

A LIFE LIVED IN CLASSROOMS:  
A FEMINIST PERSONAL NARRATIVE

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A Dissertation  
presented to  
the Faculty of the Graduate School  
at the University of Missouri-Columbia

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In Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Philosophy

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by  
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MAY 2016

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## DEDICATION

Dedicated to my wife, who is my true partner in all that I have done and will do and helped make me who I am today. To my son Jack whose soft hands and quiet belief in me has never wavered. To my son Gus whose tiny fingers tiptoed across my feet as I typed, and to Greta who changed the way I see the world and who inspired this work. To the purple trees that brought me here. To the silence forced upon so many, and to the hope that one day we will be free to speak to truth.

## ACKNOWLEDGEMENTS

I would like to thank my committee; Jeni Hart, Rozanna Carducci, Jennifer Fellabaum, and Heather Carver. I would also like to thank those who served on earlier iterations of my committee; Rebecca Dingo, Casandra Harper, and Peggy Placier. Thank you to the faculty of the University of Missouri Women's and Gender Studies Department who assisted me along the way. I would also like to thank Jackie Litt who supported me as a professional and a mentor.

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LIFE LIVED IN CLASSROOMS:

A FEMINIST PERSONAL NARRATIVE

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ABSTRACT

This project offers a counter narrative to some accepted theories regarding graduate learning practices. By using Scholarly Personal Narrative to present my classroom experience I consider how knowledge is produced in higher education. I suggest that the use of feminist theory, postmodernism, and disability studies combined with other higher education theories may expand the limits of current graduate education. This project suggests that my story is useful to the field of higher education and graduate studies, and that by making intentional connections between higher education and feminist theory as well disability studies, new perspectives can emerge about how higher education practices regarding instruction, administration, and policy can be created.

## A Life Lived in Classrooms: A Feminist Personal Narrative

### **Chapter One**

All graduate students likely feel that they have lived a lifetime in classrooms. This is both false and true; false in the sense that statistically the vast proportion of students' time was not spent in a classroom when viewed cumulatively; true in the sense that while the classroom is often considered a place of learning limited to the subject at hand, other important life factors crept into that space. What a student is experienced in their life influenced their role from day to day.

This project offers a counter narrative to most widely accepted theories regarding learning that takes place in the classroom. In presenting my personal narrative of my classroom experience, I consider how knowledge is produced in higher education and suggest the use of feminist theory, postmodernism, and disability studies combined with other higher education theories and scholarly methods may expand the limits of the current graduate educational system. This combination moves toward offering a holistic learning experience for graduate students that values their lived experience in conjunction with their traditional studies, and sees them as having an integral role in the construction of wisdom. I will suggest that my story, by its very nature of being a feminist narrative that takes place in a higher education setting, is useful to the field of higher education as a model for how theory can become practice. By making intentional connections between higher education and feminist theory as well disability studies, new perspectives can emerge about how higher education practices instruction, administration, and creates educational policy.

### **Organization**

This project will be organized into five chapters. The first chapter will introduce my topic and methodology. I will outline the purpose and significance of this project as well attend to the history and the ways in which scholarly personal narrative functions in multiple academic disciplines at present, and influences perceptions of graduate student experiences and pedagogical practice. The following chapter will review the literature in the areas of postmodern feminist disability studies, with a specific focus on how these theoretical frameworks contribute to my understanding of graduate student identity as a mother; the two main identities explored in my project. I will draw on known contributions to the field, as well as contemporary analysis of best practices to use these theories in a higher education setting. The third chapter will discuss the methodology and methods of this project. The fourth chapter will offer the narratives of my personal experience that serves as the center of this project. The fifth, and final, chapter will discuss the findings of my project as well as consider the limitations of this project and make recommendations for future work and opportunities for further study in this area.

### **Purpose and Significance**

#### **Scholarly Personal Narrative**

In this scholarly personal narrative, I will examine my experience as a lesbian mother of a child with a disability and as a graduate student using a feminist theoretical framework. It will interweave my personal narrative with academic writing to achieve this goal and will use feminist theory as well as disability studies as lenses to contextualize this experience.



Scholarly personal narrative (SPN) is a research style that provides a narrative of one's experiences supported by scholarly work in the area. SPN is perhaps most written about by Robert J. Nash (2004) professor of College of Education and Social Services at the University of Vermont, and supports a structure where, instead of research questions guiding one's inquiry into a topic, constructs do. Constructs are large ideas cobbled together out of smaller less developed ones (Nash, 2004). This approach is considered to be postmodern, in that it is a research method that allows for multiple and conflicting truths. "SPN writing is 'true' when writers are honestly self-disclosing, and when they work hard to make personal meaning of the raw material of their day-to-day experiences" (Nash & Bradley, 2011, p. 17). As such, I will explain postmodernism, and in light of my own lived experiences and theoretical frameworks, postmodern disability studies in my literature review.

In Nash and Bradley's (2011) collaborative, *Me-Search and Re-search: A Guide for Writing Scholarly Personal Narrative Manuscripts*, they explain the important distinction between scholarly personal narrative, autoethnography, and memoir. According to Heewon Chang (2008), a specialist in the field of autoethnography, SPN is a "methodological cousin" of autoethnography (p.13). In Chang's *Autoethnography as Method*, he describes autoethnography as "a qualitative research method that utilizes ethnographic methods to bring cultural interpretation to the autobiographical data of researchers with the intent of understanding self and its connection to others" (p. 13). In his forward in Nash and Bradley's work, he states that SPN shares the practice of "self-reference and sound scholarship" but what SPN does differently is "to integrate scholarly discourse and content into the self-narrative, which autoethnographers have neglected"

(p. ix). That is, autoethnography uses some similar methods, but SPN is unique in its fusion of scholarly work into one's narrative.

In considering memoirs, there are also some attributes of SPN that differentiate it from this narrative style. Vivian Gornick (2001), a writing specialist, calls memoir writing “a mining of the memory” (p. 24). This means that memoir relates past events, people, and other information with a lens of strong personal feeling guiding the writing (Gornick, 2001). SPN is concerned with the writer identifying larger themes and insights that are more universalizable for readers, and more importantly connecting these themes to academic ideas and theoretical locations (Nash & Bradley, 2011). This makes memoir a style where personal narrative is certainly present but is devoid of the scholarship essential to SPN. Having differentiated SPN from other similar styles, it is important to note the increased acceptance and potential for contributions to education that SPN offers.

Nash and Bradley (2011) recognize a shift in the acceptance of SPN at all levels in the academy, noting that “throughout the entire academy with few exceptions, and traditionally where any type of innovation has been tediously and glacially slow, more personal forms of writing are finally starting to take hold” (p. 4). Nash and Bradley note that to accept SPN as a valid method it requires one to reject the “authoritative other” that is the current measurement of successful research. More specifically, this means that good research is often measured by its alignment or support from existing research in the same, or similar, field. Nash and Bradley state, perhaps overly critically, that this fixation of expertise creates writing that is “disappointingly flat, uncreative, and impersonal” (p. 56). Putting aside the partisanship of those who advocate strict

impersonal research versus “vulnerable writing” (Nash & Bradley, 2011) of narrative styles, the idea that research is informed by the personal connects well to the theoretical frameworks guiding this project, and as such has value in this individual context as well as value in expanding education research to include diverse research methods.

Personal narrative, characterized by its sustained narrative prose style, has value to the educational process. It allows higher education educators and practitioners to think about our various social identities, and in doing so, rely on the conspiratorial, or more simply, personal aspects of scholarly personal narrative. It is important to note that personal narrative exists, and has existed, in the various higher education settings, both within other disciplines and fields, as well as higher education research itself, for some time. While perhaps not named explicitly so, there are a number of locations in education where evidence of personal narrative and/or some components of the style occur. Stephen Brookfield (1995) suggests that finding opportunity for “sustained autobiographical reflection on learning” (p. 51), should be a requirement for becoming a critically reflective teacher, and connects one’s understanding of autobiographical learning experiences makes one a more effective teacher. Thus, as learners we learn through the stories told by our teachers, and as those producing knowledge, we do so more effectively when we are aware of how we were able to absorb information ourselves.

In my project, I work to deconstruct ideas with (somewhat) concrete meanings like *student*, *educator*, *disability*, and *truth* to argue they have fluid meanings. This is significant in my personal work towards vulnerable writing and also has real-world implications for how we understand the lives of graduate students. These implications

extend to how we experience the classroom as a student and as a teacher and can help purposefully make changes to graduate teaching and knowledge production. It is important to note that these ideas/terms/identities have not gone unexamined and have been considered, as both fluid and fixed entities by a number of fields and disciplines, specifically regarding the changing identities of college students and faculty (Brown, et. al, 2007, p. 6). This project is specific to the lived experience of graduate students and the ways in which that experience can be integrated into graduate instruction and socialization. In reflecting on the influence of scholarly personal narrative in education, it is helpful to define how I understand education in this project.

### **Goals of Higher Education**

When considering the goals and characteristics of doctoral degrees in the field of higher education, Richardson (2006) asserts that these degree holders are stewards of their field and as such should be “able to generate new knowledge, understand the intellectual history of the field, use the best ideas and practices in current work, and represent that knowledge to others, both within and outside the field” (p. 251). But, what is complicated about this seemingly reachable goal is agreeing upon a universal understanding of the study of education (and within education, the study of higher education specifically). Some, as Richardson notes, consider education a field as it “borrows from and combines with other, more traditional, disciplines and often focuses on practice” (p. 253). Klien (1990) suggests thinking about higher education as an *inter-discipline*, with its “means of solving problems and answering questions that cannot be satisfactorily addressed using single methods or approaches” (p. 196) as the identifying characteristic that places it beyond a field and not quite a discipline.

For this project “education” as a clearly definable term is not as important as the idea of the inclusivity of it. More specifically, whether the term *field* or *discipline* is used does not change the work being done within education, but using Klien’s (1990) interdisciplinary way of thinking about education does allow one the space to push at the boundaries of accepted ideas of knowledge production and as such fits with my use of the term in this project.

Understanding the diversity of the way *education* is used by scholars, and clearly outlining my acceptance of a diverse definition that allows for the inclusion of many methods and approaches allows this project to expand higher education scholarship through the addition of other theoretical lenses, such as feminist theory, disability studies, and postmodernism while still operating in the (loose) confines of the field. Scholars in education, along with other social and behavioral sciences and the humanities, have attempted to understand identity-based terms such as *student*, *parent*, *teacher*, *learner*, with their own lenses and inquiry methods. It is significant that we recognize the societies in which we inhabit have powerful methods of defining identity-based words and have accepted performances associated with each; and that these performances vary by culture and, as such, are socially constructed (Berger & Luckman, 1966). The term *performance* is used in this project to describe social identities as a way to indicate that these identities have an accepted technique of actions and ideas created and governed by dominant culture. Judith Butler (1993) explains performativity in relation to social identities as “that reiterative power of discourse to produce the phenomena that it regulates and constrains” (p. 3). That is, performativity of social identity has a hierarchical power dynamic that regulates our social interactions.

Using multiple lenses as well as my own experience allows me to put forth a nuanced understanding of education and knowledge production that both considers the history and functionality of the graduate classroom, teaching methods, and socialization while also exposing the gaps in these processes. This does not mean that in doing so will yield a seamless blending of positions and perspectives that will result in a neat conclusive theory, rather that the tensions and frictions among and amongst these locations will be the site where innovation around integration of graduate student lived experiences can potentially occur and new pedagogical and practical recommendations can be constructed.

### **Learning and Identity**

Reviewing literature devoted to the art of teaching in a college classroom, the majority focuses on students learning potential, cognition, and retention of knowledge (Nilson, 2010). Regarding student learning, David Kolb (1984) charts how students learn in his Student Learning Inventory (SLI).

