her vision and out of her mind (so she hoped). Not much differently, I closed the door of my classroom. I left my keys on the desk of our department office, glad that our secretary had already left for the day. Of course this choice and these items would have to be dealt with. Even if the janitors had thrown it all away, I would still have to confront the physical reality of not having a classroom of my own. Having my teaching materials back in my possession reminded me of what I did not have back.

Finally, opening the first box, I poured out items and allowed myself to reflect on how I came to possess them. Why did I keep these things and not others? I found a brown stuffed bear with "# 1 Teacher" embroidered on its belly that had been a gift from a student my first year. He was not a very engaged student and he barely spoke to me, except to give me the item before he left middle school. I think his name was Brandon and I'm pretty sure I wasn't yet a #1 teacher that first year. There was a second bear, a tiny white bear with "I Love New York" on its belly, which someone left in my room,

presumably accidentally, and never returned to retrieve it. I set the bears on my bed, planning to give both of them to my two-year old daughter later.

There were a few cards, which I placed in my desk without re-opening. I had kept them because favorite students or colleagues had given them to me at various points, but I did not want to read them now. There were framed photographs of my brother, my children, my wedding, my husband, and postcards from places I had visited. My identification tag and lanyard were among these items. Who leaves something like that behind? I placed the stack of pictures on a shelf and put my ID in a desk drawer.

One box was full of games I had played with students, some I created using stacks of index cards and others I had adapted from their original uses to make them relevant for teaching. I threw away the notecards covered in my handwriting, but I figured my six-year old would enjoy looking through the games, so I pushed that basket towards her room across the hall. Another basket contained legal pads, colored pencils, pens, tacks, and loose papers, some of which had been used before. I threw away the paper that I had used and consciously avoided looking closely at what I knew would be my lesson planning notes. Would I ever get to do that again? I didn't think I needed to keep them. Thinking of my daughters again, I picked out and set aside colored pencils and blank paper.

I placed the last box on my desk chair without looking inside it and sat on the floor for a while, exhausted. I wondered who had sorted through these things and I felt a sting of embarrassment and curiosity. Perhaps that packer had done no thinking about the items, hadn't wondered if either stuffed bear had a back story, and had just endeavored to

collect whatever of my things seemed like they were mine. Perhaps his goal (her goal?) was just to assure that the new teacher could have some space to move into my room. My room. It is not mine now. Leaving that classroom untouched on that last day did not preserve it. It wasn't a museum, or a monument to pedagogy, or a time capsule of English language arts artifacts left for a curious researcher who would use them to reconstruct our story. Leaving things in my room on that last day I was a classroom teacher did not save me from having to confront this loss eventually. How am I a teacher now? Without a title, a desk, a room, a list of names, a schedule, can I still claim that identity? Without a room of young people waiting for their "teacher" to act accordingly who can I claim to be? What is the essence of being a teacher? How can I remain one?

## CHAPTER ELEVEN: LITERATURE REVIEW 3(LITERATURE FOR A PERSONAL CRISIS)

“In time of trouble, I had been trained since childhood, read, learn, work it up, go to the literature. Information was control. Given that grief remained the most general of afflictions its literature seemed remarkably spare.” From *The Year of Magical Thinking* (Didion, 2006, p. 44).

When my medical leave turned into a permanent departure from classroom K-12 teaching, I was overwhelmed by the loss of my professional identity, the progression of my disability, the need to collect social security money, and the general feeling of having lost control. I turned to literature for guidance, as I had before in times of crisis<sup>11</sup>. It was from this vulnerable reading stance that I encountered (anew) the writing of Nancy Mairs, an author who has written extensively about her life with multiple sclerosis. I began with “On Being a Cripple” (Mairs, On being a cripple, 1986). I had encountered the essay before; my husband teaches it in his AP English classes and has told me how much I have in common with its author. I had only read it perfunctorily in the past, not wanting to connect my experience with anyone who chooses to call herself a “cripple.”

Like me, Mairs was not always sick. For many years she used her body normally; she walked, fell in love, had children, traveled, and went to school without having to pay her physical well-being any special attention. But in her late twenties, she got clumsier and weaker, as I did. Mairs consulted a neurologist, who suggested she might have a brain tumor, before she was diagnosed with multiple sclerosis. I have a visceral reaction

---

<sup>11</sup> See “My Life as a Reader,” for a more detailed explanation of reading as a relationship.

to her clear description of her (our) condition, exactly the kinds of details I avoided knowing when I was still living in denial:

Multiple sclerosis is a chronic degenerative disease of the central nervous system, in which the myelin that sheathes the nerves is somehow eaten away and scar tissue forms in its place, interrupting the nerves' signals. During its course, which is unpredictable and uncontrollable, one may lose vision, hearing, speech, the ability to walk, control of bladder and/or bowels, strength in any or all extremities, sensitivity to touch, vibration, and/or pain, potency, coordination of movements—the list of possibilities is lengthy and, yes, horrifying. One may also lose one's sense of humor. That's the easiest to lose and the hardest to survive without. (p. 11)

Mairs is right that the possibilities are terrifying to imagine. This disease affects people in widely different ways, and one could argue that flipping through a catalog of “might happens” is not worth the terror it will likely incite. But since this disease took a much more prominent place in my daily experience, I have stopped looking away from its realities. As I read more of the essay, I was amazed by our commonalities. She is a teacher, a mother, and a wife. She also speaks candidly about our condition in a way that refreshes me after years of attempted passing and awkward conversations. “My life holds realities—harsh ones, some of them—that no right-minded human being ought to accept without grumbling” (p. 12). I agree with many things that she says, particularly her discussion of marriages, most of which are “not equipped for catastrophe: the dismay, the depression, the extra work, the boredom that a degenerative disease can insinuate into a

relationship” (p. 14). Mine is surviving, flourishing even, but we must constantly adjust to such unwelcome additions.

Along with all this candor, Mairs presents herself as someone who has found peace, despite the unpredictability of the disease. She knows that it could “at any time get worse, but no amount of worry, or anticipation can prepare me for a new loss. My life is a lesson in losses” (p. 19). My own losses are not worth recounting here, but my teaching job is the most recent and it remains tender. Still, I cannot think about having a disease all the time, even if I never fully adjust to having it. My life is too full of things that make this illness irrelevant, like when it is funny.

Mairs and I share a belief that there is “some connection between largesse and laughter” (pp. 18-19) and noticing that trend ameliorates some of the awful realities of multiple sclerosis. I may not always find a humorous spin for my health problems, but this possibility is enough to embolden me to confront many aspects of my experience. Mairs asserts at the end that she would “take a cure; I just don’t need one” (p.20). I appreciate that she has come to this conclusion, but it gives me pause. Am I still holding out for a miracle? Did passing reveal that I need to be cured to be satisfied? To be proud? With these potentially troubling revelations in mind, I kept reading.

I was not someone with a detailed plan for my life—Ph.D. included—but my illness revealed that I did hold dear a particular kind of narrative for myself, a story that multiple sclerosis—particularly my resulting disability—had disrupted. In *The Wounded Storyteller* (Frank, 1995), I found another recognition of “the need of ill people to tell their stories, in order to construct new maps and new perceptions of their relationships to the world” (p. 3). That text analyzes the nature of illness as it is portrayed in literature,

described in medical documentation, and how it is lived by real people who need to find their voices in the midst of a chaotic experience. I resonated immediately with the term “narrative wreck,” a metaphor Frank uses for the angst of many ill people whose lives have been interrupted like mine. He calls those who are suffering to begin by telling the truth, which “involves recognizing that your life has not turned out as you wanted” (p. 63) and he highlights many examples of writing that “provide models of reclaiming the self” (p. 70).

Frank calls one type of such illness stories the “quest narrative” in which authors “meet suffering head on; they accept illness and seek to *use* it” (p. 115). In such tales, the narrator “gradually realizes a sense of purpose, the idea that illness has been a journey emerges” (p. 117). I gravitate toward wanting to write this kind of story, longing for my recent experiences to be heading toward some kind of meaningful end. But what is the goal of this odyssey, if that is what it is? If one chooses to portray illness as a quest, the implication is “that the teller has been given something by the experience, usually some insight that must be passed on to others” (Frank, 1995, p. 118). What have I gained? Do I have something now, because of my illness, that I feel I must pass on? I have sought out quest stories of illness for direction in my thinking.

The subtitle of the next text I read, *Prickly Cactus* (Delgado Gaitan, 2009), is “finding sacred meaning in chronic illness,” and I turned to it hopefully. Delgado Gaitan tells a story of how she became a professor, including some (non-physical, but still profound) obstacles she encountered along the way. After securing the job she wanted in the Bay Area, her health began to fail. She describes waking up one weekend with the sensation that “every muscle and joint screamed with what felt like third-degree-burns

coming from inside, searing” (p. 51). It took a while for doctors to take her symptoms seriously, but things worsened. Still she pressed on with her normal routine, while her mind raced, “busy worrying about what was happening to [her] body” (p. 53). Once she got a diagnosis of systemic lupus erythematosus, she hoped it would be easy to manage her illness with medicine. Just like me, Delgado Gaitan says she “had no intention of amending the fast-paced life [she] led” (p. 55). She ignored “distress signals” from her body and continued to work as hard she always had, despite increased difficulty walking, acute pain, and sporadic memory loss.

Delgado Gaitan’s denial did not lessen her symptoms and she became increasingly disabled as a result of lupus. Still, she pressed on with her professional goals as best she could, stopping only occasionally to recognize that “placing work first relegated my health to a position of lower priority” (p. 69), but she continued to ignore her body until a neurologist prescribed a power wheelchair. After initially refusing to get one, she relented and realized she could keep doing what she loved, researching and teaching, without as much pain if she used a chair. But then, she had a major relapse that sent her to the emergency room, unable to walk and barely able to speak. She progressed at recuperating in the hospital, but then she took a break from work “with the stipulation that [she] would return to full-time professorship at the end of six months” (p. 139). She had insisted that she would be able to do that.

In a move to keep working while taking better care of herself, Delgado Gaitan proposed that the university change her job so she could teach partly through interactive television to cut down on driving, but it was rejected and she ultimately resigned from her position. She “grieved over the loss of [her] identity as a professor and the security of a



paycheck” (p. 161). After some time of “emptiness” she moved on to embrace a new career as a writer. Using on-line classes, she “re-invented [her] professional skills to include technical, professional, and non-fiction writing” (p. 168) and then she used her academic connections and experiences to build a network of authors and publishing opportunities. She discovered that she could have a career and take care of her health, a wonderful revelation that brought her satisfaction and a spiritual understanding she had never known before. At the end of her text, Delgado Gaitan claims that through illness “we discover who we really are. It can lead us to meeting people and traveling roads where we might not have gone had we not become ill. What better balm than to have ourselves as our own best friend in times of trouble, someone to tell us to rest, to slow down, to laugh, to forgive and to be grateful” (p. 179). Her revelations are exactly the kind Arthur Frank refers to as “reenchanting a disenchanted world” (p. 185). For Delgado Gaitan, her illness became a source of truth and inspiration for herself and those who will listen.

Arthur Frank (1995) had written positively of another illness narrative, *The Cancer Journals* (Lorde, 1980). Based on my appreciation of the poetry of Audre Lorde, I expected to gain from reading about her experience with breast cancer. I immediately resonated with her rationale for writing the text, which she did because she did not want her “anger and pain and fear about cancer to fossilize into yet another silence” (p. 9). As my illness drove me farther from the social circles I once inhabited, I felt the need to use my voice again. Audre Lorde tells an arduous and empowering story, which ultimately taught its author the value of “teaching, surviving, and fighting with the most important resource I have, myself, and taking joy in that battle” (p. 17).

As I read Lorde's vivid and candid depiction of breast cancer, her mastectomy, and her period of recovery, I began to understand Frank (1995) more clearly when he says that the hero of a quest narrative is "initiated through agony to atonement: the realization of oneness of [herself] in the world, and oneness of the world with its principle of creation" (p. 119). Facing the possibility of death and the trauma of surgery brought her existence into a new light. Lorde (1980) found that through her ordeal she "was forced to look upon myself and my living with a harsh and urgent clarity that has left me shaken but much stronger" (p. 20). Her pain is not glossed over in her writing, but it used for something important, something transformative. In the end, she emerges from the quest as an improved and fearless poet. Pointedly, she asks, "once I face death as a life process, what is there possibly left for me to fear? Who can really have power over me again? (p. 61). Our battles are different, but Lorde's words too spoke to me, begging me to look within for the value of my illness experience. What had I learned?

As I read her, I was not (or was not yet) comfortable with the role of providing inspiration like Delgado Gaitan, nor did I feel that I had become a fearless woman. What if I never have such an awakening? My deepest longing has been to remain connected to the teaching profession, and I wondered how I might make my situation useful in the arena of education theory and research. I wanted to read about more individuals who have been or remain ill (particularly those whose bodies are as uncooperative as mine) who still stay find a way to achieve their professional goals. With this outcome in mind, I found the work of Simi Linton, a disability studies scholar and advocate, and Paul Longmore, an historian and disability expert. Linton was in a car accident as a young woman and had become a paraplegic as a result. Longmore had polio as a child, which

left him without the ability to use his arms and in regular need of a ventilator and other health aides. Both had gotten a PhD and became professors *after* becoming disabled. They both overcome their share of adversity (which came more from social barriers than physical setbacks) to achieve their goal of joining the academic community. Both scholars alternate writing autobiographically or traditionally depending on the content, audience, and purpose.

*My Body Politic* (Linton, 2006) tells the story of a woman's journey from experiencing a disabling accident, growing into an acceptance of her life as a disabled person, to becoming a powerful advocate for those with disabilities and chronic conditions. Part of her growth includes knowledge of how good she had it when she was able-bodied: "I had always taken for granted that if I could go places and get jobs that disabled people couldn't, it was because *I* was strong and healthy and *they* had their deficits and incapacities." But then Linton was "pushed over to the other side" (p.3) and she began to develop a different point of view. When she returned to college, she discovered a world designed for the non-disabled student, but she relied on herself and her family for solutions. At that time, she did not think of her challenges as discrimination, thinking that "it didn't seem to be anybody's fault that a doorway was too narrow, or there were steps, or there was no way to use public transportation" (Linton, 2006, p. 27). She just persisted.

Just as Linton began to accept herself as a disabled person, "the disability movement was evolving into a recognized political entity" (p. 108) and she began to see the political side of her experiences. Throughout her education at Columbia and NYU, she brought up disability in her courses, scrutinized her environments for discrimination,

and eventually came to align herself with all disabled people. Once she became a professor, she encountered the discipline of disability studies, and she began incorporating the topic into her psychology courses. She wanted her teaching to illustrate to “how big disability is, not the condition I or others have, but the elaborately constructed network of ideas and practices that keep disabled people in place” (p. 120). She eventually left the classroom to devote herself completely to the rights of disabled people and the changes she felt were needed in how disability is presented in the academic curriculum.

In *Claiming Disability*, Linton (1998) criticizes the way disability is studied in diverse fields, including education, medicine, literature, science, history, psychology, and social work. She laments that even with “the steady growth of scholarship and courses, particularly in the past five years, the field of disability studies is even more marginal in the academic culture than disabled people are in the civic culture” (Linton, 1998, p. 3). Her text illustrates how the portrayal of disability could be and should be applied to many disciplines. Taking a critical, Foucauldian perspective, Linton places real stories of disability among the kinds of discoveries that are routinely edged out by the structure of disciplines, which endorse a finite “corpus of propositions considered to be true” (Foucault, 1972, p. 222). Linton boldly summarizes the “lies” that underlie much of the way disability is studied:

A lie that literature tells can be heard in the metaphors that create analogies between disability and insentience, or evil, or ineptness.

Psychology tells lies when it reifies through theory and measurement the concept of normal. Anthropology’s lies are found in the construction of a

culture's ideas about disability, based solely on nondisabled people's input. History tells lies when it eliminates the perspectives of disabled people, and other marginalized people, from the annals of history, or eliminates information on public figures' disabilities. Women's studies lies when it excludes disabled women's perspectives and then proceeds to make global statements about women's feelings and experience.

Education proffers the idea that disabled and nondisabled children are separate groups best taught in separate classrooms by teachers specially trained. (Linton, 1998, p. 182)

Her response to these problems is to promote disability studies, a field that “tells a different story” by working its core beliefs “through every discipline and field to assess their validity and applicability to a range of intellectual, social, political, and moral questions that we as a society face” (p. 183). Linton argues that disability should be approached differently in most disciplines and merged with the traditional curriculum rather than sequestered as an isolated area of study or applied field. The moral problem in the traditional approach to disability—the extant one that allows the lies Linton describes to endure—is exclusion. When critiqued from the perspective of disability studies, Foucault's observation that every discipline “repulses a whole teratology of learning” (1972, p. 223) seems apt. Disability studies embraces the pedagogical possibilities of the abnormal, complicated, and different experiences of many individuals.

Paul Longmore is also an advocate for improving how disability is studied and legislated. He also discusses untruths in the way it has been presented in *Why I Burned My Book* (2003), a collection of essays on the topic. Contrary to the popular idea that

those with disabilities can overcome obstacles with “an indomitable spirit and cheerful attitude,” Longmore points out that the biggest problems faced by the handicapped are “pervasive social prejudice, systematic segregation, and institutionalized discrimination” (p. 231). His story reveals such hurdles.

As a young man, Longmore contracted polio, which left him permanently disabled. Still, he earned a B.A., an M.A., and a Ph.D. and intended to teach history at the college level, facts he indicates make him appear, “from one perspective, a disabled overachiever, a “supercrip” (p. 232). But, in reality, he just wanted to teach history, and it was not easy for him to enter the field. As a student, he encountered multiple situations when someone in power dismissed him because of his disability. At that time, he notes, “there was no Americans with Disabilities Act,” (p.233) so it was not illegal to discriminate against someone like him. He also struggled to survive financially, failing many times to secure fellowships, scholarships, or money from the state Department of Rehabilitation. Once he did secure financial aid, he was limited to one class per year and was burdened and slowed down by enormous expenses related to his disability.

Longmore’s personal experiences with bureaucracy related to disability, combined with his research in the history of disability have made him a passionate advocate. He rallied against the work disincentives built into Social Security Disability, which meant that in 1984, he “could still not take even a part-time teaching position without jeopardizing the financial aid that paid for [his] ventilators and in-home assistance” (p. 249). Eventually, those were lifted, but not the penalties on receiving fellowships or royalties, which are treated like income from stocks. To protest the loss of benefits that he would incur if his book about George Washington earned him any

money, Longmore staged a book burning in downtown L.A. in 1988, which was attended by many members of the local disability community and was noticed by many others. Eventually, after years of protests and pressuring government officials, the policies were changed due to “the political tenacity and perseverance of our disability community” and Longmore notes he has only seen success “because of the achievements of the disability rights movement” (p. 257).

Longmore was eventually able to become a full professor at San Francisco State University, a position he has used to promote disability studies, particularly as they relate to history. His work seeks to “usefully contribute to advancing social justice for people with disabilities by producing and facilitating rigorous disability studies scholarship, by applying it to current disability issues and by critiquing disability rights advocacy from within” (p. 8). Longmore’s historical essays on disability are fascinating examinations of a story I feel as if I have never heard. I read for the first time about individuals such as Randolph Borne, a radical thinker from the World War I era, who also had a “highly visible disability, a twisted mouth, face, and ear from a difficult birth, a severely curved spine and stunted growth from childhood spinal tuberculosis” (p. 35). Longmore critiques the way this man’s life was and is portrayed as a tragic tale, leading to misinterpretation of much of his prose, which dared to speak from the handicapped perspective in a time of socially accepted eugenic activities, such as forced sterilization for the “unfit.” I hungered for more stories like this; thus, I had found a quest.

Longmore’s essays also teach about advocacy, such as a Depression-era group called the League of the Physically Handicapped that protested “disability-based discrimination at the hands of work-relief agencies and the federal government’s Works

Progress Administration” (p. 54). I learned about another that formed in the seventies, the American Coalition of Citizens with Disabilities, which, among other activities, staged a 25-day sit-in to protest a plan to weaken anti-discrimination protections that were built into the 1973 Rehabilitation Act. Longmore also educated me with regard to Not Dead Yet, a disability group that protests the legalization of euthanasia and insists “that the debate must focus on the impact of prejudice and discrimination and of the financial interests in both physician-assisted suicide and the entire health care system” (p. 177). Longmore offers a perspective on Jack Kevorkian and “mercy killings” that I had never encountered. Such heroic acts (as I had seen them before) do not take into account “the social factors that make the lives of some disabled people unendurable” (p. 188). His chapter on the topic includes the story of a man with multiple sclerosis who Kevorkian helped kill himself because of his fear of ending up in a nursing home. Like Linton (2006), as I connected myself to the topics raised by Longmore, I was gaining “the vantage point of the atypical, the out-of-step, the underfooted” and “becoming disabled” (p.3). The changes in my perspective were profound.

Following a citation in Longmore, I found the text, *No Pity* (Shapiro, 1993), which portrays “the rise of what is called the disability rights movement—the new thinking by disabled people that there is no pity or tragedy in disability, and that it is society’s myths, fears, and stereotypes that most make being disabled difficult” (pp.4-5). Shapiro approaches the topic as a journalist, documenting the development of this movement and raising issues relevant to the progress of disabled Americans. One theme repeatedly developed in the volume is “people with disabilities are defining themselves”



(p. 20), and he highlights many stories of such individuals, particularly those who have been instrumental in the battle for civil rights of disabled people.

One example highlighted by Shapiro is Ed Roberts, a post-polio quadriplegic who attended Berkeley in 1962, despite the inaccessibility of most of the campus. Because of his innovation, a family support network, and the advent of the power wheelchair, he was able to have a college experience. After his success, Berkeley began admitting other severely disabled students who worked “to strategize constantly about breaking down the common barriers they faced—from classrooms they could not get into to their lack of transportation around town—and dissect the protests for self-determination of minority students” (Shapiro, 1993, p. 48). That was the beginning of a life of advocacy for Roberts and an important step in the national battle for equal rights.

Shapiro also tells the story of the Americans with Disability Act, which President Bush signed into law in July 1991. The narrative begins with Lisa Carl, a teenager with cerebral palsy, who was denied entrance to a movie theater in 1988. Such acts of discrimination, as well as inaccessible public spaces, were common. Disability advocates “now turned their attention to winning passage of a broad civil rights bill” (Shapiro, 1993, p. 106). The first version of the bill was drafted by President Reagan’s “National Council on the Handicapped,” which included attorney Robert L. Burgdorf, Jr., a man who had experienced prejudice because of a post-polio paralyzed upper arm. As a young man, he had been denied employment as an electrician, an event that was instrumental in his training to be a lawyer specializing in disability law. These figures are just two of many highlighted by Shapiro as “a hidden army for civil rights” (p. 105).

As someone who became disabled as an adult, I wished I had heard these stories before my disease emerged. To quote feminist Carolyn Heilbrun, “What matters is that lives do not serve as models; only stories do that. And it is a hard thing to make up stories to live by. We can only retell and live by the stories we have read or heard” (Heilbrun, 1988, p. 37). The stories I knew of disability were not happy ones. When I received my diagnosis, I believed that if my disease followed the course that it usually does, my life would never be as full as I had planned. I needed to hear narratives of triumph that happened for people with disabilities (even if they could not overcome their condition) to combat the stereotypes of the helpless invalid I feared becoming.

If I had known more of the tale of progress in achieving civil rights, I likely would have been a better advocate for myself. I think about the period before my exit from teaching, when I was working in a wheelchair most of the day. If I had known then what I know now, I would have had a better answer for a human resources director who asked me how I could teach without walking. If I had been less afraid, I would have begun using the wheelchair years before, when I suffered incredible pain and fatigue from the physical demands of my job and life. Also, if I had been more amenable to demanding spaces be accessible, I would not have missed out on so much, like sporting events, weddings, concerts, dinners, parties, and even parent-teacher conferences.

Irving Zola, a sociologist who studied those with disabilities, had a similar epiphany when he allowed himself to stop passing, to align himself with those he researched by refusing to hide his physical state any longer. As a result of polio and later a car accident, he was “left with considerable weakness and nerve loss scattered throughout [his] body” (Zola, 1983, p. 2). With the use of a leg brace and a steel back

support, he was able to walk with a limp. During a study of Het Drop, a village in the Netherlands designed “to house people with a chronic disease or physical handicap” (pp.46-47), he elected to use a wheelchair rather than braces to improve his stance as a researcher by living as one of the residents.

Although he had used one previously, Zola was stunned by his transformation in the eyes of others once he sat down. All of a sudden, he was “no longer seen as a person who could fend for himself” (p. 52). While he engaged in fieldwork, he gained a deeper understanding of the common experiences of those who live with a visible disability. There were many epiphanies as he functioned alone in his wheelchair, such as his coming to see “what it took for a handicapped person to independently cope with even the smallest aspects of the world.” (p.57-58). In particular, he noted how difficult it was to use a bathroom, how exhausting it was getting ready in the morning, how he was treated paternalistically, and how often he was confused with other men in wheelchairs.

Zola began to feel uncomfortable with the passing he had accomplished by “sitting behind a desk or standing behind a lectern,” (p.122). He realized that by rejecting his disability, he had been rejecting part of himself. He alienated himself from his body based on “almost every account about a “successful” handicapped as well as every “success” that I have met (including myself) usually regards as a key element the self-conception, “I never think of myself as handicapped” (Zola, 1983, p. 203). Like many of us, Zola entered the world of the sickness “poorly prepared and with all the prejudices of the normal” (p. 206). He resisted looking disabled, an action he realizes that many people do at great cost to themselves. Once he counted himself among the disabled, he began to

see clearly the “infantilization and invalidation” that are common in the experiences of those with chronic illnesses or a physical handicap.

Although Zola was able to overcome adversity (such as completing his coursework at Harvard by correspondence when he was bedridden), he concludes that “if we lived in a less *healthist*, capitalist, and hierarchical society, which spent less time finding ways to exclude and disenfranchise people and more time finding ways to include and enhance the potentialities of everyone, then there wouldn’t have been so much for me to overcome” (1983, p. 235, italics added). His experiences changed his approach to life and forced him to conceive of disability as a category of exclusion, one accepted by most people including those it discounts. Zola ends his account with a call for disabled and chronically ill to advocate for their own validity, something he finally began to do for himself.