The experiential learning cycle, starting with concrete experience (CE), working through reflective observation (RO), abstract conceptualization (AC), and ending with active experimentation (AE). Individual students' learning cycles may start on any of the four poles and proceed in any direction, not necessarily circular, indicating a preference for a particular order of cognitive processing. (p. 17)

Put more simply, this formula for teaching deep learning insists that "a mind that is stretched by a new experience can never go back to its old dimensions" (Villaverde, Godoy, & Amandi, 2006, p.197). This project incorporates these important ideas about traditional learning but also considers how learning that takes place outside the

classroom, and may be specifically unrelated to a specific education subject, can also be of value. To be fair, Kolb (2006) does not distinguish where learning takes place, thus learning outside the classroom could be included in his SLI theory, but because it is created to assist educators in creating a classroom experiences that encourages deep thinking its performativity generally becomes linked to the classroom. Where my project diverges, but still very much appreciates this approach, is in the students' entry into learning. This project begins with the belief that students', and specifically graduate students', lived experiences outside of, and during class, have equal value and influence on their learning, perhaps even so much as to shift their preferred ways of learning mid-class. This requires dismantling of the idea that the classroom can be separated from other aspects of one's life, which is often the subtext of literature about teaching and as such is not a deliberate omission in higher education research rather an unintentionally neglected area where more research needs to be done.

Higher education research begins to address student learning holistically with higher education theories named as student identity models (Nilson, 2010). William G. Perry (1968) initiated this way of thinking about student development insisting students move from duality to multiplicity to relativism to commitment, with the help of good instruction (p. 71). The reliance on progression from one place to another intellectually limits the impact of life experiences on a student's understanding of a subject. It values students' lived experience insofar as it relates to them as learners but does not articulate a reciprocal appreciation for how students' lived experiences could enhance the classroom and teaching as well. Rather these identity models work to help educators assist students in learning increasingly complex ideas with the classroom and method of instruction as

responsible for students' successful progression from a lower level of understanding (whether of identity or specific knowledge) to a higher one (Brown, Hinton, & Howard-Hamilton, 2007).

Higher education scholarship has focused on ways to integrate student identity in learning; consider Fink's (2003) categories of learning. Created in response to hierarchical taxonomies of learning that reinforced the from/to binary (Bloom, 1956), Fink (2003) insisted,

for learning to occur, there has to be some kind of change in the learner. No change, no learning. And significant learning requires that there be some kind of lasting change that is important in terms of the learner's life. (p. 3)

These moments of learning and change are not sequenced in a hierarchical way and the resulting taxonomy of significant learning created by Fink (2003) is instead relational and interactive. Models like Fink's (2003) attend to the progression of students' "intellectual and ethical development" (Nilson, 2010, p. 8) and in doing so give teachers insight into individual intersectional identity formation. Brown, Hinton & Howard-Hamilton (2007) suggest that student development theories should be a first step in understanding the complexity of students' contributions to knowledge, but incorporating of other theoretical perspectives, specifically feminist theory and disability studies theory, is necessary to further understand how knowledge is produced in the higher education classroom.

Howard-Hamilton (2007) explores how using social justice based theories can help "professionals working in higher education to understand how the organization, environment, and behavior of the person all intersect to create a dynamic climate that can be compatible or clash with others in the institution" (p. 15). This goes beyond identity



models that could potentially be used to categorize students' lived experience as a phase in a continuum instead of an authentic location with long-term value. For example, if we juxtapose William Cross's (1995) Psychological Nigrescence theory with feminist theory we create two very different educational spaces. Nigrescence theory (Cross, 1995) defines the process of affirming a Black identity by moving through stages from self-hatred to self-acceptance whereas feminist theory challenges dominant masculine created narratives and encourages the acceptance of counter-narratives that include anger, resentment, and challenging of the dominant gender discourse.

The first stage of Cross's (1994) identity model is dependent upon students, or learners, to move beyond anger, to a place of comfort with their identity. The second lies in a place of (potentially) persistent unrest. In the first space students would be seen as stuck and thus their contributions able to be disregarded if they came from a place of anger, or exhibited the visible markers of immersion in Black culture. In the second, persistence in engaging with the inequity in a way that may appear angry or women-centric would be acceptable. The difference lies in the arguably imperceptible messaging that a student identity model expects some resolution. Much like westernized notions of grief (see Elisabeth Kübler-Ross's (1969) model of grief), teachers await a transition from a place of unrest to a place of consistency as a sign of progress or knowledge retention. By infusing higher education teaching and practice with social justice theoretical locations that do not infer intellectual stagnation, great impact can be made in the field. This, however, does not mean that all educational boundaries need to crumble, rather that it is not enough to consider what students identity means for individual student learning, but rather what it means for teaching as well.

To that end, some of the most socially just based work of higher education research is in dismantling the classroom divide between students and their lived experience (Baxter Magolda, 2009). These efforts often incorporate narrative and scholarship; that is, they work to understand not just how students learn but how they live their lives. Rebekah Nathan (2005), in *My Freshman Year: What a Professor Learned by Becoming a Student*, offered higher education practitioners a better understanding of what motivated seemingly baffling student behavior (e.g., lateness, not completing readings, sleeping in class) by exposing the pressures of the working class student body who now occupies classrooms. She detailed the competing needs of working, arranging for transportation, feeling isolated, and other life factors that influenced how students learned and approached the classroom. Her work made a connection between the lived experience of students and their classroom behavior.

Though Nathan's (2005) book primarily functioned to help educators understand the generation of students stereotyped as apathetic and lazy, it worked to legitimize the value of narrative, personal experiences, and students as capable of having outside lives that invariably bleed into the classroom. The reception of Nathan's work as pop-education that advocated for a shift in higher education to embrace the "anti-intellectual or as acquiescence to market-driven values" (Deans, 2009, p. 496), illustrates the discomfort the academy still has in regard to personal narrative as research as well as resistance to pedagogical recommendations to address the classroom/life divide. Some audiences viewed her work not as narrative, but as ethnographic research. Some also publically balked when she asserted that her findings should have implications for teaching.

When Nathan does step outside the participant-observer frame, and sum up the ways she has changed her teaching, the book plunges from merely banal to depressing. She explicitly advocates adopting her students' perspective on what an appropriate amount of reading is, for example, or on whether it's reasonable to expect students to remember the previous class's material. What's frustrating is that, rather than showing average students how the most successful students are frequently the busiest—the ones, that is, with the most extracurricular demands upon their time—she simply validates their feeling.

(Jones, 2006, p.1)

Nathan's scholarship could have allowed practitioners and researcher to consider the magnitude of students' outside life and influence on future pedagogical trends. The dismantling of "separate spheres," where it is assumed that one's "social world is organized around contrasting and incompatible moral principles that are conventionally linked to either public or private: community vs. individual, rationality vs. sentiment, money vs. love, solidarity vs. self-interest" (Gal, 2004, p. 261) is necessary to make progress in this type of research. This is part of a Western dominant world view. However, while there exists a belief that "these values are antagonistic" (Gal, 2004, p. 262), there also exists evidence that this is not the case and as a result there are locations where these spheres have merged in the world of research. This project works to pick up on those merged spaces and advance the infusion of other social justice based lenses, feminist theory, disability studies, and postmodernism, specifically, to create a space where higher education work like Nathan's (2005) can be seen as a contribution rather than a threat.

Moving towards a more integrated identity of multiple selves, Baxter Magolda's (2004) work on self-authorship recognizes the importance of including multiple identities as well as sources of learning in students. Self-authorship is an individually driven method of learning where "the capacity to internally define a coherent belief system and identity that coordinates engagement in mutual relations with the larger world" (Baxter Magolda, 2004, p. xxii). This is considered to be an integrated theory of college student development. Self-authorship asks the student as well as the teacher to consider basic philosophical questions such as "who am I" and "how do I know who I am" (p. 14), leading to the conclusion that knowing one's self should be the goal of all education. More recently, Baxter Magolda (2011) asserted that the educator's role was to help students allow their "internal voice to move to the foreground" (p. 11).

Vicky Gunn (2009) writes that faculty resist the idea of a student's life and a teacher's life influencing their classroom experience. Commenting on Baxter Magolda's (2004) suggestions that students' lives are intertwined with their classroom experience, Gunn (2009) states,

We need to consider our personal resistances to Baxter Magolda's views. Put frankly there are two key areas for resistance: (i) she's linked the intellectual with the personal, asking us to be both involved in the development of a broader range of capabilities and provide different types of learning environments to those we might consider as the norm within our discipline; (ii) she's an educationalist. (pp. 171-172)

Gunn teases out the exact struggle higher education scholarship has with integrating learning that takes place in the individual, influenced by their lived experience, and that takes place outside of a formal classroom setting.

By valuing both the lived experience and classroom experience equally, the standards of higher education become disrupted. Baxter Magolda (2011), and those who value and expand upon her work, take important steps to further education to appreciate students' lived experiences and integrate it into knowledge production. However, in doing so, the boundaries of higher education instruction become blurry. If the performativity of *student* changes to no longer require *teacher* it suggests a strong challenge to higher education teaching methods.

For this project, I documented my constant changing as learner over time as a graduate student in education. I worked to build upon the *internal voice* (Baxter-Magolda, 2011) of the student and consider what influence it has on learning when that voice was lost, unknown, or even unrecognizable to the student to which it belongs. In addition I used a postmodern disability studies lens to think about the learning experience. I moved one step further from the valuation of my internal voice to suggest there may indeed be more than one internal voice; one that changes; one that may produce the opposite of a learning partnership model, and instead created an antagonistic relationship with knowledge.

### **Feminism, Postmodernism, and Disability Studies**

Feminist theory, has interrogated the idea that the students' personal experiences can be separated from their classroom learning with the use of the idea that the personal is political and as such has "made these dichotomies the center of its project of critique"

(Gal, 2004, p. 262). The personal and the political becomes further deconstructed in feminist theory where both are argued to be manufactured identities

For Butler, the distinction between the personal and the political or between private and public is itself a fiction designed to support an oppressive status quo: our most personal acts are, in fact, continually being scripted by hegemonic social conventions and ideologies. (Felluga, 2006)

Joan Landes (2004) also wrote that for scholarship, the “line between public and private is constantly being renegotiated” (p. 3). I will refer to this imaginary line separating the public and the private as an artificial divide. It becomes all the more ideological rather than operational when we consider how the concept of separate spheres functions in the classroom. Physically the separation of being in different spaces when learning and living lends itself to a distinction; and I believe dismantling the artificial divide can be beneficial to transformational learning.

There is also philosophical support for the notion of self-examination as valuable for the individual as well as the collective, or the student as well as the class (Baxter Magolda, 2009). Just as feminist theory recognizes a fluid self in constant need of renegotiation of public and private in one’s learning, noted philosophers adopt an unstable view of self as well in a postmodern understanding of educational development.

For example, Foucault (1988) wrote in his later years about care of self, a revolutionary idea that extends beyond what we think of as physical self-care and instead offers a charge for humans to constantly practice cognitive and physical development within themselves. This supports the exploration of one’s own story as a way to further self-understanding and through that interrogation, the world. It then becomes a charge to

understand the self to be a better teacher, to allow students to understand themselves as better learners, and allow the efforts of each to coalesce in the classroom.

Moving from Baxter-Magolda's (2011) acknowledgement of the value of self and really the *presence* of self, the combination of feminist theory and postmodern philosophy encourage education to traverse a classroom where self is under constant change. Feminist theory complicates this view of knowledge production that relies upon performative social identities of *teacher* and *student* that take place in a classroom designed for learning. Complementary to feminist theory is disability studies, which inserts a physical manifestation of self that is often counter to the typical, to this new education framework.

Academically, disability studies views the condition of having a disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy (Garland-Thomson, 2001). The fundamental premise of disability studies is that disability is a culturally fabricated narrative of the body, a system that produces subjects by differentiating and marking bodies (Garland-Thomson, 2001). What is meant by the term *subjects* is that individuals get grouped into categories of normal and not normal, abled or disabled. Brenda Jo Bruggemann (1999) explains further that "in the way Derrida has taught us, the concepts of the 'normal' body and the 'disabled' body variously supplement, contradict, hold up, and cancel out each other. One simply does not exist without the other" (p. 3). By insisting the body and its multiplicity resides in the classroom as well, disability studies resists the artificial divide of the classroom and one's life by its very corruption of expertise as the person with the disability is the authority of their body not the instructor

of the course. Gathering these theories that often lie in other academic locations and applying them to higher education research, creates a vast opportunity for higher education to become an *inter-discipline* as Klein (1990) insisted it must.