Through reading these powerful narratives, I grew in awareness of the possibilities for growth and new understanding that having a disease has made available to me. I also became aware of a community of people who have stories similar to mine. The authors I read did not paint illness as something that is only good once it is overcome. Through the exposure of the fragility of my body—regardless of this journey’s endpoint, if there is an obvious one—I have much to learn. Among the catalog of lessons, I have learned that I am not alone. Illness, fear, stigma, pain, isolation, and loss are essential elements of the human condition; exploring their depth has much to teach readers and not just the one who is suffering. My new insight reminds me that I have new material to teach (to my readers and others).

In the spirit of Margaret Mead's "Questions that Need Asking (1961)," which asks us to stop overlooking what is in plain sight, I have also learned that my new vantage point (someone who has been marginalized, compromised, and hidden) complicates and enriches the world as I know it. I have seen certain truths drawn in deeper relief, like the need for truly inclusive education, and I have seen other 'truths' fall to ruin, such as my prejudiced views of individuals who collect disability as their source of income. Finally, I have learned that I must tell my story, as it happened. I hope that my illness story can be useful, helpful, and pedagogical, but more importantly that the telling should depict faithfully this human experience. By rendering painful events into something as powerful as a story I have changed those events. They become "suffering that has its cry attended to" rather than "suffering that is left to its own uselessness" (Frank, 1995, p. 179). Already, mine has proved to be of use.

## CHAPTER 12: A DISABLED WOMAN

Accounts of becoming disabled are usually tragic, but some are also good stories. Perhaps a woman survived a head-on collision with a drunk driver and she is thrilled to come away breathing, even if she will never walk again. Perhaps a man was injured while helping others escape from a bombed-out building and he claims that losing his leg is nothing compared to those who lost their lives. There is something romantic about these tales, especially if the injured person can accept the outcome with gratitude. They may have lost an arm or a leg, or the ability to walk unaided, but they go on, driven to overcome adversity by the chance at life that they might not have had.

This is a popular narrative, a trope invoked as inspiration for anyone who might feel like giving up. Spoken or unspoken, the moral is there: “If someone so tragically “crippled” can overcome the obstacles confronting them, think what you, without such a “handicap” can do” (Longmore, 2003, p. 139). In addition to this positive message, these tales also serve as a reminder to the fit to keep things in perspective: it could be worse; you too could become disabled. In one awful second, your body as you know it could cease to be, so don’t take it for granted now. Considering these messages, it seems the able are the intended learners, while the injured are just reference points for repeating the trope.

While acknowledging that my readers are largely among the abled, this chapter challenges the trope in several ways, not least that its repetition is *by* me, not just *about* me. Although I fervently resist the requirement that my illness/ disability story be inspirational, I will not shy away from examining of this common portrayal. I need to narrate this tale of disability by starting with the framework generally used to interpret

stories like mine since “to tell one’s story and to be understood, one is inevitably caught within webs of meaning informed by normative assumptions” (Ferri, 2011, p. 2269). To demonstrate how true stories can complicate common social understandings, I will address a few of the assumptions that relate to my situation and highlight how my case defies them.

First, it’s not always one tragic second when a person becomes disabled or sick. What if this change takes years to happen? What if disability comes sneaking into a life piece by piece, rather than after one cataclysmic event? It is tempting to envy those for whom disability becomes a fact in an instant. They have a period of mourning, and then they decide whether or not to move on with their lives. For me, after being diagnosed with MS, disability was a gradual becoming that happened so subtly that I could ignore its reality at times. When my body felt normal, I could forget this change was happening and I would find myself acting like I was fit and able again. I could go on that way for a while, making commitments, starting projects, and feeling excited about the future. Then something would give. I would be reminded by a fall on a damp bathroom floor, or a numb hand that could not hold a cup of coffee that I am not the person I was, that this is not the body it once was. Then, like the hero waking up after a horrible accident, I would have to decide not to give up. Again.

Second, my choice to keep living my life as I had before I was sick or disabled was not a noble decision that shows that I am somehow a specially motivated person. When I was still spending my days among more fit people, I often heard comments like, “Wow, I don’t know how you do it,” but there was nothing miraculous about how I kept doing it. I just wanted to keep working because I liked my job and I wanted to continue

enjoying the nice lifestyle it afforded me. I had children because I wanted them before I developed multiple sclerosis and the disease did not remove the desire. After my disease developed, I still backpacked in Europe, I still went back to school for a Ph.D., and I still taught English with passion. Although I have always been one to seek out ways to improve my surroundings, the choice to follow plans I had already made (even if the means had to change) was not made deliberately to show others the right way to live. I never saw myself as an inspirational figure; in fact, it took many years for me to accept the reality that I had actually become a disabled person.

In retrospect, it is easy to chart the development of my health problems and the progress of my disability. I can reflect back and find certain plateaus that have become real, like having to use a cane to walk any distance, or requiring a wheelchair in airports and museums, or needing to sit while taking a shower. But in the moment, it was not always clear that a transformation was happening. I just did what was necessary at the time to function. (If my left hand would not move, I could just finish typing that quiz using only the right.) Although I have had several periods of being completely incapacitated, most of the changes in my body have begun as something infinitesimal, hidden from view by the normal occurrences of my life.

It is rarely dramatic and never inspiring to become aware of a new level of disability related to my disease. Irving Zola (1983), a sociologist who devoted his career to documenting the experiences of the chronically ill and disabled, observes that this kind of change, like a death, “also constitutes a loss—of time, of capacity, of function, of appearance—and as such it has to be acknowledged and mourned before it too can be put aside” (p.230). But mourning for every difference that arises is overwhelming. How



much effort should one put into accepting, for example, the loss of the ability to stand unaided long enough to brush one's teeth? What changes are worthy of noting?

At this point in my life—i.e., 2015—I have decided that calling myself a disabled woman will lessen the pain of my losses. Accepting such a label does not remove the difficulty of coming to terms with a failing body, but it does strip away the illusion that I can treat my physical self the way I always have. This label also frees me from the trap of trying to pass as normal, a task that involved enormous amounts of energy, secrecy, and calculations. Perhaps influenced by the accident victim trope where the injured do often gain back some of their capacities, I realize now that I bought into the idea that if I tried hard enough, I could beat the odds and be successful, despite my illness. Thus, whenever I lost the battle and the effects of my disease became apparent, I isolated myself in shame.

Simi Linton, a disability studies scholar, describes the pain felt by those of who choose to pass: “The loss of community, the anxiety, the self-doubt that inevitably accompany this ambiguous social position and the ambivalent personal state are the enormous cost of declaring disability unacceptable” (Linton, 1998, p. 21). For many of us, our disability cannot be overcome; thus, it must be named and folded into our sense of identity graciously, and with pride, if we are to reconnect with others and get on with our lives.

Calling myself disabled also gives me the authority to speak from a particular perspective. Adopting this label is “the only way to get back in touch with part of myself I had long rejected—my physical disability” (Zola, 1983, p. 186). For years, my disease

and its related physical problems were sources of embarrassment, facts about myself that I would rather people did not know. I told myself that I was someone with a bundle of characteristics who just happened to have multiple sclerosis. I reasoned (and proclaimed out loud from time to time) that it did not alter my identity, that the disease was just something I had to confront from time to time and then I could set it aside and get on with my normal life. But if that choice ever seemed possible, it has since stopped being true. Having a disease has profoundly affected who I am, even when I have wanted badly to deny its influence. Erasing its reality (or attempting to create an illusion that I am well) hides too much of me. If I label myself as a disabled woman, I include an integral aspect of who I am and how I think about the world. Like a skin color, or one's first language, or a particular religious upbringing, my physical condition plays a real role in my life. It shapes what I think and see. Even if this fact separates me from others, it hurts more to hide it from view.

And there is value in the perspective I have gained from my physical state. My disease enables me to see others differently because I am in tune with the fragility of all of our bodies. To borrow from the words of Nancy Mairs, an author who shares my diagnosis, "[MS] has opened and enriched my life enormously, this sense that my frailty and need must be mirrored in others, that in searching for and shaping a stable core in a life wrenched by change and loss, change and loss, I must recognize the same process, under individual conditions, in the lives around me" (Mairs, 1986, p. 20). Like Mairs, I believe having this disease has improved my life in certain ways. One important benefit is that it has made me a better teacher. First, it has made me kinder. When I criticize the ideas and writing of students, I remember how fragile we all are, even if appearances

would suggest otherwise. Second, it has improved my empathy for young people. A life of constant adjustment enables me to understand the difficulties they face as they confront the dramatic changes of adolescence. Third, I teach with gratitude. The time I spend as an educator is a respite from my physical struggles and thus I approach my subject area with joy and enthusiasm.

I admit that lessons like that are not worth getting sick, but they are worth something, and I have been changed by the learning. I am glad to have become more thoughtful, more understanding, and more patient than I was before. It is not easy having this disease, nor is it always easy to live in this body, but realizing that I have benefited from these experiences ameliorates the pain and diminishes the shame. That said, I want to steer clear of another trope, a theme disability historian Paul Longmore calls “compensation.” In this storyline, “God or nature or life compensates handicapped people for their loss, and the compensation is spiritual, moral, mental, and emotional” (2003, p. 138). The insight I have as a disabled person is not a gift; it is a frame through which I understand the world, a valuable perspective to have gained.

Disability comes in many forms, but selecting to use the name to describe my physical state offers solidarity with others who do not fit in with the world of the able. There is a movement among the disabled to reject the notion “that there is something sad or to be ashamed of in their condition. They are taking pride in their identity as disabled people, parading it instead of closeting it” (Shapiro, 1993, p. 20). The world of medicine and the life of the chronically ill and disabled is often one of isolation, but owning this label can work against that trend. If individuals with disabilities “have the temerity to emerge as forthright and resourceful people, nothing like the self-loathing, docile, bitter,

or insentient fictional versions of ourselves the public is more used to” (Linton, 1998, p. 3), they can demand the world become more inclusive and create a clearer picture of the diversity contained in the label. Through accepting that I am a disabled woman, my personal trials are no longer just my own, but part of a larger political movement and in that movement I am a teacher.

I have never been one to make demands. So my part of the movement will not take place at a demonstration, nor will I be testifying in front of an elected body on the needs of the disabled community, although I believe that both of these matter. Instead, I will do my fighting through text. There are dominant narratives of disability— some told as entertainment and others told by the medical community. Rarely are those of us who become ill asked to construct our own stories and it is rarer yet that are invited to tell a story that describes more than our negotiation of the disability. Arthur Frank, a scholar who has extolled the perspective of “the wounded storyteller” laments that “ill people are often taught how to be ill by professionals. Illness is not presented to the ill as a moral problem; people are not asked, after the shock of diagnosis has dulled sufficiently, what do you wish to *become* in this experience?” (Frank, 1995, p. 159). That is the question I am compelled to answer.

The experience of developing a disease has included moments of terror, immeasurable pain, and even some inspiration, but more than anything it has been a story of becoming a different self. There have been other times when I became a different self—when I became a reader and when I became a teacher—and for those transformations, it is easy to see that they enhanced my life. Reading opened to me the real and imagined worlds of diverse authors. Teaching provided purpose and direction for

my intellectual life. It might be more difficult to prove that becoming disabled added something to my identity that I lacked when I was able-bodied, but that is one of the lessons I will try to teach. I hope that my work will illustrate that this new self, a disabled woman, is something less *and* something more than I was before.

## CHAPTER 13: ON BECOMING A NUMBER

“...There is a burden that we the chronically ill in general and we the physically handicapped in particular carry. In every interaction, our baggage includes not only our own physical infirmity but the sense of infirmity we evoke in others and their consequent incapacity to deal with us” (Zola, 1983, p. 202).

I have never had much interest in medicine. I remember taking one of those career aptitude tests in high school and I was surprised to see “general practitioner” at the top of the list. I imagine my love of studying led to that result, as well as my general concern about humans, I suppose, but a medical doctor was not a viable career choice for me. I was shy, and the mere thought of touching the bodies of people I did not know made me squeamish. The career test did not know that when I tried to give blood in the gym, just the sight of the needle made me faint! I wonder how different it would have been to get sick if I had been starting a career as a physician when it happened, rather than a teaching career. Would I have been better prepared for the pain? Would I have expected getting diagnosed with a chronic disease to be so impersonal? Perhaps I would have been less vulnerable if I had known what was waiting, even if it was still going to be a harrowing experience.

On the day I was diagnosed, I drove to the hospital reluctantly after taking a too leisurely lunch. A general practitioner I had seen a few times suggested I check in as a patient for a series of tests, until they figured out why my legs were getting weaker, why my balance was getting worse, and why physical pain made it increasingly difficult for me to concentrate. Looking back it was obviously Multiple Sclerosis, which I would

have known if I had been to medical school. I gave my name to several people in the hospital lobby and, after a tedious admission process, I received an official hospital bracelet and a room assignment. My first test was going to be the spinal tap, which I had *heard of*, but I just knew that it was something bad. In a cold, white room filled with stainless steel medical accessories and a plethora of cupboards (was this a storeroom?), I put on a horrifyingly giant hospital gown and waited, struggling to stay warm while lying on the papery sheets of an examination table. A nurse came in alone and asked me the exact questions I had just answered when I registered. No, nothing had changed in the last hour, except that I was shivering now. Impassively, she noted my answers and told me that she would inject my spine with a numbing medicine to make this procedure go smoothly. I sat up and looked away as she gave me a shot in my back, which surprised me with its burning pain. I hoped that it would be the worst part of this test.

Then, the doctor came in the room, but did not introduce himself. I turned around to face him and read his name from a lanyard while he looked through my paperwork. The nurse came over to my side of the table and placed a pillow on my lap. I was puzzled, but it was nice to hold something soft, even if it was encased in stiff, abrasive material. She told me to lean over and hold the pillow tightly while they did the test. “Keep your eyes on me,” she said firmly. I felt the cold, dry hands of the doctor on my back and then a series of unbelievable strong undulations of heat, pressure, and nauseating pain followed. I closed my eyes and pulled the pillow close to my stomach. I felt the nurse place her hands on my shoulders, and I managed to open my eyes. She was smiling slightly, which granted me comfort in this white, cold well of disorientating pain into which I had landed. The excruciating procedure continued and I managed to look at

my surroundings. There were windows, covered with white blinds, but I focused on the sunshine that still managed to seep through. I looked for a clock, but time was probably not moving anyway.

When it was finally over, I lay on my side on the examination table and reached around to feel a series of small bandages on my spine. They didn't feel big enough to be the physical reminders of *that* event. I began to feel dizzy as I struggled to dress myself. Just then, my husband, David, arrived from work and I was thrilled to see him. He helped me get dressed and we headed together to my hospital room to wait for more tests. I allowed myself to believe that none of them could be as awful as the first. I remember as we walked (I had to lean on him for support, but I could walk) that I squeezed his arm and said, "I am glad you weren't here for *that* test," although I am sure we both knew it was a lie.

There were other tests (and many more needles) before I would hear anything that sounded like a diagnosis. Even when I did, it was not an event with any fanfare and even less of a personal touch. The general practitioner I knew came to my room in the hospital, where I was trying to sleep. I was on strong medication for pain—narcotics that made me feel sicker—and I longed to recover from what had been a disorientating, difficult couple of days. I sat up and straightened my hair, wishing I had on normal clothes. She sat down next to the bed and told me, matter-of-factly that the neurologist had read the results of my spinal tap and the other tests and had concluded that I had "a condition consistent with the symptoms of multiple sclerosis." I avoided looking at her while I tried to process this information. How could she just say that?



That befuddling description of my condition was the closest thing I got to a diagnosis during that hospital stay. It was as carefully worded as they have all been. I do not remember my response, but I recall the urge to get myself out of the hospital before the words could be affixed to me permanently. As long as I was in this sickly lit room, tucked into a narrow bed, attached to IVs and monitors, where doctors and other nameless hospital employees look downed at me, I was someone with this awful thing that was “consistent with” multiple sclerosis. I fantasized that I could just walk out as soon as she left, keep the outcome of this hospital visit a secret, and return to my previous, normal existence.

My reaction was an attempt to deny reality, but I was not really *surprised* by the test results. It was the irony of the situation that got to me. I had just started a job that gave me satisfaction, but at the same time I discovered that my body might not let me pursue it. With the comfort of two incomes, we had rented our first house and had started making plans to have children. Our house had several flights of stairs, which had lately become difficult for me. Also, I had no idea if I could or should have a baby, just when I realized I wanted one. At that point in my life, I was proud of certain labels for myself: teacher, wife, reader, scholar, traveler, graduate student, sister, scrabble player, writer, grammarian, comedienne, foodie, and lover of poetry. Yet none of these distinctions mattered in the hospital, except perhaps ‘wife’ because that explained why David was a regular visitor. On a white board on the wall of my room under the label “patient,” various medical personnel wrote my name, then mostly numbers—my temperature, my heart rate, my medications and dosages, my husband’s phone number, the date I arrived,

my weight, the number for food service, and so on. Under a second heading of “goals,” the board remained blank. More irony, I thought.

Being reduced to numbers and categories did not end when I was discharged. In the week after my hospital stay, I was grounded by pain in my legs, which I am sure was worsened by the figurative weight of the situation. Once I was finally able to walk well enough (aided by the first of many courses of steroids), I visited the office of the neurologist who had performed the spinal tap. I was feeling optimistic that we would find a way to manage this disease with medication, so I could get back to my life as it was. This time, the doctor introduced himself, but he still stayed far across the examination room and glanced at papers on a clipboard as he talked. He described relapsing-remitting multiple sclerosis, the condition most consistent with my symptoms. I noticed that he never said that I *had* a disease, a fact I had been trying to digest for weeks. He explained that most people have a gradual increase in disability in the first ten years, but this can be slowed with the use of the right medication. After that, unless the condition goes into remission, many people develop a more progressive form, which leads to increased disability and generally shortens the life span. I interrupted him with an attempt to make a joke: “Well, that’s a relief. My grandma just died at 104!”

The doctor, suddenly looking more human, raised his eyebrows and looked at me. After several awkward moments, he looked back down and began discussing the “therapy” he recommended for me: an interferon delivered weekly through intramuscular shots. It would begin with a training program at my home, with a nurse who would help me learn to administer the medicine myself. Wait! I wanted to stop him again, but I did not know how. All of this was too much, the information too overwhelming to be coming

from someone who did not know me. This stranger did not know how afraid I was to see a needle, much less give myself or anyone else a shot. He did not know about the interesting trio of health conditions that ran through my family tree: infertility, dementia, and longevity. My family had developed a macabre joke in the face of such proclivities: we would live forever, albeit alone, but we could look forward to not knowing that was happening. I don't know what the doctor would have done if I tried this joke. He only knew the test results, which put me in a category in which I did not want to count myself. This man had no understanding of how strange it all was. I began weeping.

I am not someone who cries, not even when I might like to, not even when I am alone. Coming from a long tradition of stoicism (within which stories of keeping cool in a crisis are celebrated, like my mom, at 15, who did not cry as they buried her mother), I have always taken pride in my self control. Yet here I was, looking across a room at a stone-faced doctor I did not know, crying. Trying to regain composure, I wiped my eyes and said I needed to go to the restroom. "We are done here," he said with finality. Before I left the office, I turned back to see him poring over the paperwork again. With a shaky voice, I asked him if we could "talk about all of this," motioning toward my face and then in the direction of his clipboard, but he looked squarely at me without offering a new expression. We stood regarding each other for a moment and then he said plainly, without any noticeable gesturing, "You come back after you've sorted this out. Then we can talk." I quickly stifled my crying and left without another word. As I drove home, without any tears, I added finding a new neurologist to my list of problems to solve.

I wish that I could say that was the last time I was treated impersonally as part of my trajectory of learning to live with multiple sclerosis. Developing a disease was the

most personal event I have ever experienced, but this change forced me to depend on a depersonalized system. Although the general perception that those in the medical field do good work is not really wrong, the avenues available to patients are limited. The apparatus of medicine of which doctors are part can feel like a gargantuan, inescapable labyrinth with entrenched traditions, detailed laws, and little room for negotiation. I was surprised how often the individuals I encountered (who *work in* hospitals) seemed unable to understand how deeply pain, decreased mobility, and the loss of independence affected me. Once I had a diagnosis, I found that there was not space in the treatment of this disease or in the realm of mainstream medicine for me to be anything but a patient. My story became that of an MS patient, my living became a series of statistics and probabilities, and my future aspirations dwindled down to one goal: get better.

Getting worse or better, according to the medical world I had begun to inhabit, was depicted through numbers. When practitioners read the results of my tests, uninspiring statistics spoke on my behalf. Weakness, dizziness, lost appetite, myelin reduction, numbness, pain, low vitamin levels, thyroid dysfunction, weight loss, blurred vision, depressive ideations, and infections were all quantified and recorded. They replaced whatever else I am. They became my story. When I saw doctors (and there were suddenly many), I was shocked at the incredible amount of detail contained in my burgeoning medical files, which still told them almost nothing about *me*. I thought of inserting pages detailing my favorite novels, vacation spots, great jokes, or even stories in which I made a fool of myself. I longed for something personal, or even something “consistent with” personal.

As I became a more seasoned sick person, I began to connect my experiences with some of my students whom I feared felt alienated by a depersonalized school system. I had always been on the look out for “caring occasions” (Noddings, 1988) when I was teaching, but this experience brought me closer to understanding the (likely negative) influences of many of the institutional practices designed to help students. Thinking of the profound effects of the words and actions of medical practitioners I had encountered, I found truth in Nodding’s assertion that goodness and wickedness “are both, at least in part, induced, supported, enhanced, or diminished by the interventions and influence of those with whom we are related” (Noddings, 1988, p. 176). My disease often made me exposed and vulnerable; those involved in my care had tremendous power to affect my experience as well as the course of my treatment. Was this how it felt to be designated as something like ADHD or learning disabled, for all teachers and school personnel to know? I wondered if placement into a category was too much of a price to pay for access to services and accommodations.

I did not previously appreciate how terrible it can feel to be reduced to numbers and set categories until something as personal as my physical well-being was represented that way. In seeking medical treatment, my diagnosis (as affirmed by a thick folder of records) defined me, more than any personal trait, skill, or attitude. Someone with “relapsing-remitting multiple sclerosis” was just the same as any other person with that designation, as far as the recommended course of action was concerned. The methodical approach I experienced from medical professionals was not a comfort during the chaotic period of adjusting to life with this disease; I felt reduced from full person to a case, filed neatly away in a neurology office alongside similar patients. But this crisis was uniquely

mine. My experience with this disease was personal and I longed for medical personnel who would treat it that way.

I have been assigned numbers for many reasons, all of which make sense from a functional point of view. Certainly things like banks, school districts, government entities, and airline companies cannot deliver their products or serve their clients well according to names or personal attributes. How very unwieldy it would be to do business that way! The same applies to the industry of medicine, which serves a large clientele and cannot afford to be bogged down with dilatory facts that cannot be represented numerically. But when you are one of the clients who has an extenuating circumstance, like someone who must change a flight for significant personal reasons, someone who has a panic attack during a timed test, or someone who is sick in more dimensions than just those that fit into extant categories of modern medicine, these situations reveal the rigidity of a quantified approach to serving humans. Laura Nader appeared to be right that “[q]uestions of civil rights, of freedom, of social structure, of democracy, of quality of life, or of equality are not easily discussed numerically or through modeling. Numbers also dilute the dangerous and the unthinkable: the distancing function” (1996, pp. 263-264). The remoteness I felt from the very places and people I went to for help with something as personal as my health was palpable.

I think about certain students I have known: those who always did poorly on standardized tests, those who did not speak English, those who were terrified of peers, those who struggled to stop taking drugs, those with adult-like burdens at home, those who often missed school for illness, and all those who did not succeed in regular classes for whatever reason. Although there are networks of assistance for young people who do

not fit into the mainstream program (e.g. IEPs, resource periods, social workers, personal aides, counseling sessions, foster homes, mentoring programs, home-bound education, tutoring, behavior plans, modified schedules), the safety nets are often delayed, inadequate, not well-designed, stigmatized, and accessible only after crisis conditions emerge. If a 'don't fit' student (Deschenes, Cuban, & Tyack, 2001) realizes that he or she is always left out by the program of school that fits everyone else, what effect could that awareness have? I think about my bitterness toward a certain airline or a particular doctor and wonder what it would be like if I had to keep depending on the measly accommodations they were willing to make. If I could not just take my business elsewhere, there would be no relief, no looking back disdainfully on a situation I would rather forget. For students who do not fit in, life in school could be comprised of simultaneously being dehumanized and subordinated by a label or a number that is integral to their identity in that context.

Before I was diagnosed with a chronic illness I had felt compassion for students who were left out or marked in some way; I do not think one must experience something as acutely as I have to feel sympathy. That said, my experience of this disease has shown me the frustration and pain of confronting an inescapable system that cannot or will not bend its rules, no matter how profound the extenuating circumstances may be. These situations feel like a betrayal, particularly when the rule-keepers claim that their actions are in the interest of the individual, and even more so when that individual has always believed that claim. The point is not to lament my medical care, per se, but rather to critique its incessant subjugation. In the treatment of my disease, I don't get to be

agentive. I am never a peer, never a collaborator, but instead just a recipient of care, just a patient.

It has hurt emotionally and physically when I have hit dead ends I did not anticipate. But I am glad for the deeper understanding of hardships some individuals experience while the majority lives happily protected by a system, unaware of the harsh realities outside of it. Perhaps less acutely than long-term medical patients, but students and teachers are also reduced to numbers in a depersonalized machine, based on administrative logistics, legal mandates, financial constraints, and convenience. I wonder if everyone needs a chance to step outside of the shallow protection of this logical system to see its flaws, to imagine a different way of dealing with idiosyncratic, live human beings. I wish I could have gleaned this wisdom without getting sick but I can testify, in the words of Audre Lorde, “I would never have chosen this path, but I am very glad to be who I am, here” (1980, p. 77). If I am still a teacher (and I *am* still a teacher) then there are lessons to share from a life lived both in schools and hospitals.



## CHAPTER 14: ULTIMA

“The tragic consequences of life can be overcome by the magical strength that resides in the human heart.” From *Bless Me, Ultima* by Rudolfo Anaya p. 249

Monday, January 6<sup>th</sup>, 2014

Words of the week: curandera, adobe, vaquero, vagabond, linger

Unit: *Bless Me, Ultima*

Supplies: index cards, writing utensils, paper

New Seats: Students gather supplies and find their places on the chart (groups of 3 or 4)

**Activity:** On index card, fill in the blanks with something that was/is true for you.

**“I thought that \_\_\_\_\_ would be great, but unfortunately, I was excluded because I \_\_\_\_\_.”**

Samples (write on the board; create more if needed):

“I thought that being in a musical would be great, but unfortunately, I was excluded because I was too shy to sing in front of people.”