In the contemporary classroom a postmodern feminist disability studies research approach helps further research as a form of resistance where according to Fairn Herising (2005)

The movement away from established places of knowing, and embarking on/engaging in research as a process whereby we are confounded and dislocated, where there are no easy answers or even “successful” research outcomes, or where we fail to map the start and endpoints of our linear research processes, where we are unable to find language, may indeed be the very knowledge and ultimately the learning we require in representing ourselves. (p. 290)

That is, interrogating the methods of teaching and learning is a naturally disorienting process. It requires higher education practitioners to move away from traditional models of achievement and instead redefine success in ways that challenge years of socialization. As noted above, higher education is moving ever closer to making this leap. Going back to Virginia Richardson’s (2006) assertion that education doctoral students should be stewards of promoting change and improvement in the field, this project is attempt to do just that.

### **Limitations**

It is important to discuss the limitations of creating a research study in this way. Though I will address this in much more detail in chapter 5, I am asking the reader to believe my interpretation of events by employing a personal narrative style, and as such I



am taking a risk regarding my credibility, that my story may or may not be believed. Finally, perhaps the biggest limitation of this study is that it has no beginning and no discernible end (as would a traditional qualitative or quantitative project), and can produce no reliable fact on which to rest a new theory or prove anything unequivocally. However, I suggest that the positivity produced by scientific methodological research is limiting in its rigidity, whereas the freedom to produce knowledge without tethering it to a replicable theory is liberating.

Perhaps a limitation of all qualitative research, that ambiguity and call for further research become the inevitable conclusion, exists in this study as well. A potential outcome of this project will be for increased awareness regarding the complexity of knowledge production. More specifically, it will suggest that current epistemologies of higher education become more holistic and inclusive by explicitly valuing the lived experience of students. Borrowing theoretical frameworks of postmodern feminist disability studies allows for my personal narratives to engage with the way in which graduate learning, teaching, and socialization are performed and illustrate the places where valuing lived experiences would be beneficial. I will also suggest new that new possibilities for pedagogical, administrative, and socialization practice; becoming comfortable with a lack of resolution; as well as sitting with unrest as a field is in itself important. Naturally, this process comes with some assumptions as well.

The assumptions of a scholarly personal narrative dissertation speak back to the limitations of this study, as we must assume that I am recounting what I know, or knew at the time, to be true. Poking holes in the very idea of truth as an inherently false construct makes this evermore challenging, but the reader should assume dates/times/places to be

*true* to the best of my knowledge. Further I invite the reader to engage with my truth using the postmodern feminist disability studies lens I myself use, which lends itself to seeing the experience of the individual as useful to the collective.

### **Definition of Terms**

For the purpose of this study the term *postmodern* will refer to the idea that truth is not a concrete absolute but rather a created and blurry narrative that differs for each individual. As Robert J. Nash (2004) states, “we made up all our truths, lock, stock and barrel...we believe the truths that we need” (p. 33). Most specifically truth in education has had a very specific function that translates into administrative and governing principles that produce great limitations on educational research,

Educational studies of time are rooted in modernist conceptions of segmentation and linear progress. These conceptions assume that isolated parts of complex systems (like schools, people in schools, or curriculum) can be divided into coherent and cohesive segments (like grade levels, control groups, or subject matter disciplines) and measured quantitatively without contamination. (Slattery, 1995, p. 612)

This study will use the term *feminism* to refer to a social movement that works to dismantle the interlocking systems of oppression such as sexism, racism, and homophobia. Feminism comes in many shapes, sizes and permutations, and for the purpose of this study when I use the term *postmodern feminism* I use it to mean that notions of women, whether biologically based or socially created, are impossible to extricate from other aspects of one’s identity and thus the subjugation of women has many causes and many layers (Butler, 1990, p. 12).

This study will use the term *motherhood studies* to refer to an emerging field of study housed loosely within women's and gender studies, sociology, and the humanities that examines and critically engages with the way motherhood is constructed in our various societies. The scholarship of this field will be used primarily in my personal narrative. According to Anita Iltis Garey (1999), popular culture tends to study women exclusively when considering caregivers of children, and most often focus on working mothers, "the general image of mother in popular magazines is of the professional or corporate woman, briefcase in hand" (p. 4). Garey's research illustrates how the media masculinizes mothers who participate in the labor force and rarely make room for interrogating the powerful cultural structures that reproduces these ideas and normalize them within our culture. Motherhood studies encourages questioning of traditional ideas of motherhood (their roots, their functions in society, their link to female subjugation, and their attachment to power and privilege) and offers counter-narratives to popular parenting literature and can be considered at the very least, loosely related to feminism if not outright feminist in nature. My identity as a mother is a large focus of my personal narrative scholarship that falls between feminist theory and motherhood studies and will be represented in my SPN.

This study will also use the term "disability studies," which refers to an academic field that looks at disability from an historical lens, but more importantly for the purpose of this study, challenges the notions of ability and disability and calls for a more nuanced understanding of the body and mind that moves away from a hierarchy of normalcy and stigmatization (Garland-Thomson, 2001). Disability studies removes normal from the center of standardization and in doing so creates spaces where bodies and minds no

longer strive to reach a universally agreed upon performance of mastery. More specifically, instead of neatly dividing the world into “able” or “disabled,” disability studies skews the idea of normal and asks that we consider how each person is comprised of different abilities making a classroom highly individualized.

Whenever the “normal” spontaneous body sense is invoked, we need to keep in mind that this sense operates along something like a continuum with multiple axes. Even in “normal” people the intentional arc of perception and motion that we take as universal and foundational to thinking is often, in reality, awkward, incomplete, or flawed. (Leach & Scully, 2008, p.95)

Disability studies is also critical of the medical model of disability and while it acknowledges the usefulness of medical technology, it seeks to change the perceptions of ability versus disability so prevalent in medical and other care giving fields (Snyder & Mitchell, 2006). Disability studies, much like feminist theory works to connect theory to practice as often as possible.

### **Summary**

This chapter introduced the theoretical framework this study will employ and also asks one to think about the meaning of terms and identities such as *woman*, *truth*, *teacher*, *learner*, *knowledge*, and *disabled*. This chapter has established that I will combine personal narrative and traditional academic writing, a style known as scholarly personal narrative, to complicate the idea of knowledge production and move toward a field of education that is inclusive of personal experience in its pedagogy and practice. In the next chapter, I will review the current literature in the areas mentioned above, as well as research devoted to graduate student identities, and note where they converge and

diverge. I will provide an understanding of postmodern feminist disability studies as well as motherhood studies, and outline how all these lenses can be used together in new and innovative ways to think about higher education graduate instruction and administration. As well as how the identities of graduate students can incorporate multiple selves, which can contribute to advancing higher education.

## Chapter Two

### Review of Literature

Reviewing literature that uses a postmodern feminist disability lens to examine motherhood, graduate student experiences, or even higher education is complicated. Even feminist writers are typically multidisciplinary, rather than interdisciplinary, in their approach to any given topic (e.g., Lauri Umansky [1996], Sharon Hayes [1996], Josephine Donovan [1992]). That is, they look at mothering or disability from feminist perspectives, but rarely do they blend motherhood studies with disability studies in an interdisciplinary analysis that explores the intersections and tensions between all areas: feminist theory, motherhood studies, and disability studies (Bordo, 1995). The same can be said for postmodernism, which historically is applied to an existing framework or academic discipline to enhance or further complicate this location regarding the consideration of truth production. Consider philosophers like Lev Semyonovich Vygotsky (1961) or Ursula Guin (1990) who use postmodernism in its traditional iteration within philosophy to further obscure one location; human nature, existence, pain. The social identity of graduate students, which if addressed, is typically relegated to the higher education-specific scholarship, where postmodern feminist disability studies has some influence (especially when used as individual theories and in contemporary work) but is rarely used as an overt lens.

Additionally each of these theoretical locations employs different styles. One would likely find narrative and memoir in motherhood studies, which is populated by collections of creative non-fiction and poetry in anthologies such as *My Baby Rides the Short Bus* (2009), *Love You to Pieces* (2008), or memoirs such as Rebecca Walker's

(2007) *Baby Love: Choosing Motherhood After a Lifetime of Ambivalence* or Peggy Orenstein's (2007) *Waiting for Daisy*; traditional academic writing in feminist theory; and perhaps both in disability studies (e.g., Barbara Hillyer [1997], Rosemarie Garland Thompson [2001], Brenda Jo Brueggemann [1999]). Postmodernism is steeped in scholarly philosophical style (see Derrida (1967), Butler (1995, 2004), Foucault (1975, 1988) as examples). Education often includes pedagogical research on student learning, case studies, and recommendations for policy change. All of these approaches use different research methods, from quantitative studies to qualitative analysis, making integration an effort on the part of the reader to reconcile the differences and allow one to imagine these different, and at times divergent, theoretical and methodological locations existing within the same framework.

This literature review will offer a review of feminist theory, disability studies, postmodernism and motherhood studies to offer a postmodern feminist disability studies understanding of motherhood, with specific attention paid to graduate student mothers. This review will then uncover the locations where these theoretical foundations conflict with one another as well as places where their infusion is logical and furthers a theoretical fusion. Finally, this review will offer some suggestions for ways in which these theories can be combined in hopes of creating a more sophisticated understanding of graduate student mothering, which will be offered as recommendations for new approaches to classroom pedagogy, administrative procedures, and other locations for research in the final chapter of this project.

While this progression through theories seems linear, with each lens or area of inquiry building upon the one before it and informing the narrative of my project, in

actuality it is much less so. It may be more accurate to consider these areas of thought as intersecting with each other in numerous and diverse ways. While each lens or discipline will be presented as separate, I put forth that they are continuously engaging with and informing each other in my project.

### **Feminist Theory**

Feminist theory has an interesting history. It is important to consider feminist theory as varied and capable of great nuance. It is not a theoretical lens that can be applied in a monolithic way; rather at its simplest, it uses gender as a valid and necessary category of analysis. According to Wiegman (2002), a feminist scholar who studies applied feminist theory, feminist theory is often associated with women's and gender studies, which itself is frequently considered the academic off-shoot of the women's movement of the late 1960s and early 1970s. Women who identified as activists added to the political/civil rights model of policy change most prevalent at the time and created an academic location where the subjugation and discrimination of women could be studied, typically known as women's and gender studies, feminist studies, or women's studies (Wiegman, 2002).

Women's and gender studies had a somewhat long road to standard acceptance in the academy, and still experiences struggles with legitimacy (detailed later in this section). The first women's studies program was created at San Diego State University in 1970 (Buhle, 2000). Grassroots women's movements across college campuses were the initial inspiration for women's studies programs, as female faculty began to form organizations and/or committees to discuss the discrimination facing female faculty, and by extension women students, and the masculine dominated curriculum by which they



felt constrained (Buhle, 2000). The University of New Mexico, under the leadership of Mimi Reisel Gladstein, in 1971 began to organize a women's studies program when she and other women faculty discovered the levels of unfair compensation and curricular bias in their English department (Gladstein, 2000). Portland State University followed in 1972, as they became interested in creating a women's studies program after a preliminary research project uncovered deep frustration with the limitations of the curriculum in their own departments (Porter, 1972).

As physical programs were created across the country, literary and periodical publications were founded to reflect the new outpouring of scholarship. *The Feminist Press* was founded in 1972 by Florence Howe and Paul Lauter, which quickly gave way to *Women's Studies Quarterly*, *Feminist Studies*, *Women's Studies*, and *Signs*, all peer reviewed academic journals that continue to circulate today (Buhle, 2000). Likewise, the responsibility for the creation of a curriculum for these newly created courses was placed into the hands of the creators. As Electa Arenal, founder of the women's studies program at Barnard College, discovered when trying to create syllabi for her newly created courses, "there was a desperate lack of varied role models for women in our society," the task to create the articles and books to use in classes fell upon the women who were creating these new courses (Arenal, 2000).

This literature gap allowed for the creators of women's studies programs to shape a collective feminist pedagogical understanding of women's studies as a subject in the academy. Although certainly each text and article is as varied as the author, and there is room for any number of existing and emerging theories, there now exists an arguable acceptance of women's studies in the academy, though contemporary debate still

occasionally flares such as a recent attack on women's studies departments and programs by David Horowitz in his 2007 book, *Indoctrination U: The Left's War Against Academic Freedom*. Another example being the 2010 effort to eliminate women's studies and a women's research center at Florida Atlantic University amid budget cuts) (Arocho, 2010). Additional critiques such as Ellen Messer-Davidow's (2002) *Disciplining Feminism* suggest that the entrenchment of women's studies in the academy proves its divorce from its activist roots. The institutional legacy of women's and gender studies is one that has fought for its place within the academy and has proven both its need and its purpose through contributions to academic scholarship.