“I thought that going to Disneyworld would be great, but unfortunately, I was excluded because I was sick with strep throat again.”

*Give students time to think and write. Help them, if they are struggling for ideas.*

Now all students will share something with the class that they wrote in one of the blanks, like “going to Disneyworld” or “I was too shy to sing in front of people.” Segue into a conversation about exclusion, which is an awful feeling that happens to most (all?) people. Then turn back to my stories of being left out. What do they reveal about Mrs. Bossman? (I am shy, I like music, I did not enjoy Disneyworld, I get sick frequently etc.)

**Instructions:** Turn over your notecard. I will read (twice) a passage where the narrator of the book we will be starting is describing his exclusion. Listen and jot down 3 observations you could make about him: \*\* Have copies available.

I gathered my lunch and slipped out of the room. The strangeness of the school and the other children made me very sad. I did not understand them. I sneaked around the back of the school building, and standing against the wall and tried to eat. But I couldn't. A huge lump seemed to form in my throat and tears came to my eyes. I yearned for my mother, and at the same time I understood she had sent me to this place where I was an outcast. I tried hard to learn and they had laughed at me; I had opened my lunch to eat and again they had laughed and pointed at me. (Anaya, 1972, pp. 58-59)

*After students have written something, instruct them to share answers with the members of their group. Then they should select a writer (for today) who will put a few good observations from the group on the board. After every writer has had a chance to add answers, have a brief class discussion. What kind of person is he? (Young, emotional, different) How is he feeling? (sick, lonely, homesick, angry) Why is he being excluded? (Strange school, not understanding, different lunch) Answer relevant questions.*

**Assignment due by bell:** Take out the piece of paper. At the start of the book, this same character describes “the magical time of childhood.” Your task is to write a paragraph describing something in your childhood (an event, a summer, a friendship) that you would describe as magical. Write an accordion paragraph! That’s 8 sentences! \*\* Create model, if time permits.

\*\*\*

After my hospitalization in October of 2013 and during a leave of absence of work, I created a unit that I never got to deliver. It would have begun on my first day back, a return that continued to get pushed off onto a later date. Until then, I passed on material I had not covered yet, along with scheduling some of the required sessions at the career center during English class. Although I only met with the substitute once, I had it on good authority that she was faithfully representing my plans. Still, I could not wait to return to teaching, even if I had to do it from a wheelchair some of the time. In reality, I needed something to do. During my leave, I had been instructed to avoid work—particularly my graduate work, which I missed enormously. I tried to relax and I tried to find something that would entertain me. I had never been much of a television or movie fan, so I had some catching up to do. But after watching so much *West Wing* and *Sherlock* and anything else Netflix thought I might enjoy, I longed for a purpose.

I recalled the unused optional novels from the closet in my department. My students had already read *Night* (Wiesel, 2006) and *Speak* (Anderson, 1999), but our mighty curriculum guide asked for one more novel. I did not mind; I loved taking on literature with adolescents (even if I had to drag them along with me). I had taken inventory of the text options when I first started my job and I recalled several boxes of *Bless Me Ultima* (Anaya, 1972) tucked away in the book room. I had been assigned this title in college and I shuddered to remember that I had read it perfunctorily for a discussion class that all students had to take. Looking back, I think it was cool that my college had such a program, but we did not always appreciate the literature. I am sure I read the book late on the night before the class, probably with the use of caffeine and

some blaring music to keep me awake. Actually, I have always loved returning to books that I originally encountered at a very different stage of life. The reading reveals a new book as it is filtered through a different self and context; yet, there is a kind of homecoming as I reunite with certain characters and scenes from years before.

This time, I was struck immediately by the poetic nature of *Ultima*, which begins with the narrator declaring that “the magical time of childhood stood still” (Anaya, 1972, p. 1). One of my specialties as a language arts teacher has always been close examination of elegant, deep writing. I had spent many spirited classes (I was spirited, anyway) illustrating this kind of well-crafted text anywhere I could find it. My students tended to get it, or at least they led me to believe they did by listening to me prattle on about examples without too much complaint. And this text was about a boy who speaks Spanish but must go to school and speak English. His family has a culture that others don’t understand. It is a coming-of-age novel. Really, I was thrilled how well it fit my students! I wondered why I was so quick to discount it in college.

Frustrated by my “vacation” from teaching, I threw myself into planning. I called our secretary to get a number of books, and when I needed more I ordered the collection from the other high school, where it also sat on a shelf unused. The weekend before my return, I focused on the life of Rudolfo Anaya, whom I was loath to admit I knew nothing about. Without going into detail, I can report that I was fascinated with the author and ready to begin. The books were in my classroom waiting, according to a note from our secretary (who happened to be a friend). This was going to be great, assuming my health would cooperate with a return to work.

The morning I came back to my classroom, I saw much cleaner place than I ever kept, but I also saw a note from my department chair on a sticky note on my desk. In cheery font, it displayed only the message “See me ASAP!” I looked around the room, noticing that the bulletin boards I had made months ago were completely unchanged. That was kind of eerie, yet sweet. I had told the substitute to feel free to do whatever she wanted with the space and she just made it neater. I wondered where she had put the Anaya books. At that moment, our secretary came in, looking alarmed. After a brief reunion hug, she told me that the books had been sent to the other high school and that I would not be allowed to teach that novel.

What? I marched (although that verb does not describe the combination of limping and plodding I used) to see our department chair. Looking up from grading, she smiled, but informed me impassively that I could not teach *Ultima* and that it had been sent away. Before I could protest, she explained with a tone of finality that the book “has only been approved by the board for sophomores.” I waited to respond. I was furious, but what would I accomplish by getting angry? I thought about my doctor telling me that stress slowed my recovery. What should I say? I knew myself—and my penchant for having a sharp tongue—well enough to answer by nodding and leaving her room silently.

In teaching, there are often moments in which improvisation is the only choice. Sometimes, things happen right in the middle of lessons. Fire alarms ring, children throw up, cockroaches run across the floor, fist fights break out, phones ring etc. I have had to punt in all kinds of situations. But this felt different. This was not just one of those random events that happen in the life of a school. This was someone using their power to obstruct something I had planned to do, that I had longed for months to do. I had allowed

myself to be a teacher again, imagining how lectures and assignments and group activities might be built around this text. I had envisioned lively conversations about language, religion, diversity, poetry, and dreams. The text was not like the reading they usually do in high school and I was excited to see their responses; my teaching would have built from my students and the text and my own interactions with both. Damn it, what now? I thought, when I ran into my substitute heading back to my room. She had come in to help me make a transition that morning. I wanted to show her my gratitude, but instead I smiled weakly and asked her what was in the box she was carrying.

She apologized for not telling me on Friday, when our chair had told her about the books having to go. She assumed I would start with “something simple” on my first day, but she wanted to come in and help me find a new text. There were only three titles that had enough copies for all of my students and our chair (along with other teachers) had told her that the students would love *Ender’s Game* (Card, 1985), which even had a movie coming out. She set a box full of paperbacks on my desk. I felt conflicted between my fury at my department leader and my tendency to make the best of impromptu teaching situations. I also did not want to appear ungrateful for the help of my substitute teacher, who probably had not had an easy time dealing with my heavy teaching load and a few students who came immediately to mind. So instead of swearing or crying or fomenting a revolt in our department, I sat down and thanked her for the books. “I printed off this study guide,” she said, pulling a thick stack of papers out of her bag.

Setting aside my opinions about materials one might print off the internet rather than allowing curriculum to be built organically around a reading situation, I thanked her again and we got to work on the first lesson. I had read *Ender’s Game* before, and it was

not a text that I liked. (If I wanted to teach science fiction, there are better options I would select first. One of my favorite authors, Kurt Vonnegut, comes to mind). My negative opinion had been made worse by the controversy related to the author's history of homophobic comments, like an editorial in which Card stated plainly that gay people already have the right to marry, as long as they "find someone of the opposite sex willing to join them in marriage" (Card, 2004). The film rendition of the book was about to come out and LGBT groups, along with others who fight bigotry, were calling for a boycott I had no problem joining. I attempted to bracket these reactions to the author and his views, hoping my students and their parents would not think that my teaching a book condoned everything related to it. Instead of trying to switch books, we wrote vocabulary from chapter one on the board and asked our secretary to make copies of the study guide. This was not how I teach, I thought, but it would have to be acceptable at this moment.

My students were happy to see me. I had forgotten, in all of the drama of the morning, how wonderful it would be just to talk to them again. I had also forgotten, in my focus on being a teacher again, that my love for students was more important than the lesson plans I had made without them. The lesson plans and approach to the novel as presented in the study guide were as empty and generic as I thought they would be, but it did not matter *what* we were working on. I was sitting on my favorite teaching stool again, with vocabulary words on the board behind me, in front of adolescents who were actually listening to me (and occasionally to each other). Regardless of the topic of discussion, I was in my element. At the end of each class, I asked students to write down the world they imagined for their own grandchildren, and I was delighted by their creativity, optimism, and honesty. Some of them appeared to have dreamed of fighting

aliens at some point in their futures! I would depend on their enthusiasm to get through the book.

At the end of an afternoon class, a student (one I knew had been a terror to my substitute) gave me a card he had made by folding a piece of paper. Inside, it said “Thank you for coming back, even though you have a disease.” As I read it, I smiled broadly and said “No, thank *you*,” as he scrambled out of my room to catch his friends. Thank you, I thought again, as I began to create plans for my *second* day back.

It sounds like a platitude to say that one learns from students, but these young people were integral to an important lesson about the essence of my pedagogical existence and commitment to teaching. My desire to return to class sustained me during my absence. Rather than watch the entirety of another Netflix series to pass the time, I had preferred to read a novel and imagine how I might experience it with young people. Even as I considered my different classes and anticipated relevant discussions and assignments, I remained aware that the caprice of adolescents would ultimately shape the unit.

I have come to expect students to surprise me, but sometimes I forget about other elements and people I cannot control. Leaders in education (principals, department chairs, secretaries of education, governors, superintendents, state boards and so on) make moves that can affect teaching profoundly. I have had to stop worthwhile practices and cut out favorite texts and I have had to enforce policies I do not condone. In those moments, when I feel the most powerless, I must focus on the love of teaching I am lucky to



possess. It would have been better if I could have pursued the unit as I had planned, but I am thankful my identity came back when I needed it to sustain me.

I have witnessed, again and again, that good teaching is not only what is taught, but who is teaching. Teachers who struggle (including me) must remember that the essence of who they are always comes through to students who watch them during moments of conflict. If a teacher responds to adversity with pedagogical ingenuity, love, and flexibility, students will notice. Recently, over social media and news outlets, I have read letters from teachers explaining why they had to leave their jobs. Most of them have very good reasons. These letters are striking, tragic reminders that teachers are often in danger of losing the heart to keep fighting to do their jobs. I appreciate their integrity and commitment to practices that have been banned or books that have been removed from the curriculum, but I long for these noble, beleaguered teachers to stay anyway.

I know from experience that it hurts to be disciplined, interrupted, confined, isolated, scrutinized, insulted, or curtailed by those with the power to inflict such actions. But in these trying situations, there are still opportunities to express the identity of a teacher and to show care. And that *is* power! Whenever and however it is possible, if educators choose to think of the students above all else (like teachers do) the members of their classes will be thankful, but I cannot promise that it will be as obvious to see as words on a hand-made card.

## CHAPTER 15: WHAT MY KIND HAS TO OFFER

There are rewards for making the world physically and emotionally accessible to all people, including benefits that accrue to society as a whole. The more perspectives that can be brought to bear on human experience, even from the slant of a wheelchair or a hospital bed, or through the ears of a blind person or the fingers of someone who is deaf, the richer the experience becomes. If it is both possible and pleasant for me and my kind to enter, the world will become a livelier place. You'll see.

From *Waist-High in the World* (Mairs, 1997, p. 106)

When I began to inhabit different parts of society (hospitals, neurology offices, handicapped sections, pain clinics, pharmacies, infusion centers, medical trials, wheelchairs, the ER, physical therapy, etc.), I realized how often I have failed to look closely at my surroundings. Before I was sick, I was often so absorbed in my own agenda that I could shut out anything or anyone that might have distracted me from whichever task was most urgent. I built a reputation for obliviousness. Now I spend several hours a month at the hospital, where I get an infusion of a drug that may or may not be helping me, despite its exorbitant price tag, and I must stay still for two hours for its delivery through an IV. I usually bring books to read, but I end up listening to nurses, other patients, the noises of the infusion machines, the announcements on the intercom, and the incessant beeping that seems to be part of every medical facility.

Outside of this room, while I slowly make my way down to a car that I am still lucky enough to be able to drive, I observe my surroundings with a different awareness. I find myself watching people in every imaginable stage of wellness, life, and mobility. And there are myriad emotional and personal moments on display at the hospital: balloons and flowers for new babies, medicine flowing from bags into veins, monitors recording blood pressure and heart rates, oxygen tanks clicking, children without hair clutching stuffed animals, and visitors who appear to be lost, exhausted, or devastated. I am part of all of this now, I think, but then I realize that I have always been. So I appreciate whatever brought me to this awareness, even if it is something as horrible as multiple sclerosis.