Feminist theory, the theoretical lens employed in women's studies, has also gone through many changes since it first began. Perhaps the most notable is the creation of many different critical areas of study that complicate the idea of the shared identity of "woman" (Herndl & Warhol, 1997). One of the biggest influences in the deconstruction of the notion of shared identity is postmodernism, or more specifically postmodern feminist theory, which will be explained in detail later. These different critical areas do not exist merely to criticize mainstream (or original) feminist theory, but rather to recognize that identity includes a broad spectrum of cultural categories. It would be more accurate, according to feminist theorist Josephine Donovan (1992), at present to talk about feminisms rather than one feminism. This understanding has led to the creation of Black feminist theory, lesbian studies, Latina studies, disability studies and others (Donovan, 1992, p. 2). Using feminist theory alone one can say human identity is "multiple and unstable" but infusing it with another lens that is dependent upon one's

social status or perceived identity makes it a useful tool when trying to understand the “experience of individual humans in a complex world” (Garland-Thompson, 2001, p.16).

### **Disability Studies**

In thinking about U.S.-based disability studies, it helps to consider the history of disability and how it has functioned in Western society in order to define it. Beginning in the late 1960s, and perhaps peaking in 1990 with the passage of the Americans with Disabilities Act, which required both public and private sectors to accommodate what we think of as people with disabilities, disability itself was recast as a civil rights issue in the United States. The academic offshoot of disability activism and policy reform is disability studies (Snyder & Mitchel, 2006). The first degree program in disability studies was offered in 1998 at the University of Illinois (Snyder & Mitchel, 2006). Currently, much as with women’s studies, there are degree options in disability studies, as well as a rich and thick body of work regarding the history, theory and application of it as a discipline (Snyder & Mitchell, 2006). While disability studies’ origins can be likened to sociology (Garland-Thompson, 2001), it has recently taken up residence in the humanities where it “undertakes a radical critique of disability” (p. 1) that asks readers to consider what makes a person disabled, or even more broadly, what makes a person a human.

Academically, disability studies views the condition of having a disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy (Garland-Thomson, 2001). The fundamental premise of disability studies is that disability is a culturally fabricated narrative of the body, a system that produces subjects by differentiating and marking

bodies (Garland-Thomson, 2001, p. 14). What is meant by the term *subjects* is that individuals get grouped into categories of normal and not normal, abled or disabled. “The properties of bodies are supposed to be pre-social. Socially constructed interpretations and assessments of neutral corporeal properties consign people with various kinds of bodies to advantageous or detrimental social roles” (Silvers, 2007, p. 275). To further explain disability studies, it is helpful to think of a narrative, or story, of one’s body being authored by an outsider, that is, someone other than them self. This narrative is subject to the mainstream social standards of the world in which the individual lives and once it is written it is placed on a spot in a hierarchy and given assigned status based on how far from “normal” one falls. Disability studies uses the *ethnicity model* (Garland-Thomson, 2001, p.1) to reframe the idea of disability by placing it into a social context to show that the difficulties that people with disabilities face are a result of the cultural environment that is created to oppress them and not necessarily the failing or ill health of their physical bodies.

Imagine a continuum with normal in the most coveted location and with all people with a perceived disability placed somewhere below normal based on what an outsider (in most cases the dominant society) perceives as the severity or distance that they fall from normal. This is problematic for a number of reasons. Perhaps most importantly because *normal* is nearly impossible to define and is culturally specific, that is, *normal* varies from culture to culture (Garland-Thomson, 2001). Additionally, this way of thinking about bodies as abled or disabled makes the embodiment of disabled bodies political.

Take, for example, the case of disability itself. Disability is not an absolute, not the (im)pure and physically evident “other” to ability, normalcy, completion. We have constructed a binary between disability and ability/normalcy. The construction, as all cultural and categorical constructions are, is rhetorical; and here I mean rhetoric as something more than just a critical tool...it is not so much that people are disabled- a passive portrayal of some “others” out there beyond our own bodies- but that they are us; moreover, they/us, quite actively are involved with a politics of disablement. (Brueggemann, 2006, p. 3)

But even with a perfect definition that considers body diversity is the writing of one’s body narrative by an outsider and the constant comparison to this shimmering standard of *normal* for which people with disabilities fall short. “Disability studies demands a reckoning with the messiness of bodily variety” (Garland-Thompson, 2001, p. 10). Disability studies asks for a complete re-write of the body narrative, one that does not end with a place on the hierarchy between normal and not, rather one that addresses our discomfort with difference but does not attempt to normalize or fix it.

Higher education has taken a stance on disabilities that is more closely aligned with the medical model. The medical model, though it does contain variation, “is that disability is a nominative pathology; a defect or deficit located in the individual,” (Scully, 2008, p. 25) one that is in need of being repaired. Strauss and Sales (2010) write, “historically, disability services was administered and staffed by predominately non-disabled professionals who sought to be experts in disability conditions, and to provide accommodation, rather than address accessible design of the higher education environment” (p. 80). Specifically, the response from higher education (as an institution,

not from autonomous scholars) has been to accommodate the deficiencies of the student so that they may succeed in an environment that has proven to be inadequate to people of body variety, rather than reconfigure the system itself. Disability studies asks that people with disabilities be recognized as a social class, and in doing so, can work toward dismantling those classroom impediments that make accommodation necessary, “because they believe that social recognition is critical to the proper formation of the self” (Scully, 2008, p.136).

While the medical model views disability as a problem to fix, and thus much of disability studies critiques its approach, Strauss and Sales (2010) note that theoretically higher education and disability studies do share the perspective that disability is a “socially constructed phenomenon” (p. 80). That is, in the minds of disability studies scholars, disability aligns as another social identity category to be deconstructed and discussed with nuance; but in higher education policy, it has been history linked to policies that relegate bodies into categories of normal or abnormal. It is within this tension between a medical model of policy creation and the scholarship of academic research that progress can be made. As Strauss and Sales (2010) write, “joining together [these] disparate areas remains difficult, yet has already resulted in synergies that are furthering the field” (p. 84). One such synergetic example is feminist disability studies.

### **Feminist Disability Studies**

Feminist disability studies is a way of thinking about disability that takes gender and social history into account and makes links between how women and those who are disabled are viewed (Smith & Hutchinson, 2004). Feminist disability studies has made connections between disabled bodies as well as women’s bodies being considered deviant

as well as inferior. Abled women's bodies, and especially according to Patricia Hill Collins (1990), bodies of women of color, have routinely been categorized similarly to disabled bodies. Going back to Aristotle (1944), women were described as "mutilated males" (p. 1). Consider the enduring cultural images of witches and madwomen; these are arguable images of disability in the female form. People with disabilities become viewed as individuals trapped in their ungovernable, helpless, dependent, weak, vulnerable, and incapable bodies (Smith & Hutchinson, 2004, p. 3). The terms that describe disability in relation to ability render disabled people useless and in need of repair.

*Imbalanced, deformed, hearing loss, weak tone, cognitive delay:* these are all the terms that are associated with disability that work to write a narrative of a person with a disability's body as being perpetually deficient. Both from a simple appearance standpoint to a medical one, society is focused on making disabled bodies conform to cultural expectations of normal. This is an idea perhaps described by Foucault, (1975/1979), as he details the great effort of "disciplining bodies" that women's bodies, non-white bodies, and disabled bodies must undergo to fit into the molds of normalcy as dictated by dominant society. Much as with the feminine form, the disabled body is something that must be shaped and forced into one specific attractive mold. This does beg the question, what can be done to challenge or change these systems of oppression?

Academically as we embrace the paradoxes that emerge from challenging a social system as big as gender or ability, confusion looms. Instead of collapsing into chaos, we can develop a methodology that allows for internal conflict and contradiction. There are real world implications for using feminist disability studies as a lens when creating

policy, some ways in which this theoretical world can collide with the practical. As Garland-Thomson (2001) states, “feminism’s often conflicting and always complex aims of politicizing the materiality of bodies and rewriting the category of woman combine exactly the methods that should be used to examine disability” (p. 4). That is, the self-reflexivity of feminism, or feminisms, serves as a model location for how one should begin to think about the complexity of disability studies.

What this suggests as a way for higher education to grow with this framework as guidance is for higher education to acknowledge both the ability to teach a room of students with confidence, but reject the idea of intellectual mastery. More specifically, that policies are created to govern the student body that also acknowledge the limitations of this, and any, institution to fully accommodate the complexity of student experience. Additionally, that difficult questions are posed, which allow for flexible epistemological methods in seeking the answer. Both feminist pedagogy and disability studies demand these alterations (Hillyer, 1997). Feminist disability studies subverts the idea of changing the individual to fit the structure and instead advocates change the structure to fit the individual, or at the very least diversify the structure to fit multiple individuals with divergent needs. Understanding higher education as a fluid location, that is one that can (and should) adapt to the multiple ways which learning occurs, there is potential to create different types of institutions.

The balance between the universality of policy and the attention to the individual is difficult to find. In looking at early intervention programs intended to serve the PreK-12 students (with the logical extension to higher education), creating a feminist disability studies classroom is a challenge, but possible according to Patricia A. Jessup (2009).



Jessup writes about the ways in which ability and our perceptions of ability function in preschool settings. She noted that “the discourse about children with disabilities-shaped by policies and practices - served to constitute children with disabilities in particular ways” (p. 240). She goes on to conduct a study comparing a head start program, which included all children regardless of ability, and a kindergarten program that required students meet specific milestones before entering (thus eliminating some children with disabilities from participating). She concluded that because the head start program “shaped an inclusive discourse about children with disabilities,” it promoted policies and structures of inclusivity, whereas the exclusive kindergarten program shaped a discourse that “emphasized difference and required categorical language to slot children into particular types of classrooms based on the extent of their perceived abilities” (Jessup, 2009, p. 256). By considering the weight of discourse and allowing for variety in abilities, Jessup located a feminist disability studies educational setting.

However, feminist disability studies is a theoretical location, not necessarily a physical one (Garland-Thomson, 2001). Feminist disability studies does not suggest that women and/or people with disabilities should not use modern medicine to improve their lives or help their bodies function more fully (Garland-Thomson, 2001). Rather, feminist disability studies offers a counter logic to the powerful cultural mandates to be normal and beautiful at any cost. It even goes further to say that one’s worth is not determined by the shape of one’s body and how much it does or does not align with the cultural ideal. It offers a counter narrative to the pervasive notion that one must be “fixed” to minimize any trait found undesirable, and instead offers a paradigmatic shift that views bodies and minds as capable of variation, and that this variation is favorable and has value to offer to

people as individuals and to our society (Chinn, 2004). This acceptance of variation and move toward imagining difference without assigning disparity “can reveal a truth otherwise inaccessible to the regime of the visible, a truth that’s all about inhabiting a narrative very different from our own” (Chinn, 2004, p. 193).

### **Postmodernism**

Philosophically, the idea of postmodernism itself is so often misunderstood, as well as used in such various and nuanced ways, that it emerges as both an insult and an identity (Butler, 1995). As Judith Butler writes about contingent foundations of feminism,

a number of positions are ascribed to postmodernism, as if it were the kind of thing that could be the bearer of a set of positions: discourse is all there is, as if discourse were some kind of monistic stuff out of which all things are composed; the subject is dead, I can never say “I” again; there is no reality, only representations. (p. 4)

She goes on to say that so much confusion about the term exists that arguments about what constitutes postmodernism are more prolific than writings claiming to be postmodern. Historically, it is linked to Derrida, Foucault, French feminism and the avant-garde (O’Brien & Kollock, 1997). But what does this mean for feminism, disability studies, and motherhood in particular?

Capitalizing on the ambiguity of the term, I wish to define postmodernism as the understanding that reality is fragile and subject to constant re-write, review, and re-, or, de-construction. I subscribe to Butler’s (1990) assertion that “conceptual mastery” of postmodernism is “paradoxical at best,” and thus a waste of time (p. 8). I question the

assumptions that “some piece of the text is representational, that it stands for the phenomenon, and that the structure of these positions can be properly and economically discerned in the structure of the one” (Butler, 1990, p. 5). More simply, in looking at the way that feminism, disability, and motherhood are used in past and present literature, I will offer counter readings to the accepted definitions. I will insist these terms live an artificially divided existence and that the maintenance of this artificial divide is how we can best see the roles of power, hierarchy, and subjectivity function in society. The deconstruction of these terms, especially a deconstruction that allows for a postmodern reading of them, is one way to expose this artificial divide and move us closer to a postmodern feminist disability studies understanding of motherhood.