My life has been fundamentally changed by illness, disability, and a plethora of losses that have accompanied these forces. Not all of the alterations have come in the form of new deficits, however. As revealed by my epiphanies at the hospital (and in many other places), my perception has been transformed in good ways. One such change is evident in the way I notice others whom I might have ignored in the past: an elderly woman waiting for the accessible van with large bags of groceries tied to her walker, a woman near my age dressed smartly in a black dress and tall boots driving a motorized chair, a man slowly walking into a coffee shop with a noisy oxygen tank in tow, a tiny girl with twisted limbs attending a hockey game in a padded wheelchair decorated in team colors. If I saw them before (and I generally did not), I do not think I would have thought of myself as better, but I would not given a second thought to feeling pity or wondering how I could help them. It is not bad to feel sympathy or look for ways to care for others, but this kind of paternalistic oversimplification of the needs and experiences of

strangers is a common occurrence I have come to know. What the fit often fail to recognize is that individuals “with disabilities are not who or what we have been taught to assume they are. The experience of disability is not what we have been told. Most of the reigning social thought about disability is distorted” (Shapiro, 1993, pp. 13-14). My change in status has illuminated such errors.

When I was not a disabled person, it was easy to divide the physical world into those who fit in easily and those who didn't. Those who were challenged by the stairs, doorways, sidewalks, or narrow spaces I once navigated seemed like one homogeneous group that the rest of us occasionally, benevolently, invited to join us. If someone came to a concert, or a bar, or a sporting event in a wheelchair, I thought accommodating them was something nice, but my thoughts on the topic were vague. If I gave this person any thought, I might have been impressed with this individual's indomitable spirit or a particularly obsessive love of something, since he or she is willing to get there “anyway.” I doubt I would have entertained the possibility that this disabled person might have exactly the same motivation I did for coming to that space. The woman who happened to be in a wheelchair might also have won free tickets, or been bored on a Thursday, or she might have planned to meet some friends from college, or she could have just been on a date with her husband. There need not be a noble or monumental reason for someone who is disabled to choose to engage in normal activities. My esteem for someone who was simply doing the same thing as me would have proven my ignorance and illustrated the pervasive prejudice against individuals with disabilities that I once possessed.

Another awareness I have gained through becoming disabled is the inaccessible nature of many places. For example, restaurants I used to eat at regularly are now too far

from handicapped parking, too full of tables and chairs, or perched at the top of unnavigable hills. They have only recently become out of my reach, but the spaces I once haunted have *always* excluded people. This new perspective has challenged my earlier belief that such a fact was inevitable, and not based on any conscious decision about who will or will not be included in public spaces.

Simi Linton, upon her return to college after becoming disabled, recalls her original thinking that “it didn’t seem to be anybody’s fault that a doorway was too narrow, or there were steps, or there was no way to use public transportation; these seemed to be just facts of life, random incidents, not governed by any principle” (2006, p. 27). I once believed that too. But such choices—including the choice to remain ignorant to the true diversity of human physical conditions—dictate exactly who is wanted in certain spaces. The nature of many physical places, including who is never seen there, adds to an invisibility that is a hardship faced by most disabled people. As long as we do not speak about this exclusion, “those with handicaps and those without—all—are deprived of the knowledge, skills, resources, and motivation necessary to promote change” (Zola, 1983, p. 211). This loss harms all of us.

My newly enlightened ability to look at my surroundings is an ethical and intellectual boon, but how could I employ it in service of education? I have not lost the drive that made me a dedicated teacher and I want my growth to attend to that desire again. When I was teaching, even when I was not literally in the classroom, I constantly looked at the world for its potential to improve my work. I never stopped thinking about how an experience I was having might be relevant to a lesson. Perhaps it was something in the movie I was watching, a song I heard on the radio, the funny thing my daughter

said at dinner, a current event, or a crisis within my family, but all of it held pedagogical potential. I shared my life with my job and I could never easily disentangle the two. But now without a formal classroom, how can I still transform my experiences into educational opportunities?

Nancy Mairs claims that welcoming the perspectives of “her kind” will “make the world a livelier place” (1997, p. 106). What does my kind have to offer the particular world that most concerns me? Why does education, and the larger realm of educational theory, research, teacher preparation, and policy need the voice of a “wounded storyteller” (Frank, 1995) like me?

The purpose of schooling is constantly under revision and is often a source of heated contestation, but for many young people it functions as their primary source of socialization outside of their homes. Chief Justice Earl Warren in the unanimous *Brown v. Board* (1954) declared the school to be “a principal instrument in awakening the child to cultural values.” So what value is conveyed by the way disabled children are treated at school? What is the message if they are not there? When students are placed alongside other young people at a school, they are often forced to confront differences they had not before encountered. In their immediate circles, they may not have ever met someone who speaks a language other than theirs, someone of another religion, or someone with a different skin color. When students meet these new people, it may result in “a painful, critical, re-examination of their active ignorance about difference” (Mayo, 2004) and teachers can find themselves engaged in mediation between students who are finding it hard to live together. As young people watch their teachers acting in this capacity, they are learning strategies they may never have needed before.

To return to the experiences of many disabled people, their invisibility, their exclusion, and their inability to fit in were often first made most apparent at school. When I was a student in elementary school, the physically and mentally disabled students were, for the most part, kept away from the “normal” student body. If we saw these students at all, it was only briefly as they passed our classroom or left the cafeteria as we arrived for lunch. (If I were a generation older, they might not have been in the building at all.)

I remember looking up from my work at the sound of squeaking walkers, buzzing wheelchairs, or moans in the hallway. “Don’t stare,” I recall my second grade teacher scolding us. Later, in secondary school, the visibility of disabled kids increased slightly when a few would join the rest of us for assemblies and occasional gym and music classes. Still, these events were irregular, and the inclusion of this group was treated as something special, a coming together that was carefully facilitated by adults. Having absorbed messages about what disability meant, it is no wonder that for those of us who become disabled later in life, the prospect was terrifying. I wonder what I would have thought if I had been aware of disabled people as something other than tragic cases or oddities that one is not to look at or insult. What if I had actually *known* one of these people? What if I had known a disabled person to be competent, thoughtful, or at least multidimensional?

Complete inclusion of disabled students, which is often named as a goal by school leaders, has been rare in my experiences as a teacher. In my training, I had one required class in special education that discussed different forms of disability, but beyond that, my experiences match the observation that “the study of disability is isolated in the

specialized applied fields (e.g., special education, rehabilitation psychology, physical therapy), and that information is usually available only to majors in those fields” (Linton, 1998, p. 80) . When I worked in school buildings, I found that disabled students were generally kept apart from those in my general English classes. I did occasionally have a student with an IEP for a particular disability who was included in general classes, but their inclusion was contingent on their ability to fit in with the rest of the class. The accommodations for these “mainstreamed” students rarely went beyond what I would do for any struggling individual.

If a student with a disability needed more, he or she would be moved to a “co-taught” class. I had the chance on a few occasions to teach this kind of class, which meant that for one period, my classroom included another teacher who brought with him or her a group of students, the same group this person chaperoned to other classes in the school. Each of these young people had an IEP, which was the product of a meeting facilitated by his or her assigned special education teacher. I attended some of these meetings, but my input was minimal. While I did my best to include all of the students equally, the special education visitors generally arrived together and acted as a social unit. Their separation was also frequently made apparent when “their teacher” removed the group for remediation or to read tests or materials out loud. If the larger milieu of education included more voices of thinkers who were themselves disabled, the dream of inclusion might be replaced by actual ideas and solutions that are applicable to general education. I might have been better prepared to disrupt and question the segregation of disabled students. Also, if more teachers (and teachers of teachers) were disabled, the



separation of students based on a bifurcated system of abled/disabled would become less obvious and perhaps less appealing.

Including the voices of scholars of my kind in education would also aid in the battle of disabled people against skewed images presented in media. There are certain tropes of disability that are ubiquitous in movies, literature, news, and on many television shows. One particular favorite is the person who can overcome the odds, “the inspirational disabled person.” This figure is “deeply moving to most nondisabled Americans and widely regarded as oppressive by most disabled ones” (Shapiro, 1993, p. 16) The person with polio who later won Olympic medals for track, the one-armed pitcher who threw a no-hitter, or the blind pianist “were all so good that no one knew or had to be aware of their handicap, and therein lay part of their glory” (Zola, 1983, p. 201). These stories aid in the distortion of thinking about those with disabilities. The rest of the world did not have to accommodate these extraordinary people; thus true greatness for a disabled person is succeeding without accommodation.

That leaves disability with two tropes at opposite ends of poles of a spectrum—the heroically impressive and the very limited that we keep a distance and mildly pity—a spectrum without a middle. We need better stories, even if the heroic ones are seductively heart-warming. Such tales would include a “voice that speaks not of shame, pain, and loss, but of life, delight, struggle and purposeful action. Writers are needed who can demonstrate that success in terms of disability is more than a personal triumph over physical adversity; it is a life that consciously reckons with the social forces that oppress and control” (Linton, 1998, p. 113). Education could be a field that includes—and

empowers—these kinds of middle voices and this kind of truth-telling in its curriculum and practices.

I used to think I was a good teacher when I could count myself among the able-bodied, but now I have to add a caveat to that former professional pride. I *was good*, but not for all students. My teaching (and my training) was complicit in proffering the distorted portrayal of disability that most of us learn. Because my training did not include much focus on special education, I left the education of “those students” to a different set of teachers. I did not question the segregated cafeteria, the private hallways, the separate buses and bus schedule, the isolated special education courses, or the systematic distancing of disabled students from “regular” students. I also taught literature, which I would have approached differently if my training had included the study of disability. Now, as I look back on texts included in my courses, I can identify stereotypical characters that fueled misunderstandings of disability. If I had known then what I do now, my teaching would have included explicit, critical attention to these portrayals.

Paul Longmore, an historian and social critic specializing in disability identifies that, in many stories, “physical handicaps are made the emblems of evil” (2003, p. 133). For nefarious individuals—like the one-handed Captain Hook (Barrie, 1980) or Count Rugen, the six-fingered man in *The Princess Bride* (Goldman, 1998)—their physical deformity is central in their characterization. Another trend Longmore points out is “the depiction of the disabled person as a “monster” which, like the deformity trope “[expresses] to varying degrees the loss of an essential part of one’s humanity” (p. 135). For examples, he cites Lenny in *Of Mice and Men* (Steinbeck, 1963) and Quasimodo from *The Hunchback of Notre Dame* (Hugo, 2002), characters that elicit sympathy, but ultimately

cannot be included in mainstream society. In a different light, characters with disability are also portrayed as special individuals who have been compensated for their loss by some gift that is “spiritual, moral mental, emotional” (Longmore, p. 138). As I noted earlier, this trope remains very popular. The audience generally appreciates this character, but not because of their complex humanity. Rather than portray these individuals as real people who have conflicts, goals, failures, losses, and joys (like everyone), the stories depict those with disabilities as distant or exaggerated inspirational figures.

The voice of the wounded storyteller—my voice in particular—would be part of the necessary act of dismantling the systematic distortion, marginalization, and segregation of disability. As an education researcher working with a deep understanding of disability studies, my work would introduce “contradiction into the polarized categories of weak and strong, normal and abnormal, revered and reviled, dependent and independent, expendable and essential. It reveals these as false dichotomies, and reveals the epistemological underpinnings of the privileged position in each pair” (Linton, 1998, p. 186). My experience, and that of many disabled people, could bring into focus the problems these divisions create for all of us. My kind, a disabled scholar/ researcher/ teacher, can offer a clearer, more complex, picture of reality.

## CHAPTER. 16: WHAT IF THIS COULD HAVE HAPPENED?

I am the decisive element in the classroom. It is my personal approach that creates the climate. It is my daily mood that makes the weather. As a teacher, I possess tremendous power to make a child's life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or humor, hurt or heal. In all situations it is my response that decides whether a crisis will be escalated or de-escalated, and a child humanized or de-humanized. (Ginott, 1972, p. 13)

These words by a teacher cut to the core of something I believe: there is nothing more important that happens in a school building than what occurs between teachers and students. There are other factors that impact young lives, of course, but teachers have the chance to construct a microcosm of learning, love, and possibility in the spaces they share with students every day. I have always taken this opportunity seriously. Moreover, if other teachers were to read this Ginott's statement, I think most would agree. Still, I have learned that this perspective is not shared by everyone involved in schooling. Others would point to the importance of the various physical facilities, course offerings, test results, textbooks, curriculum writing, or school leadership, as what most matters. I won't say those don't matter; they do. But even if a school gets all the rest of these components right, the learning, the flourishing, the celebration and cultivation of intellect still might not happen if the teacher/learner relationship does not work.

Here, I create a fantasy of sorts, not a true account of something I did as a teacher, but rather something I wish had occurred. It takes an event that was one of the worst in my professional life and transforms it to what *could* have happened, if my administrators and district leaders believed Ginnot's words as deeply as I do.

\*\*\*

The bell that marks the beginning of sixth hour buzzes, appearing to surprise the huddle of young people near my classroom door. They spring into action, hurriedly saying goodbye to each other and rushing to their various destinations. I am late for my meeting, I realize. I shuffle the large piles of papers on my desk to make its top visible before I leave the room. My fifth hour has worn me out a little; I genuinely like teaching this group, but it is full of strong personalities. During my medical leave, some of the kids were particularly terrible for my substitute teacher and we are still working through some tension that increased in my absence. I have been back for almost a month and, in general, it is good to be here again. I am using a wheelchair most of the time, which helps me more than it gets in the way. My students had a little trouble adjusting to a teacher in a wheelchair at the start, but now they just treat me like they did before. On my second day back, I began my classes by sharing the exciting discovery that teachers in wheelchairs are still allowed to send children to the office. "Isn't that good news?" I asked. Things were pretty normal after that. They seem to like me, as students do, despite occasionally getting annoyed with my enthusiasm for vocabulary words or the singing that I tend to include in writing lessons.

Today I am meeting with my principal and the director of human resources to discuss how I can get through the rest of the year. I am struggling to work full time and I am worried that I am pushing myself too hard, teaching all day and then returning home for my parental and family duties (and disease management). My teaching is also not as good for seventh hour, which exacerbates the troubles this group has. I worry about this class, which includes several kids who have been chronically absent, two who were

suspended for getting high at school, and a junior who is taking freshman English for the third time. Their grades are my lowest and our class times the least productive. They deserve a more energetic teacher. I hope we can figure out a way for that teacher to still be me. When I asked the human resources director if we could talk about my job, I was nervous and excited that she had made it for the next day during my plan period. I had to prepare quickly for something so important.

I grab my purse and make my way to the elevator, a task that is much easier since I do not have to maneuver my wheelchair through crowds of young people. In the beginning, the sight of me in a wheelchair caught many students off guard; they often apologized and got far out of my way so I could pass easily. Now, I am just another teacher for whom they might move, when they get around to it. Even when their manners are nothing to praise, I like high school students. I appreciate their candor, their earnestness, and their willingness to talk to me bluntly about my physical condition. On my first day back, I was incredibly nervous about how I would explain the health crisis I had just endured. I worried that my weakened state would undermine my authority or make it more difficult to control classes. I was wrong. One of my afternoon students saw me wheeling to my room before the starting bell. He rushed over to me excitedly and then stopped and looked down at my wheelchair. "I heard you have a disease," he said. I couldn't help but smile, "Um, yes, I do. MS." Without blinking, he said, "That must suck." I agreed that it did, and then the conversation about me was over. It is refreshing to spend my days with kind, but self-absorbed teenagers again.

I enter the principal's office through a narrow hallway, a space always crowded with large boxes and assorted furniture. I am glad to finally have a new wheelchair,

which was designed and special ordered to fit my small frame. Its size and flexibility make it easier to manipulate in tight spaces, but it is still a struggle. Our district's director of human resources sits waiting at a table, next to an open space reserved for my chair. She finishes taking a drink of her coffee and stands up to shake my hand. In a moment, my principal comes in and takes a seat across from me. "Thank you for meeting," I say nervously. "As you know, I returned to work full time this month. I am very happy to be here, but I am worried that I am doing too much. I wondered if we could brainstorm about strategies to get through this semester without another leave." I had practiced my opening line at home, wanting to get this right. The human resources director opens her briefcase and begins pulling out materials. "I have some information for you," she says matter-of-factly as she places papers on the table, "about disability and retirement." Before I can protest, she adds, "but I don't want it to come to that. You have been with us too long for us to let you go so easily. But I still need to give you the information, just in case." I smile, remembering a conversation I had with a friend who said something similar about my return to the classroom. "You have too much to offer to quit!" Derek had exclaimed over dinner the other night.

"I agree," says my principal. "But, in my opinion, I have not had you in my school long enough, and we will do whatever we can to keep you here, with the students who need you." I relax, glad that we are thinking about this together. "So, what do you need?" he asks. "What would help you?" I had thought about some solutions for my fatigue, knowing that the cheaper the idea, the likelier it would be that we could do it. "What if my team meeting could move to my classroom?" At the time, I had to wheel all the way across the school each morning to a conference room to talk to a group of

freshman teachers with whom I shared most of my students. My room was free, so this made sense. “Probably,” my principal says. “I will try to keep it a little cleaner,” I added, thinking of my ridiculous stacks of papers. “Also, I wondered if I could get a student aide.” There was a study hall in the room next to mine and I have, on a few occasions, asked for volunteers to come over and help me move furniture or put up a bulletin board. If I got an aide assigned to me full-time, I would remember to ask for help every time I did something like that. Also, I knew that many students liked helping their teachers, particularly if it got them out of other classes. “Good idea!” the director notes, as she pulls out another piece of paper from her case.

“Have you worked with an occupational therapist?” She inquires, handing me a brochure. “I did, a little bit, while I was in the hospital.” I say. This person was one of many professionals that came to visit me there when I too overwhelmed and worried to listen very well. “Occupational therapy will give you suggestions to make work easier,” She says positively. “They can help us keep you here.” I smile, feeling optimistic. After a moment’s hesitation, I suggest boldly, “I was also wondering if we could talk about changing my job for next year....I think I can get through this semester, but I am not sure after that. I *am* almost done with my PhD.” Both of the administrators smile now. “Wow!” My principal says. “Good for you.” I had thought long about this part of our conversation. I love teaching, but I also do not want to get worse. I was worried they would just dismiss this idea or worse, but I felt loyalty to the district where I had student taught and worked for a decade. “Hmm.” The director responds minimally. “What were you thinking about? What else could you do?” She asks directly.



“I know it has not been done,” I say hesitantly, “but what if I taught part-time and worked in the central office part-time?” (I knew that this situation did in fact happen in other districts, including one local one that we competed with frequently, but I did not want to mention it.) “Well, that is something to think about,” my principal interjects. “What will your PhD be in?” I pause before talking, not wanting to appear like his question bothered me. In truth, this conversation had happened several times before. “Education, policy and curriculum” I state. Now the human resources director opens her case again and begins flipping through papers, earnestly searching for something. “I have it here somewhere” she says, “We are considering adding this position for next fall.” She finds a piece of paper and hands it to me. It is a job description, likely written to inform members of administration who might want to change positions. “Assistant curriculum director” it says. “We are planning on this being a full-time position downtown, but we could reconsider,” she says thoughtfully. “I will need to talk to everyone at the central office, but it might be great to have someone in our midst who is a teacher too. I cannot promise anything now, but it is worth a thought.” I smile, genuinely happy that I have been honest about my health concerns. I feel relieved that they wanted me to keep working here as long as possible. “Thank you!” I exclaim. I suddenly wish my wheelchair could jump a little, just to show my delight more vividly.

“I cannot promise anything right now, Dottie,” the director repeats, letting me down a little, but then she adds, “but we will do everything in our power to keep such a good teacher in a classroom.” I look at my principal, hopefully. “We can get you some student aides pretty easily,” he says. “As for the team meeting, let me ask the other teachers how they feel. As for next year, I admit I have no idea how we could change

your job here to part-time. I wonder if we could work out a schedule for a fifty or seventy five-percent teacher. Let me talk to the counselors and your department chair.” As I gather my papers together to get myself to seventh hour before the bell, the two administrators begin speaking to each other in hushed tones. “Can we meet again next week?” I ask the human resources director. “I can come to your office.” She looks over at me, nodding in agreement. Just as I am almost out the door, my principal says loudly, “No, let’s meet here again! I want to be a part of this conversation.” I agree, and thank them again, hurrying to navigate my way back to the elevator. It is going to be okay, I think, relieved. And I hurry to my seventh hour, invigorated, planning to do my best teaching yet.

\*\*\*

Based on the previous chapters of this document, it should already be clear that the fantasy scenario is not near what happened. Not all of this story was fiction, however. I did, in fact, request such a meeting with two administrators with the intention of discussing how I might continue to serve the district while still taking care of my health. I did rehearse my opening line and I did entertain the idea of working part-time or as a curriculum specialist, but I knew it was a long shot. Unfortunately, there was no discussion that day. After I spoke, the human resources director merely told me that resignation was my only option and my principal remained silent while the director described the paperwork and logistical steps I would need to complete before I left.

Of course it was a loss for me—I was no longer welcome to practice the profession I loved and, I think, had become pretty good at. But I think it was also a loss

for students who could have seen a wheelchair-bound professional still prove to be an adept practitioner. It was a loss for my colleagues, because that day a voice fighting for both my professional autonomy and theirs was lost. Finally, my departure was a loss for the disability rights movement, which my inclusion and success would have advanced.

My story illustrates that in the sphere of education, learners and educators are not treated as whole people, but as parts of a machine that are designed to work together to manufacture a complete product. To carry this metaphor further, if any of these cogs are broken or have become less efficient, a competent mechanic would choose to replace just that part, rather than adjust what is already working. If teachers are not considered to be the most essential element in learning, keeping them in their positions would never be a high enough priority to change the way things are done in schools. To my administrators, my devotion to teaching and my expertise were not enough to make up for my inability to work the way I once did, when I was not disabled. What I had to offer, as a teacher, had been lost. I would be replaced and then the machine would run as it did before. From this functional perspective, my love of Emily Dickinson, my rapport with students, and my passion for improving my pedagogical art are not elements that matter to the overall task of producing education *efficiently*.

I admit that my body brings less physical energy to the task of teaching than it used to, but as a result of recent experiences, my brain now is now deeply engaged by anthropology, philosophy, memoirs, considerations of institutional design (both hospitals and schools), sociology, and by disability studies. I have so much more that I want to teach. When the HR director did not extend the occupational therapy brochure, when the district assistant curriculum coordinator position was never actually suggested, when the

meetings weren't relocated to my classroom, when my professional worth did not warrant a conversation like the one I imagined, it was the start of a thorough and personal investigation into what it meant for me to continue to claim the identity I loved. I have learned much as a result of this exploration, but the most important discovery I have made is that I still remain a teacher. My ability to assert and hold fast to this part of myself continues to delight me, no matter the cost.

## CHAPTER 17: FROM HERE (AN EPILOGUE)

This dissertation depicts a journey of learning and living, much like the “quest stories” described in *The Wounded Storyteller* (Frank, 1995), and it is an example of the “literature of personal catastrophe” (Mairs, 1994), in which I reflect deeply on the nature of disease and loss. There is value in reading this kind of memoir and certainly there are lessons to be gained from my story, but the narrative also serves as an instructive picture of the hazards and the realities of the very divided space of education. There are divisions between special education and general education, between teachers and administrators, between researchers and practitioners, between policy makers and school officials, between those who create theory and those in charge of implementation that were, originally, created for convenience. Demarcation of whom and what was included in each group enabled those involved to provide services, allocate funds, and to divide up the monumental task of facilitating education for the nation.

This sort of configuration is a matter of administrative convenience (Labaree, 2010); it has enabled specialization and expertise to develop while the daily needs of students and communities are still being met. These divisions were created by humans, intended to be used functionally, as one form of political technology to improve lives. But when such barriers develop a life of their own, when they limit or dictate human reactions to unexpected developments, their hazards become more apparent. My experience, particularly my departure from teaching, connects to the departure from work and civic life forced on many disabled people. This phenomenon has convenient elements; most people are able to work forty hours a week for their adult lives and their ability to do this can support those who cannot keep up this pace. Logically, and

financially, this system works. The same logic underlies the separation of disabled and special education students from the “normal” population (Deschenes, et al. 2001). Only some students need aides, medical supervision, remediation, tests read out loud, Braille textbooks, wheelchair-accessible spaces, and so on. It makes sense to separate these individuals from the general population for their protection and to allow them to have access to the things they need that others do not require.

But my experiences in the past few years, as this dissertation depicts candidly, call into question the benefits of such separation. It may be financially beneficial and functionally easier to keep certain kinds of people isolated, but what is the cost? It should not surprise readers that I have found my new location on the other side of such barriers to be an unpleasant development. Susan Sontag asserted that all of us has have “dual citizenship in the kingdom of the well and the kingdom of the sick” but, as long as it is possible, “we all prefer to use only the good passport” (1978, p. 3). One of the features of a life of chronic illness is the distancing that occurs from the world of the well, occupied by individuals who (still) do not have to pay so much attention to their physical health as they go about their lives. If Sontag is right, then consorting with me is a depressing reminder that this could happen to anyone. It is true that removing me from the working world has improved my health in some ways, but it has damaged my self-esteem and stripped away from my sense of purpose. These losses, as well as my isolation, should not be surprising developments in a culture where worth and identity depend so much on employment. The new wisdom I have gained, the perspective I have developed, and the ways that becoming disabled have actually enriched my life tell a different story. This tale begs to be heard.

My district could not envision a way to retain me as a teacher, despite my expertise and devotion, because they conflated full time with fully able. Their lack of creativity reveals a system of dealing with humans that often lacks humanity. Education, as a sphere of social experience ultimately focused on what individuals are able to do, is always going to contain unpredictable forces—adolescent caprice and chronic illnesses are only two examples—and such events will always require unique reactions, if individuals are going to be enabled to do what they must. No administrative mechanism, no legislated guidelines, and no scripted lesson can consistently provide this intellectual flexibility; only humans who know other humans can respond to their diverse needs appropriately. The removal of voices like mine, the casting aside of people who can offer so much in terms of compassion, mental dexterity, and ingenuity only makes it harder to foster the kind of nuanced thinking that education will always require.

I have not created a traditional dissertation. Its unorthodox format honors the wide, circuitous route by which I have always gained knowledge. I have learned from diverse scholars, from my experiences with illness, and from analyzing closely the nature of epistemology within my field. From here, I cannot imagine that the story of me as an educator ends with the creation of this document. I have gained too much and learned too much that I am obligated to pass on to other teachers and thinkers in the field of education. I also know I am not done learning and the only way I have ever done that is by thinking pedagogically. Only when I consider the educational value of an experience do I give myself completely to a task. Thinking like a teacher is, frankly, how I do my thinking.