With the arrival of Kant’s (1781) *Critique of Pure Reason*, *subject* has meant the knowing, *individual* person, who is responsible for her/his own actions. Postmodernism (and to be fair, poststructuralism as well) offers a less individualistic understanding of subject where, “the actions instituted via that subject are part of a chain of actions that can no longer be understood as uni-linear in direction or predictable in their outcomes” (Butler, 1995, p. 10). Thus, subjectivity is not individual but connected to social constructions like gender, race, sexuality, ability and other social identity categories. This new understanding of the subject is significant because it provides us with an opportunity to think about subjectivity beyond just the individual and instead consider the social or communal aspects of the subject. This is useful when considering disability specifically, as “the postmodern rejection of the grand narrative of normality and the decentering of the normal subject are both ways of shifting our conception frameworks that we no longer feel obliged to think of variation as deviation” (Scully, 2008, p. 7). This expands

the importance of social categories like disabled or mother to become meaningful sites for further deconstruction and moves scholarship away from finding universality in groups where one must fit some place or another, and instead asks us to discard the desire to fit and embrace the impossibility of such a request.

### **Postmodern Feminism**

I use the term *postmodern feminism* in this project to mean that notions of women, whether biologically based or socially created, are impossible to extricate from other aspects of one's identity. As such the subjugation of women has many causes and many layers (Butler, 1990) – so many that it is nearly impossible to develop a true understanding of one's identity, as one's identity is fluid and fluctuating and subject to internal and external influences.

Bound to seek recognition of its own existence in categories, terms, and names that are not of its own making, the subject seeks the sign of its own existence outside itself, in a discourse that is at once dominant and indifferent. Social categories signify subordination and existence at once. In other words, within subjection the price of existence is subordination. (Butler, 1995, p. 10)

Liberal feminists may argue that legal and economic equality will free women from subjugation, but postmodern feminism is much more slippery in that it offers no clear path towards freedom (Donovan, 1992). In fact, one of the largest critiques of postmodernism is that it places itself beyond power, where a fragile reality unravels before spinning us into disarray. I will delve further into critiques of postmodern feminism later in this chapter; however, I choose to step back and see postmodern feminism as allowing us the possibility to question how power is authorized and how, as

Butler (1990) puts it, “a position becomes a position” (p. 9). In this case, I ask how the terms *disabled*, *women*, *mother*, and *student* exist as a performative identity. And, perhaps most importantly, I use the term postmodern feminism to indicate that there can be no blanket acceptance without further deconstruction of truth. That is, truth as a clean and concise concept is impossible, truth becomes a blurry and shifting idea, capable of rewrite and revision at all times.

### **Motherhood Studies**

Contemporary messages about motherhood are everywhere. Asking what makes a good mother is a question fraught with so much history, societal expectations, and media messages it is nearly impossible to get a clear answer. Motherhood studies, as a field of inquiry, uses a feminist lens to examine motherhood (Alaimo & Heckman, 2008). Made most popular by Andrea O'Reilly of York University, motherhood studies looks at the societal expectations of mothers. She says about the field,

They just assumed motherhood does not have a history, does not have a culture, doesn't have an ideology, it just is. And that's completely wrong. Motherhood's an institution like anything else and it has a very complicated history and differences cross-culturally. It has a psychological, cultural, anthropological element, but because it's so naturalized in our culture we don't give it any economic value, societal value. (2009, p. 1)

Using the term “mother outlaws,” writers in the field of motherhood studies deal with subjects related to mothering not typically covered by mainstream media (e.g. working mothers, childcare, mothering styles, pregnancy tips, and I argue student mothers). These outlaw topics include queer mothering, mothering and disability,

motherhood and grief, single motherhood, narratives of motherhood, and other topics that stray into the theoretical and out of the advice-based realm of parenting literature (e.g., *What to Expect When You're Expecting*, *The Girlfriends Guide to Parenting*) or the sentimental canon of literature about children that graces the pages of popular magazines (e.g., *Parenting*, *Working Mother Magazine*). Motherhood studies also has a vast and growing presence online in the form of blogs (web-based journals) and subject based message boards. Within this strain of motherhood studies poetry, creative non-fiction, and personal essays are often the modes of communication (Alaimo & Heckman, 2008).

Motherhood studies should be understood as different than writing about mothering or about being a mother. Motherhood studies is devoted to unraveling the complicated history and social expectations of motherhood in society (Garey, 1999). While there exists much literature about being a mother, work that falls into the category of motherhood studies uses a lens that while not always overtly feminist, does value the experience of mothering in way that runs counter to the dominant logic that mothering does not deserve a diverse and in-depth discourse (Garey, 1999).

An example of motherhood studies in mainstream media are books and articles devoted to examining issues unique to mothers. These tend to move in more popular press circles and have been responsible for new analysis of motherhood that, while primarily concerned with equity in the traditional workforce, has offered new legitimacy of *motherhood* as a site for research (Stone, 2007). This includes the idea of the *opt out revolution* (Belkin, 2003), or the *mommy track* (Lewin, 1989), concepts of work/life balance, and the push for equity in the workplace. These are typically found in journalistic fields and use qualitative studies combined with policy analysis as a writing

style (Stone, 2007). This liberal feminist focus on policy change and equal access to earning power uses the model of feminist theory that assumes a shared experience of women everywhere, and as such has some significant limitations. It also typically focuses on women in the United States, on working mothers of healthy children, and those of the middle or upper socioeconomic class. Consider Pam Stone's study on why women were choosing to opt out of the workforce in favor of raising their children. She focused on six women, all of whom had bachelor's degrees, most of whom had advanced degrees, and all who worked in white collar fields like stock trading, editing, and accounting (Stone, 2007).

Perhaps the most well known in this genre of motherhood studies is the work of Joan Blades and Kristin Rowe-Finkbeiner (2006) founders of the Move On organization, who wrote *The Motherhood Manifesto: What America's Moms Want- and What to Do about It*. They outline the economic and political needs of mothers of children in the United States and also launched an internet campaign to utilize legislation and elected officials to make change. They define the motherhood movement as about "professional women who hit the maternal wall...the success of companies that have discovered the value of good family policies, families who are making it work, model childcare programs, and legislation that supports the families" (p. 7).

In addition to motherhood as subject within the personal press of the blog-o-sphere and popular press, there does exist a growing and important area of motherhood studies in the academy. Carmen Armenti (2004) studied the impact of the structure of the professoriate in her article *May Babies and Post Tenure Babies: Maternal Decisions of Women Professors*. Her study of the leave policies and the timing of the tenure clock

suggest that women were “particularly vulnerable in their ability to seek and receive parental leave” (p. 211), and as such university policies were failing women. She used a feminist critique to argue for those in power to change the structures that produce this inequality and to reframe the policies, which most view as “gender neutral by virtue of its focus on merit” (p. 226) to create innovative and progressive career trajectories.

Armenti’s call for change is similar to the overarching themes of disability studies; it is not the individual who must change to fit into an inflexible structure, it is the structure that must adapt to the individual. Lester and Sallee’s (2009) *Establishing the Family-Friendly Campus: Models for Effective Practice* examines family friendly policies in higher education settings that actually work. In it Lester and Sallee (2009) reframes the argument that these policies are created for women and instead puts forth a more nuanced understanding of policy that illustrates how flexible work options are beneficial to all members of an institution.

In an even more in-depth analysis, Amy Scott Metcalf (2011) connects Foucault’s (1979) work on direct relationships that placed work and life into relational power structures that rewarded traditional academic workers. Metcalf explains that academic cycles guide policy and that “biological cycles are not fully considered, which is the underlying tension that gives rise to policy solutions for the reproductive capacities of academic workers” (p. 13). Metcalf argues higher education policy is often considered “representational of the social order” (p. 16). She interrogates these policies to help us think more globally about what maternity/paternity leave actually means (leave from teaching but what about work responsibilities that are implied?) and how it could be applied to parents in circumstances other than birth (e.g., crisis, disability). With this



deconstruction of leave Metcalf offers a reframing of work-based policies where in the past “sex has become the central category of analysis but people are left out of the picture” (p. 3). This way of thinking moves the responsibility of primary care giver and worker out of the gendered playing field and into the vicinity of the worker. Metcalf questions the illusion that thinking in a gender-less way does not have direct implication for women and mothers specifically. Instead she challenges “feminism’s reliance on equity strategies that ignore multiple gender affiliations and thus prevent potential alliances throughout the academy” (p. 3) and in doing so fits well into the motherhood studies umbrella.

Now that I have described the basic assumptions of feminist theory, disability studies, postmodernism, and motherhood studies, I will discuss the critiques and contradictions that exist among and amongst the various lenses and theories I have explored. Beyond providing a simple synthesis, I must be aware of where the blending of these lenses can be difficult and/or generate contradictions and theoretical impasses that impede progress and require further effort before putting forth a unified lens.

### **Critiques and Contradictions**

When considering the critiques and contradictions between each of these theoretical lenses it is important to note that critiques and contradictions exist within each of them as well. For the purpose of my project, each individual lens is being used in a specific way as detailed above and thus, it is not necessary to dissect the smaller frictions that exists within the theories but instead more useful to explore how each complements as well as contradicts the other as a way of moving us closer to a unified theoretical framework.

### **Critiques and Contradictions within Feminist Disability Studies**

As with any effort, combining two distinct disciplines or theories rarely makes for a neat and perfect analytical tool. There are complications with any such application. Specifically, one area that complicates connecting feminist theory and disability studies relates to the longest held tenets of feminist theory. One of the most broad and pervasive aspects of feminism and feminist theory is locating personal autonomy and independence as a site for liberation. As Silvers (1995) writes in *Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities*, disability studies muddies this thinking for the very practical reason that personal autonomy (in its most basic understanding) is not always possible, in fact dependence upon a care provider may be necessary for some people with disabilities. Barbara Hillyer (1993) asks, “what does it mean to be a whole person when your mind or body is incomplete?” (p. 5). Forgiving Hillyer of using the outdated metaphor of complete/incomplete present in early iterations of feminist disability studies, her point remains important and could perhaps be better asked as how does those who are viewed by society as having their mind or body be incomplete be considered, as whole people?

Further complicating this issue are the gendered dynamics of care work. According to the American Psychological Association (APA, 2011), “The percentage of family or informal caregivers [of people with disabilities] who are women range from 59 percent to 75 percent” additionally, “women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income” (p. 12). What about these women? What does feminist

theory make of their personal autonomy potential, or the autonomy efforts they provide on behalf of their child or loved one?

This acceptance of conventional autonomy is a theoretical location where feminist theory has to change and adapt as well as deconstruct the meaning of autonomy in a world where the traditional understanding of the term cannot apply, but where aspects of its essential meaning can. For example, if feminist theory takes the stance that autonomy includes one's state of mind, or one's ability (even through assistance) to reach their self-directed goals, feminist theory and disability studies can potentially reconcile this contradiction.

Hillyer (1993), in writing about her experience watching her daughter with a disability, Jennifer, grow up notes that she felt feminism would be the answer to the problems of both her daughter who does not have a disability and her daughter with a disability,

We all knew that someday they would be women like me and that my feminist work would make their womanhood better. Supporting their personhood was as rewarding as nurturing them in infancy had been. When she was ten Jenny [her daughter with a disability] changed her name to Jennifer...It was the last gesture she would make that would fit comfortably in my feminist theory. (p. 23)

She goes on to write about Jennifer's recognition that while girls could supposedly do anything, Jennifer could not due to real physical and mental limitations. Hillyer (1993) wondered how she could reconcile her former understanding of feminism without accepting a belief in biological determinism that undermined her feminist perception of women.

Clearly traditional feminism needs to change its understanding of personal autonomy, but how can this change take place? Catriona Mackenzie (2010) points to relational feminist theory as a place where the idea of autonomy can expand beyond the traditional definition. She writes “relational theories acknowledge the importance of individual autonomy and bodily self-determination. However, they argue that individual autonomy is socially constituted” (p. 84). This gives feminist disability studies the framework needed to re-think personal autonomy and could be a potential starting point for engaging in a reimagining of what liberation means.

Feminist theory and disability studies also have an uneasy relationship when it comes to reproductive rights as the very act of defining a fetus as undesirable requires some writing of a body narrative by an outsider. Tension arises when fetuses (and by extension people) are considered undesirable and expendable. According to Hubbard (1990) in her work, *Who Should and Should not Inhabit the World*, feminist theory supports reproductive rights of women, and through inclusive readings of reproductive rights, the right to terminate unwanted pregnancies (including those pregnancies of fetuses diagnosed with disabilities through prenatal testing). Although this does not present an immediate and outright contradiction, disability studies scholars find tension in the way that feminism, and with it feminist theory, makes reproductive rights one of their defining issues (Hubbard, 1990). This perspective does not invite the paradigm shift that changes how we view desirable and undesirable bodies that disability studies demands.

By structuring the dialog as purely a political one centered around reproductive rights, feminist theory ignores the call to reframe how we view bodies and how we classify children (as well as all people) as acceptable (Hubbard, 1990). Feminist theory

need not cease the efforts that support reproductive rights, but rather expand the conversation to identify the connections between the classification of bodies as acceptable or unacceptable within its mission. That is, feminist theory can include a political dialog but also be clear in putting forth a feminist bioethical argument that is inclusive in the consideration of disability. This would link the experience of women's bodies being policed with the way in which disabled bodies are judged within its collective dialog.

Additionally, while both feminist theory and disability studies work to challenge the social structures of gender and ability neither requires (nor requests) that one refuses medical treatment to make their bodies function more fully. This makes logical sense as one would be hard pressed to find any scholar who would suggest otherwise, but it does create a source of cognitive dissonance where one's theoretical location does not match one's physical one. Feminist theory specifically does little to address this. Disability studies does address this through its reconciling of one's physical limitations by allowing to self-definition of one's own. Philosopher Elizabeth Grosz (1994) called for a more fluid way of thinking about the relationship between one's mind and one's body. She uses the terms, *embodied subjectivity* and *psychical corporeality* (p. 22) to re-contextualize the mind/body dualism. Using the metaphor of the Möbius strip she states, "the torsion of the one into the other, the passage, vector, or uncontrollable drift of the inside in to the outside and the outside into the inside" (p.xii) to explain the fluidity of the role illness or disability plays in the body.

Being in such an uncertain theoretical location is not an easy problem to approach but both fields can work together to find a mutual and satisfying conclusion.

Hillyer (1994) states,

Science and technology are among the most conspicuous products of masculine values, so we are skeptical about their use and cautious about integrating them in our lives. But women with disabilities and women who give care to people with disabilities rely heavily on technology to chance and simplify daily life -- and often just to survive. For these women, the issues is not whether to use technology but how best to integrate it with self-concept and with body awareness. (p. 173)

Feminist disability studies interrogates the pressure society places on people with disabilities or physical impairments to use, as Susan Bordo (1993) calls it, “cultural plastic”(p. 246) to look more normal. Foucault (1975) too recognized how this cultural battle for control over members of minority groups (e.g., women, people with disabilities) bodies functioned as a vast effort to make citizens into “docile bodies” (p. 135)

Despite the research and implications for women and people with disabilities who use medicine as needed while still bucking the will to normalize nonstandard bodies and the friction this creates, neither theory specifically addresses the strain on the individual that this dissonance produces. Philosophers and writers of other fields have delved into this subject in their own personal writing, both Plato (1969) in *The Last Days of Socrates* and Virginia Wolf (1948) in *On Being Ill* offer personal forays of the *healthy* experiencing illness. They both marvel at the frustration with the physicality of their body impeding upon the functionality of their minds (even just by distraction). Wolf (1948) demands a body of literature that describes “the daily drama of the body” (p.9) and illness, specifically speaking not just about the larger theoretical complications discussed

above but the very personal discord it created by asking us all to consider ourselves “temporarily abled” (p. 17). It is within personal narratives, such as Plato (1969), Wolf (1948), and others such as Audre Lorde’s *Cancer Journals*, that the individual application of feminist disability studies emerges.

Finally, when examining the contradictions between feminist theory and disability studies, we must again look at one of the more foundational aspects of feminist theory. Feminism has often concerned itself with ending the sexualized subjugation women’s bodies receive, while disability studies has frequently noted that people with disabilities become sex-less or incapable of being viewed as a source of sexual pleasure (Bordo, 1993). Feminism misses a chance to connect with disability studies on a broader level over this issue, where again bodies (whether female or disabled) are subject to the critique of others. Jennifer Bartlett (2011) writes about this feeling,

There still exists the paradigm that the things people believe able-bodied women *should do* (or feel obligated to do) are the same things that people believe women with disabilities *shouldn’t do* [emphasis in original]. There are still complexities between the disabled and feminist communities: Feminists fight not to be forced into mothering; women with disabilities fight to HAVE children [capitalization in original]. Feminists want to be looked at as more than sexual objects: women with disabilities are rarely considered sexual. (November 5)

Here Bartlett teases out that she feels feminism has left the needs of those with disabilities behind in its constructions around issues like mothering and sexuality.

Recently, feminist disability studies scholar, Sarah Rainey (2011) wrote about sexuality and pleasure as being an integral part of the abled/disabled couplings of those

she studied in her book *Love, Sex, and Disability: The Pleasures of Care*. In this work, Rainey (2011) also identifies these partnerships as a site for a feminist reimagining of gender roles, as the ability of one partner often served as the deciding factor in their contribution to the couple. For example, men no longer automatically served as primary wage earners nor women responsible for housework. Because she only looked at heterosexual couples, Rainey discovered what queer theorists have been asserting since the 1990's, (Anzaldua (2009), Butler (1995); without the dominant paradigm of the gender binary dictating relationships, organic and more egalitarian divisions of labor emerge.

The connection between women and people with disabilities highlights the intrinsic connections between the two fields that make them logically complementary.

As Garland-Thomson (2001) writes:

I must wearily conclude that much of current disability studies does a great deal of wheel reinventing. This is largely because many disability studies scholars simply do not know either feminist theory or the institutional history of Women's Studies. All too often, the pronouncements in disability studies of what we need to start addressing are precisely issues that feminist theory has been grappling with for years. (p. 487)

Garland-Thomson is able to get to the core of the issue, which is that a feminist lens can often be useful to consider disability studies issues. She notes that both are created around the shared idea of a socially constructed reality. And while the various criticisms of inclusivity outlined above are valid, there are ways to address the conflicts between the two areas of study.



**Critiques and Contradictions within Postmodern Feminism**

A major critique of postmodern feminism is that there is no concrete action associated with the theory, and thus feminist postmodernism becomes a meditation on what words mean and a departure from the type of feminism that is associated with social change (Butler, 1995). I counter that by suggesting that working to understand the nuance of the idea of “subject” is in itself an action and a deliberate way of thinking that counters the pervasive social pressure to accept the cultural norms. Often blamed for “killing” feminism, or making it meaningless, deconstruction through postmodernism actually provides a more rich life for the continuation of feminist thought (Butler, 1995). As Judith Butler states,

To deconstruct the subject of feminism is not, then, to censure its usage, but, on the contrary, to release the term into a future of multiple significations, to emancipate it from the maternal or racialist ontologies to which it has been restricted, and to give it play as a site where unanticipated meanings might come to bear. (p. 22)

While postmodern feminism is criticized for insisting that the category of woman has no solidarity nor shared identity, and thus invoking the death of feminism, it is only by deconstructing the idea of a shared identity and moving the idea of woman from static to fluid that actual agency can be reached. Foucault (1979) called sex (referring to the biological designation) a “fictitious entity” (p. 47) and when feminist theorists who are frustrated by postmodernism suggest it negates materiality, specifically the materiality of the body, I counter that postmodernism allows the problematically dualistic categories of male and female to be deconstructed and thus peels away at the compulsory gender

performances that subjugate all bodies. It is true that removing the shared identity of women is slippery and could, *potentially*, lead to misuse of postmodernism to negate the experiences of those assigned the category woman, or the existence of women's studies, but *feminist* postmodernism guards against this oversimplification and instead complicates gender, sexuality, race, ability, etc. by making room for these categories to buck the compulsory attributes assigned to them placing the power of self-definition in the hands of the individual to further the work of the collective.

### **Critiques and Contradictions between Feminist Theory and Motherhood Studies**

The very term, motherhood studies, is complicated when viewed through the lens of feminist theory. By studying motherhood exclusively it creates an environment where one must ask, "what makes a mother?" The outlaw mothers discussed above and those explicitly using a feminist lens to examine motherhood make room for all types of mothers, whether adopted, queer, foster, or otherwise different than the traditional notion of mothers. However, I would be remiss not to note that fathers, or other partners of any type, are not the focus of motherhood studies. The field does claim something intrinsically study-able about mothers specifically, which can be problematic for the very same reason that claiming mothering a child with a disability is life transforming (whether through grief or enlightenment) (Hillyer, 1997). It is agency that is wrestled with and it is indeed a challenging topic as something (or in this case someone, a child or children) is making the subject worth of study. It could be said by those who study disability, or by feminist theorists, that by leaving out the child and studying the mother we are stripping the child of their agency, identity, and voice (Silvers, 1995).

The language of mother or motherhood becomes important as it clearly stands for something definable (albeit defined differently depending on the location). L.S.

Vygotsky (1961) in his essay on language, clarifies how a word, or the speaking of a word, becomes a cultural artifact.

The structure of speech does not simply mirror the structure of thought: that is why words cannot be put on by thought like a ready-made garment. Thought undergoes many changes as it turns into speech. It does not merely find expression in speech it finds reality and form. (p. 86)

The word *mother* takes on a form and a social reality through the cultural importance that is placed upon the word. Feminist theory, and postmodern feminist theory especially, take issue with the word standing for the whole and push at the boundaries around the idea of mothering and motherhood to make it include less obvious locations of care taking and relationships. Postmodern feminist disability studies also focuses on the dominant and less dominant social performances of motherhood in specific cultures and in doing so broadens the idea of what mothering encompasses. Looking back to the liberal feminist work on mothering, postmodern feminist disability studies would deconstruct the ideas of work, class, and sexuality that are implicit in that type of research.

### **Critiques and Contradictions within Disability Studies and Motherhood Studies**

As discussed above, disability studies asks for a rewrite of the cultural paradigm that places abled bodies as the norm and disabled as abnormal. It reframes the medicalized argument that disabled bodies need to be fixed and asserts that the world needs to see a range of bodies as acceptable. Motherhood studies often conflicts with

disability studies in that mothers of disabled children express great sadness and even grief at the disability of their child. In fact, the term “chronic sorrow” has been used by many in the psychology field since the early 1960s to explain the feelings of parents of children with disabilities (Olshansky, 1962). Despite studies on the subject, the expression of grief over the occurrence of a disability can create tension between these two areas.

Social expectations are both reified and fragmented in grieving for a child with a disability.

People with visible disabilities and those who care for them are expected to mourn because the disability itself is seen as a tragedy, analogous to death, by the rest of society. Visible grief reassures the observers that their own values are appropriate and that their own nondisabled condition is “normal” (Hillyer, 1997, p. 78)

This creates two specific problems, one for mothers and one for people with disabilities. The pervasive understanding of grieving in Western culture is that one progresses through stages and ultimately reaches a level of acceptance (e.g., Elisabeth Kübler-Ross’s (1969) model of grief where one advances through stages of grief ultimately accepting the loss they experienced and thus ending their identification as a grieving person). The chronic sorrow that mothers of children with disabilities experience runs contrary to this accepted grief narrative and as such is perceived as pathological (Hillyer, 1997). Judith Butler (2004) writes on grief that “loss becomes the condition and necessity for a certain sense of community then turns out to oddly fecund, paradoxically productive” (p. 468). But this chronic or intermittent grief does not have a logical conclusion. Additionally the existence of a person with a disability as being the site for this sorrow is immensely

problematic and is specifically antagonistic to the paradigm shift away from valuing ability over disability that disability studies calls for.