Where does that conclusion leave me, then? I will always yearn to teach and I believe I can still occupy an important place in the realm of education, but that it will have to be different than the one I cherished for a decade. With certain adjustments, such as the use of a wheelchair for lecturing, on-line or distance courses, or part-time employment, I believe I can stay part of the academic community. As a professor, a writer, and a scholar with a wealth of wisdom earned from my experiences, I can still contribute to the herculean, endless task of educating the populace and improving continuously at that endeavor. My voice, my personal approach to research, and my unique perspective can enhance and complicate the conversation in a productive way.



## WORKS CITED

- Albom, M. (2002). *Tuesdays with Morrie*. New York: Broadway Books.
- Anaya, R. (1972). *Bless me, Ultima*. New York: Grand Central.
- Anderson, L. H. (1999). *Speak*. New York: Penguin.
- Aoki, T. (1992). Layered voices in teaching: The uncannily correct and the elusively true. In W. F. Pinar, & W. Reynolds, *Understanding curriculum as phenomenological and deconstructed text* (pp. 23-31). New York: Teachers College Press.
- Au, W. (2010). The idiocy of policy: The anti-democratic curriculum of high-stakes testing. *Critical Education 1*, 1-15.
- Ayers, W. (1993). *Seeing the student*. New York: Teachers College Press.
- Ayers, W. (2010). *To teach* (3rd ed.). New York: Teachers College Press.
- Ayers, W. (2013). *Public enemy*. Boston: Beacon Press.
- Ayers, W., & Asch, C. M. (2008). And who gets to define "freedom?". In C. M. Payne, & C. S. Strickland (Eds.), *Teach freedom: education for liberation in the African- American tradition* (pp. 130-149). New York.
- Barrie, J. M. (1980). *Peter Pan*. Charles Scribner's Sons: J. P. Piper.
- Biesta, G. (2007). Why "what works" won't work: Evidence-based practice and the democratic deficit in educational research. *Educational Theory*, 57(1), 1-57.
- Biesta, G. (2010). Why 'what works' still won't work: From evidence-based education to value-based education. *Studies in Philosophy and Education 29*, 491-503.
- Booth, W. C. (1988). *The company we keep*. Berkeley, CA: University of California.
- Bourdieu, P. (1991). *Language and symbolic power*. Cambridge: Harvard University.
- Brown v. Board of Education, 347 U.S. 483 (USSC 1954).
- Buck, P. S. (1931). *The good earth*. New York: Washington Square Press.
- Card, O. S. (1994). *Ender's game (The Ender quintet)*. New York City: Tor Science Fiction.
- Card, O. S. (2004, February 15). Civilization Watch. *The Rhinoceros Times*.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry*. San Francisco: Jossey-Bass.
- Cochran-Smith, M., & Lytle, S. (2009). *Inquiry as stance: Practitioner research for the next generation*. New York: Teachers College Press.

- Csikszentmihaly, M. (1996). *Creativity: Flow and the psychology of discovery and invention*. New York: Harper Collins.
- Darling-Hammond, L. (2010). *The flat world and education*. New York: Teachers College Press.
- Delgado Gaitan, C. (2009). *Prickly cactus*. Fort Bragg, CA: Cypress House.
- Deschenes, S., Cuban, L., & Tyack, D. (2001). Mismatch: Historical perspectives on schools and students who don't fit them. *Teachers College Record*, 525-547.
- Dewey, J. (1897). My pedagogic creed. *The School Journal*, 77-80.
- Dewey, J. (1909). *Moral principles in education*. Boston: Houghton Mifflin.
- Dewey, J. (1934). *Art as experience*. New York: Penguin.
- Dewey, J. (1938). *Experience and education*. New York: Touchstone.
- Dewey, J. (1958). *Experience and nature*. New York: Dover.
- Dickinson, E. (1960). *The complete poems of Emily Dickinson*. (T. H. Johnson, Ed.) Boston: Little, Brown & Company.
- Didion, J. (2006). *The year of magical thinking*. New York: Vintage.
- Eisner, E. (1991). What the arts taught me about education. In G. Willis, & W. H. Schubert, *Reflections from the heart of educational Inquiry* (pp. 34-48). New York: SUNY.
- Eisner, E. W. (1992). Education reform and the ecology of schooling. *Teachers College Record*.
- Ellis, C. (1995). *Final negotiations: A story of love, loss, and chronic illness*. Philadelphia: Temple University.
- Ellis, C. (2004). *The ethnographic I*. Lanham: Altamira Press.
- Ellis, C., Bochner, A. P., & Adams, T. E. (2011). Autoethnography: An overview. *Forum: Qualitative Social Research Vol 12 (1)*, Art 10.
- Ferri, B. A. (2011). Disability life writing and the politics of knowing. *Teachers College Record* 113, 2267-2282.
- Field, J., & Latta, M. M. (2001). What constitutes becoming experienced in teaching and learning? *Teaching and Teacher Education* 17, 885-985.
- Foucault, M. (1972). *The archeology of knowledge and the discourse on language*. (R. Swyer, Trans.) New York: Pantheon.
- Foucault, M. (1977). *Discipline and punish*. New York: Vintage Books.
- Frank, A. (1995). *The wounded storyteller*. Chicago: University of Chicago.

- Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.
- Geertz, C. (1973). *The Interpretation of cultures*. New York: Basic Books.
- Ginott, H. G. (1972). *Teacher and child*. New York: Avon.
- Giroux, H. (1988). *Teachers as intellectuals*. Westport, Connecticut: Begin & Garvey.
- Goffman, E. (1963). *Stigma*. Englewood Cliffs, NJ: Prentice-Hall.
- Goldman, W. (1998). *The Princess Bride (25th Anniversary)*. New York: Ballantine Publishing Group.
- Greene, M. (1973). *Teacher as stranger*. Belmont, CA: Wadsworth Publishing.
- Greene, M. (1993). Diversity and inclusion: Toward a curriculum for human beings. *Teachers College Record* 95, 211-221.
- Hamann, E. T. (2003). Reflections on the field: Imagining the future of anthropology if we take Laura Nader seriously. *Anthropology and Education Quarterly*, 34(4), 438- 449.
- Hawthorne, N. (1850). *The scarlet letter*. Boston: Ticknor, Reed, and Fields.
- Heilbrun, C. (1988). *Writing a woman's life*. New York: Ballentine.
- Hobbs, W. (2004). *Bearstone*. New York: Atheneum Books for Young Readers.
- Holmes, D., Murray, S. J., Perron, A., & Rail, G. (2006). Deconstructing the evidence-based discourse in the health sciences: Truth, power and fascism. *Journal of Evaluation in Clinical Practice*, 180- 187.
- Hostetler, K. (1997). *Ethical judgment in teaching*. Boston: Allyn and Bacon.
- Hostetler, K. (2014). Beyond reflection: Perception, virtue, and teacher knowledge. *Educational Philosophy and Theory*, DOI: 10.1080/00131857.2014.989950.
- Hugo, V. (2002). *The hunchback of Notre-Dame (modern library classics)*. New York: Modern Library.
- Inglis, F. (2003). Method and morality: Practical politics and the science of human affairs. In P. Sikes, J. Nixon, & W. Carr (Eds.), *The moral foundations of educational research: Knowledge, inquiry, and values* (pp. 118- 133). Maidenhead, Berkshire, England: Open University.
- Kincheloe, J. (2003). *Teachers as Researchers*. London: RoutledgeFalmer.
- Kuhn, T. (1962). *The structure of scientific revolutions*. Chicago: University of Chicago.
- Labaree, D. F. (2010). *Someone has to fail: The zero-sum game of public schooling*. Cambridge, MA: Harvard University Press.

- Lageman, E. C. (2000). *An elusive science*. Chicago: University of Chicago.
- Latta, M. M. (2001). Letting aesthetic experience tell its own tale. *Journal of Aesthetic Education* Vol. 35, 45-51.
- Latta, M. M., & Wunder, S. (2012). *Placing practitioner knowledge at the center of teacher education: Rethinking the policies and practices of the education doctorate*. Charlotte, NC: Information Age Press.
- Latta, M., & Wonder, S. (2012). Investing in the formative nature of professional learning: Redirecting, mediating and generating education practice-as-policy. In M. Latta, *Placing practitioner knowledge at the center of teacher education: Rethinking the policies and practices of the education doctorate* (pp. 3-25). Charlotte, NC: Information Age Press.
- Levinson, B. A. (2008). Preface. In D. Stevick, & B. A. Levinson (Eds.), *Advancing democracy through education?* (pp. ix-xii). Charlotte, North Carolina: Information Age Publishing.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University.
- Linton, S. (2006). *My body politic*. Ann Arbor: The University of Michigan Press.
- Liston, D. (2004). The lure of learning in teaching. *Teachers College Record*, 459- 486.
- Longino, H. E. (1990). *Science as social knowledge*. Princeton: Princeton University.
- Longmore, P. (2003). *Why I burned my book*. Philadelphia: Temple University.
- Lorde, A. (1980). *The cancer journals*. Argyle, New York: Spinsters, Ink.
- Lortie, D. (1975). *Schoolteacher*. Chicago: University of Chicago Press.
- Mairs, N. (1986). On being a cripple. In N. Mairs, *Plaintext* (pp. 9-20). Tucson: University of Arizona.
- Mairs, N. (1994). *Voice lessons: On becoming a (woman) writer*. Boston: Beacon Press.
- Mairs, N. (1997). *Waist-high in the world: A life among the non-disabled*. Boston: Beacon Press.
- Manen, M. v. (1990). *Researching lived experience*. Albany: SUNY.
- Manen, M. v. (1991). *The tact of teaching*. Cave Junction, Oregon: Althouse.
- Martusewicz, R. A. (1997). Say me to me. In S. Todd, *Learning desire* (pp. 97-113). New York: Routledge.
- May, W. T. (1993). Teaching as a work of art. *Theory into Practice* 32, 210-218.
- Mayo, C. (2004). Relations are difficult. In C. Bingham, & A. M. Sidorkin, *No education without relation* (pp. 121-135). New York: Peter Lang.

- McDougal Littell. (2006). *The language of literature*. (A. A. al., Ed.) Evanston, Illinois: McDougal Littell.
- Mead, M. (1961). Questions that need asking. *Teachers College Record*, 63(2), 89-93.
- Meier, D. (2002). *The power of their ideas*. Boston: Beacon Press.
- Nader, L. (1996). *Naked science: Anthropological inquiry into boundaries, power, and knowledge*. New York: Routledge.
- Nixon, J., Walker, M., & Clough, P. (2003). Research as thoughtful practice. In P. Sikes, J. Nixon, & W. Carr (Eds.), *The moral foundations of educational research* (pp. 86- 104). Maidenhead, Berkshire, England: Open University.
- Noddings, N. (1988). An ethic of care and its implications for instrumental arrangements. *American Journal of Education*, Volume 96, 215-230.
- Noddings, N. (2012). *Philosophy of education*. Boulder, CO: Westview.
- Palmer, P. (1998). *The courage to teach*. San Francisco: Jossey-Bass.
- Postman, N. (1995). *The end of education*. New York: Vintage.
- Ravitch, D. (2010). *The death and life of the great American school system*. New York: Basic Books.
- Russell, S. J. (1997). The role of curriculum in teacher development. In S. N. Friel, & G. W. Bright, *Reflecting on our work: NSF teacher enhancement in K-6 mathematics* (pp. 247-254). Lanham, MD: University Press of America.
- Shapiro, J. P. (1993). *No pity*. New York: Times Books.
- Sikes, P., & Goodson, I. (2003). Living research: thoughts on education research as moral practice. In P. Sikes, J. Nixon, & W. Carr (Eds.), *The Moral Foundations of Educational Research* (pp. 32-51). Maidenhead, Berkshire, England: Open University.
- Sizer, T. (1992). *Horace's school: Redesigning the American high school*. Boston, MA: Houghton Mifflin.
- Sizer, T. (2004). *Horace's compromise*. Boston: Houghton Mifflin.
- Sizer, T. (2013). *The new American high school*. San Francisco: Jossey- Bass.
- Smith, D. G. (2006). *Trying to teach in a season of great untruth*. Rotterdam: Sense Publishers.
- Sontag, S. (1978). *Illness as metaphor*. New York: Picador.
- Steinbeck, J. (1963). *Of mice and men*. New York: Bantam Classics.

- Stengel, B. (2004). Knowing is response-able relation. In C. Bingham, & A. M. Sidorkan, *No Education without relation* (pp. 139-152). New York: Peter Lang.
- Varenne, H., & McDermott, R. (1998). *Successful failure*. Boulder, CO: Westview Press.
- White, B. (2011). The vulnerable population of teacher researchers. *English Education*, 321-340.
- Wiesel, E. (2006). *Night*. (M. Wiesel, Trans.) New York: Hill and Wang.
- Wilhelm, J. (2008). *You gotta be the book*. New York: Teachers College Press.
- Wolcott, H. F. (1992). The current boundaries and the future directions of ethnographic research. In M. D. Compton, W. L. Millroy, & J. Preissle, *The handbook of qualitative research in education* (pp. 1-44). San Diego: Academic.
- Zola, I. K. (1983). *Missing pieces: A chronicle of living with a disability*. Philadelphia: Temple University.