Disability studies scholars can potentially be offended by the notion of the life of a person with a disability (and in the location of motherhood studies, typically children) being a site for grief. Yet mothers write that watching their children struggle while functioning differently in the world is grief inducing, such as the optimistic and yet clearly grief infused collection *Love You To Pieces* edited by Suzanne Kamata (2008) that shares parents personal narratives regarding their feelings towards their children with disabilities. Even Hillyer (1997), one of the most prolific contributors to feminist disability studies scholarship, wrote about her impetus to research the field that “I did not know that her [Jennifer, her daughter with a disability] losses and mine were appropriate occasions for grief, that I could live with such grief and not die of it” (p. 248). Hillyer and other scholars (Smith & Hutchinson, 2004) have suggested that there is room for both emotions and that within the field of disability studies (and feminist disability studies, in particular) more work must be done on the experience of mothers, parents, and other care providers. Hillyer writes that, “personal narratives are the best source of information about women’s disability experience” but that they are “rarely feminist” (p. 21). In fact, the majority of these personal narratives fall into the category of memoir and rarely, if at all, critique the complicated notions of disability, gender, class and/or consider feminist implications for disability and mothering.

Janet Read (2000) published a study of mothers of children with disabilities in the UK and found that overwhelmingly mothers reported grief, exhaustion, and difficulty

with the social services and medical providers who worked with their children. She writes that

while women might be assumed by staff to be loving and competent in their role as mothers, it was also almost universally taken for granted that they were ignorant of those things deemed to be in the area of competence of the professional (p. 63)

Relegated to care givers and stripped of value, mothers of children with disabilities became the shadow of their child, putting the needs of their children first and waiting until they were needed.

Representing the complete opposite problem of the expression of grief from mothers is what I refer to as the *blessing books*. These publications on parenting a child with a disability nearly always conclude with the child being a source for personal enlightenment. Perhaps best summarized by the essay by Emily Perl Kingsley (1987), *Welcome to Holland*, the author writes that having a child with a disability is similar to planning a trip to Italy, only to find oneself in Holland instead. Kingsley argues that it would take time, and a shifting of expectations, but soon one would find that Holland was a lovely place, just not what they expected when departing for Italy. The overall message is that having a child with a disability is a hidden blessing that encourages parents (but especially mothers) to accept what life has given them in the preciousness of their child with special needs. This notion has gone on to infect memoir after memoir of parenting a child with a disability and serves as the guiding framework for a great deal of literature dealing with the topic: memoirs like *Road map to Holland: How I found my way through my son's first two years with Down Syndrome* by Jennifer Graf Groneberg (2008), *This*

*lovely Life* by Vicki Forman (2009), and *A Pound of Hope* by Michele Munro Kemper and Jennifer Kemper Sinconis (2010). These books/essays/articles typically focus on the parent initially finding themselves sad and shocked when learning of their child's disability but eventually coming to terms with their child's disability and learning a valuable lesson about unconditional love and concluding that all things happen for a reason. Each include a redemptive arc where parents (again, overwhelmingly mothers) experience a fleeting dalliance with grief but all push past the negativity for their children's sake, and as a result their children benefit.

This trend of seeing children with disabilities as locations for parental growth causes an altogether different clash between motherhood studies and disability studies. This notion is potentially offensive to individuals with a disability as it strips them of any agency or desires of their own. It reduces them to a conduit for mothers to learn valuable life lessons. I previously argued that there does exist a canon of literature that bucks this trend, but it is usually with the passage of time that we see a more complex understanding of disability by authors. In 2009 I wrote,

I read Jane Bernstein's book *Loving Rachel* where she takes her audience on a journey through her daughter's diagnosis of mental retardation and vision impairment and ends with her ultimate acceptance and optimism at her child's future. Then I read the follow-up *Rachel in the World* where Bernstein was now divorced, stuck with a violent and maddeningly difficult child who needed constant care that not only wasn't affordable but didn't really exist. Here was a mother who had left Holland behind and landed somewhere less fun, like reality.

(p. 69)

It is a danger in motherhood studies generally to use the experiences of their children as transformational to their own lives but this is particularly dangerous when it comes to children with disabilities. “The idea that ‘good’ mothers accept and love their children no matter what interacts with stage theories of grief to cause many mother to perceive prolonged sorrow as a personal flaw” (Hillyer, 1997, p. 78). Writing about children with disabilities in a way that confirms the social construction of mothering as self-less, and grief as capable of resolution, leaves mothers whose experiences are contrary outside the boundaries of this version of mothering and as such, outside the socially accepted traits of being a good mother.

Those contributions to the field that examine adult caregiving relationships, such as Rainey’s (2011) study of adult heterosexual couples, one of whom was typically abled and the other who was a person with a disability, attempt to redefine these relationships as mutually fulfilling but in doing so marginalize the work of care. Arguing that caregivers receive fulfillment (and care themselves) from their relationships with people with disabilities is not particularly revolutionary. It is based on the assumption that culturally we see providing care as burdensome (Rainey, 2011, p.17). Liberating the relationship of caregiving from this binary, as Rainey (2011) attempted to do, is problematic in that by freeing caregiving relationships from one binary automatically places them into another, where care is a joy to provide and fulfilling to give. The oversimplification on either end, care as burden or care as fulfillment, are both inaccurate and suffer from a limiting dualism that gives caregivers little room for complex understand and exploration of their experience. And being that Rainey’s (2011) work is so emphatic in its thesis that the fulfillment caregivers receive as a result of their efforts is



a way to subvert the dominant discourse, it works to further silence a more complex experience of caregiving from developing and instead aligns with traditional notions of those who provide care being satisfied as well as selfless.

The caregiving piece of disability is not often addressed by disability studies, so in that respect, contributions like Rainey's (2011) are important, but still leave a gap where caregivers, and for the purpose of this project, mothers specifically, are left without agency. Hillyer (1997) writes,

My own experience as the mother of a young woman with both physical and mental disabilities is not reflected at all in feminist literature, even though mother-daughter relationships are often discussed there. Likewise, in literature about disabilities, the feminist implications of our situation are seldom addressed (p. 9)

This sentiment carries over into the realm of education, which can be linked to care-work by its very nature of spending time with people with disabilities and during that time providing care for them (Strauss & Sales, 2010).

Teachers legally act *in loco parentis*, or in place of the parent in the United States (Strauss & Sales, 2010), and as such, their care, attitudes, and treatment of children with disabilities is relational to societal expectations applied to parents. In pre K-12 education, success of children with disabilities is measured by the social expectation of productivity and independence. "A teacher of children with disabilities may, for example, be judged successful if she transfers an increasing share of instruction to the mother to be done at home" (Hillyer, 1997, p. 11). The conflation of learning and life skills becomes a guiding principle for success outcomes during these grades for children with disabilities (Strauss & Sales, 2010), while for typically abled children mastery of categories such as

vocabulary, critical thinking, mathematics, (or what we think of as typical curriculum) are categories that measure success.

### **Disability in higher education.**

This section will briefly highlight how disability has been seen, accommodated, and created policy in higher education. Higher education has not fared much better than other locations in managing the accommodations of people with disabilities according to disability scholar Simi Linton (1998) in his book *Claiming Disability: Knowledge and Identity*. The act of providing care and guidance on behalf of a child with a disability may extend beyond the timeframe of traditional parenting and as a result mothering of a child with a disability may require encountering institutions, such as those of higher education, that fall outside the typical timetable of parenting (Linton, 1998). An outcome can be intense frustration with providing care to adult children. Hillyer (1997) writes of her daughter, “her need to separate from me, the one who interprets her world to her and to others, was in a sense self-destructive, as separation would leave her unprotected and un-interpreted” (1997, p.13). This gap in disability studies literature leaves higher education institutions locations particularly problematic locations for both mothers and people with disabilities, who according to Linton (1998) “have only recently entered everyday civic life” (p. 4).

For example, professors often misunderstand what the American’s with Disabilities Act means regarding provision of adequate accommodations and retreat to referring students to other academic offices that act on the student’s behalf, as an another form of surrogate mother (Grossman, 2001). A general lack of knowledge around

disability and an adherence to higher education values that emphasize a system of merit creates

a source of suspicion and fear [for professors]. Some, for example, worry that providing accommodations will force colleges and universities to lower academic standards and foist onto society a generation of unqualified professionals, or simply compel faculty to violate their own concepts of fair treatment of all students (Grossman, 2001, p.3).

Disability studies, with its keen focus on the empowerment of the individual and deconstruction of ability, leaves out the mothers' uneasy navigation of these systems designed for the exclusion of parents at the betterment of young adults. Mothers of children with disabilities have "more than average contact with patriarchal institutions and less than average choice about the ones with which they interact...regardless of the woman's preferences, they are dependent on the institutions for services" (Hillyer, 1994, p. 14). This includes institutions of higher education.

Mothers must manage their relationship with higher education institutions limited by the same constraints of contemporary notions of care work. Mothers have interactions with colleges and universities that are similar to their relationships with other educational systems in that their role goes beyond parent and they are often tasked with managing the acquisition of disability services for their children. Moving from the specific policies and procedures, traditional higher education also falters under the theoretical application of feminist disability studies.

### **Feminist disability theory in higher education.**

As the goals of higher education shift to meet the needs of students, it must, according to Kegan (1994) “articulate the mental demands of modern life” (p. 185). These demands must teach students to integrate “epistemological, intrapersonal and interpersonal capacities in a complex way of making meaning” (p. 184). More specifically to this project, Kegan’s (1994) idea of self-authorship allows higher education to be the perfect venue for truth to be interrogated and for knowledge, both that originates from the teacher that, which comes from within the student, to live its own autonomous existence.

Kegan (1994) states it is  
an ideology, an internal identity, a *self-authorship* that can coordinate, integrate,  
act upon, or invent values, beliefs, convictions, generalizations, ideals,  
abstractions, interpersonal loyalties, and intrapersonal states. It is no longer  
authored by them, it authors them and thereby achieves a personal authority  
(p.185, italics in original)

In the classroom of higher education institutions, pedagogy becomes a transformational opportunity where new knowledge mixes with one’s personal experiences to create a self-authored understanding of truth, facts, and memory.

The importance of knowing, and telling, one’s story becomes especially important in a higher education setting as it is the very place where we, as teachers and as learners, devote time to thinking about how knowledge is created, how it is best transmitted, and what each participant’s role is in this exchange. Paul Trowler (2009) explains that in classrooms, there is interplay between the structural and agentic factors between social reality and social change. On the structural side lies the power of disciplines to condition

the behavior of academics, their practices, values and attitudes. On the agentic side lie questions of narrative, identity construction and power plays. Social worlds are both constructed and enacted. (Trwoler, 2009, p. 182) That is, there are many forces at play in a classroom on behalf of both the instructor and the learner, among them each side's construction of reality.

This idea can be contradictory to tradition methods and approaches to teaching and learning. More specifically, if higher education uses a feminist disability studies lens the creation of knowledge. According to Polanyi (1967), making tacit knowledge more overt makes it more distortable and it is better to keep in mind when thinking about knowledge that it is never impersonal nor even entirely expressible in words. Thus, students and teachers bring the inexpressible into the classroom, their lived experience, their daily life, their feelings; all these things influence the ebb and flow of knowledge throughout the room (Polanyi, 1967).

As Leo Buscaglia (1983) states,

When life brings suffering to us, we must choose between the alternatives of entering the experience head on and trying to know its deepest and fullest meaning, or of turning aside from our own feelings and emotions with a denial that they exist and a pretense that we are unaffected by the dark side of life (p. 45).

I have chosen through this project the former.

Although motherhood studies and disability studies can find ways to adapt and change to be inclusive of both the agency and autonomy of people with disabilities, as well as the needs of their care-givers, more work needs to be done in these areas. A more

seamless connection could be created between the two theoretical lenses if there was more intentional engagement with one another. Specifically more engagement between mothers who provide care to people with disabilities and people with disabilities around their shared experiences and the social construction of reality governing both their roles in society. A postmodern project such as this one cannot accomplish this connection but can reflect on the messiness of these two locations coexistence and attempt to make strides towards making change.

### **Graduate Student Identities**

Little research has been devoted to graduate student identities (specifically female graduate student identities). Most is tangentially located in literature designed to instruct future teachers of higher education. “Perhaps it is the nature of the educational experience that explains a plethora of research on undergraduates and a paucity of research on graduate students” (Gardner & Barnes, 2007). What is missing from much of this literature is a research on graduate student identity that considers the intersectionality of these students. In Gregory Colon Semenza’s (2005) *Graduate Study for the 21<sup>st</sup> Century* he provides a practical guide for how to succeed in graduate school, the ultimate goal being to obtain an assistant professor position. While the book is clearly a guidebook, it does not trouble the complications that occur when life outside the classroom intercedes with the clear trajectory Colon Semenza (2005) paints from choosing a program to accepting one’s first position. However, just as research that mimics this style ignores the complicated graduate student experience, other research in the field views it as a problem for the student to overcome, specifically that of female students.

Beginning with early works devoted to the emotional life of students, female graduate students in particular stood out as a population of high emotional distress. Here Erikson reflects on how to best deal with the overly emotional female graduate student.

Although some degree of difficulty such as I have described here can be expected in a great many college women...help can come from many other sources—from the spontaneous process of maturation and growth which comes as well from new responsibilities and, above all from meaningful encounters and experiences.

(Erikson, 1969, p. 184)

The approach to what is seen by higher education practitioners as a psychological problem is to fix it, not accept it as part of the natural life of graduate students (both male and female). Much as with the stigmatization of prolonged grief in motherhood studies, higher education literature sees emotion that bleeds into the classroom as a problem in need of repair through external services, rather than a natural experience of the human condition that can have value to a student's learning identity.

In addition to what falls into the realm of psychological problems, the overall culture of graduate education is one that is devoid of gender and primarily focuses on removing experiences students have outside the classroom. "The socialization of graduate students is an unusual double socialization. New students are simultaneously directly socialized into the role of graduate student and are given preparatory socialization into graduate student life and the future career" (Golde, 1998, p. 56). Tinto (1993), who worked most frequently on undergraduate student development also created a graduate student persistence theory. His theory relies strongly on the initial personal persistence of each graduate student but later asserts that "the character of the candidate's

commitments to those communities, such as families and work, and the support they provide for continued study may spell the difference between success and failure at this stage” (p. 237). What is not clearly articulated by Tinto (1993) is the increased burden of family and work, as well as a decreased connection to support experienced by female graduate students.

Since 2006, female enrollment has risen dramatically with only small increases in male doctoral enrollment. In 2001 – 2002, for the first time, more women received doctoral degrees than men in the United States (National Center for Education Statistics, 2006). This can be easily seen in the literature on faculty socialization as many women with children have reported disparate and negative experiences (Ward & Wolf-Wendel, 2004). Interestingly, a large portion of the literature regarding female graduate students is within Science, Technology, Engineering, and Mathematics (STEM) careers (Bystydzienski & Bird (2006), National Research Council of the National Academies (2010). This literature reflects the general literature about graduate students reflected above (socialization, persistence) but also does move towards interrogating the policies that govern academic progress with women in mind (Bystydzienski and Bird, 2006). In looking at research devoted to graduate student mothers the selection becomes even slighter.

Given the discourse on women in the academe, “graduate student mothers find themselves questioning their place in academe which constructs combining careers and life in academe and family as a challenge and problem” (Williams, 2007, p. 24). More specifically their entire existence is problematized as a disadvantage before they have even entered the classroom. Higher education’s response to graduate student mothers has



been to enact leave policies that reduce, if not remove, the penalty of stopping coursework for childbirth (Williams, 2007).

This policy-based response is important and necessary for graduate student mothers to prosper in their chosen programs, but this project is more narrowly focused on the classroom and socialization experience of graduate student mothers, one that I argue, is different to each individual, but does hold something uniquely valuable to understand in order to create new ways of learning.

We lose ourselves in what we read, only to return to ourselves, transformed and part of a more expansive world. Excluded, inadequate, or an afterthought, graduate student mothers are caught in untenable and irreconcilable discourses that constructs “mom” and “student,” “family” and “the academy,” “self” and “success” as unattainable (Williams, 2007, p 43).

My project uses a postmodern feminist disability studies lens and in examining my experience as a graduate student who was also a mother of a child with a disability, extrapolates meaning to other graduate students to offer suggestions for future change within higher education. While I examine carefully each aspect of my student identity, which includes multiple and intersecting selves I illustrate how knowledge functioned during each of these identity points. The implication is through more thoughtful understanding of my individual experience the way higher education approaches knowledge production can accommodate such individuality and contributions in ways consistent with postmodern feminist disability thought.

The relevance of using a postmodern feminist disability studies lens when thinking about graduate student mothers is to muddy the research methodology that

makes student experiences generalizable. That is, rather than relying on large data that extrapolates findings based on shared experiences, plucked from the highly individualized stories of graduate student mothers; this project suggests that it is within the individual experience that higher education practitioners can learn. Using a postmodern feminist disability studies lens to think about higher education makes the experience of the individual valuable. Going further, it not only values the experience of the individual, but holds a space for an individual's experience to stray from traditional constraints of time and place (e.g. the act of parenting is just as valuable to how one learns as a classroom experience) and also inserts value into a non-linear way of thinking that decenters traditional methods of understanding. Whether that is found in the folds of feminist disability studies that trouble the hierarchical characterization of knowledge, or under the wing of postmodernism where one's ability to accumulate knowledge becomes secondary to one's fluctuating relationship with knowledge, each rung on this particular frame complicates traditional ways of knowledge and allows for new entry points into how we understand learning as a discipline and positions knowledge production and reception as fluid rather than static. As such, it is particularly useful to the complicated experience of graduate student mothers whose voices have yet to be viewed through a lens such as this one that allows for a counter narrative to research produced about this population and furthers practitioners understanding of learners' reflexivity and positionality.

### **Summary**

Using a postmodern feminist disability studies lens to understand motherhood is complicated at best. Arguing the impossibility of truth is even more complicated.

However, the current literature as reviewed leaves a starting place to begin thinking about what might be the result of examining graduate student motherhood, through this type of lens. A personal narrative that offers a postmodern feminist disability studies perspective is one that not only tells a story while attending to the multiple and intersecting political rhetoric and positions of feminism and disability activism but one that also looks at the influence of time. As Hillyer (1997) states, time is important to all narratives as “humans measure time, schedule time, attach different values to different uses of it, assign ownership of it” (p.1). That is, time changes depending on who is watching the clock. Engaging with truth in a feminist disability studies way makes room for a narrative that allows for grief and joy, guilt and innocence, autonomy and dependence to exist in the same place at the same time and recognizes the precariousness of doing so.

This literature review explored some of the current ways we understand each of these fields or theories and offered some a way to combine them in this project to examine the experience of graduate student mothers. The following chapter will explain the design and methodology of this research project.

### **Chapter Three**

#### **Research Design**

The design of my research project is, on the surface, quite simple. I will tell my story as a graduate student who is also a mother of a child with a disability. This is a scholarly personal narrative (SPN) methodology that values my personal experience as a useful focus of study. My story will be told three times, each time it will be guided by a narrative themes, or constructs. Each narrative will document my classroom experience during a specific period of time using the lenses of family, doubt, and loss. While I will

work to build a linear narrative it will be postmodern in its construction as each will present multiple and conflicting truths and perhaps most importantly, illustrate how different aspects of my identity were foregrounded during different times.

It is not my intent to argue the validity of any one truth over another but rather use the truths produced by my narratives to argue the fluidity of truth. Using Jane Flax's (1990) understanding of postmodern feminism, which asserts that "if there is no objective basis for distinguishing between true and false beliefs, then it seems that power alone will determine the outcome of competing truth claims." (p. 42) I hold that multiple truths can exist without claiming one true over another. I offer a modified understanding of truth that is subject to revision and allows for repeated engagement because its properties are always changing. My intent is not to oppress but expand the limits of truth to create and document change over time and within different circumstances. Truth, in this project, is alive.

These narratives, I will argue in chapter five, allow for a postmodern feminist disability studies understanding of truth and graduate student identity as they attend to the multiple and intersecting aspects of feminist theory and disabilities studies while also questioning the social construction of truth. More specific to higher education these narratives provide a portrait of a graduate student mother of a child with a disability who inhabited different identities at different times in and outside of the classroom. However, it is the graduate student identity that, I will argue, bent and changed with life experiences influencing the learning I was able to absorb, the style of scholarship that attracted my interests, and the topicality of the research I focused on at any given time. It is with these narratives that I reason graduate education needs to be flexible in its

acceptance of life experience. Rather than try to contain the life occurrences of students' lives through identity models or other practical guides to approaching graduate student life I ask that we as higher education practitioners embrace the postmodern muddiness of truth and consider this personal growth as an outcomes of student success.

### **Narrative Contradictions**

The narratives in chapter four will offer a portrait of a graduate student, a mother, and a mother of a child with a disability. These intersecting and sometimes contradictory identities allow for three stories. First, a story of a family. Of twins, August and Greta, born on a stormy April night, triumphantly entering the world within 25 minutes of each other through various medical heroics. Of hazy new born days filled with bees buzzing through lilacs and endless late nights of infomercials and the tearless cries of not one, but two infants. Where fall leaves fluttered over their sparsely haired heads and we leaned out our upstairs window to taste and feel their very first snow. Where I composed term papers and PowerPoint projects in the late nights between endless feedings and television reruns, refusing to step away from a graduate program I had loved so much. A story of perfection, of the imperfect kind, where a little family, once of three (my partner and our then 3 year old son) made into five, stumbled our way through all the mistakes, mishaps and most of all surprises of the first year of having multiples.

Then I will offer a narrative of doubt. A story of endless questions between my partner and I about Greta. How she held her legs so stiff. How we insisted at her newborn appointment at just 4 days old that she never put her tongue into her mouth. How she did not roll over at 4 months, at 6, at 8, at 12. How she could not or would not use her left hand. How we, my partner and I, begged doctor after doctor to consider

something might be wrong. How I skipped class after class, making up excuses about stomach flus and runny noses to sit watching our daughter and struck dumb with how to carry on. How our daughter was placed under a microscope, and with it we were too. How a seizure we caught on tape won us the MRI we both had been demanding for months that finally exposed the source of our doubts, the stroke that occurred shortly before, during, or after her birth.

Finally, I will offer a narrative of loss. The story of twins born on a stormy April night. How during the 25 minutes between August, or Gus as we had come to call him, entered the world, Greta suffered a stroke causing permanent brain damage that would result in a diagnosis of cerebral palsy at 9 months of age. How this damage to her brain would change the way she sees, hears, moves, feels pain, and experiences the world around her. How after that diagnosis the words blurred on every page of every text I read, the meaning lost on a preoccupied, and perhaps broken, heart. How the next year of her life would be marked by therapies, doctor visits, worries about the future, the near collapse of our family. And perhaps most importantly, how each class felt like a particular type of torture designed just for me.

### **Limitations and Ethical Considerations**

It is important to note that this is my story and not a traditional study with anonymous or confidential participants. As such it will contain information about my family, colleagues, the medical community, and many other individuals without their permission. Because I adhere to a postmodern reading of truth of philosopher Jean-Francois Lyotard (1984) where “we can no longer believe...in the availability of a privileged meta-discourse capable of capturing once and for all the truth of ever first-

order discourse” (Fraser & Nicholson, 1990, p. 22) I am comfortable with multiple and conflicting truths existing in the same place at the same time. In simple, their truth is not my truth; my story is not their story. I hope to write the truth as I remember it, but accept that others may engage with my truth in different ways than I did. As Nash (2004), states I narrate my story “in such a way that it might help [my] reader see the world a little differently, not to accept [my] view of the world” (p. 63). The ethics of this method can, and should, be discussed further in this project but I invite the reader to consider my unreliability as a storyteller as well as my bias throughout the narrative.

According to Sandra K. Dolby-Sahl (1985), folklorist, personal narrative “simply introduces us to the never-ending struggle to determine what a text means” (p. 45). She contends that the text is alive and “textual criticism must contend with the unpredictable moods of a living creature, the variable acts of the speakers and listeners, writers and researchers” (p. 45). This idea of a text offered by the author that is changeable and elastic goes back to the idea of deconstruction where Derrida (1967/1978) explains that one can cautiously make intertextual connections through this process of viewing the text as having different meanings in the hands of different people. Further, it aligns with SPN to be comfortable with this type of reading and writing being outside the typical realm of critical work (Nash, 2004). That is, SPN is free from the constraints of traditional ethical constructions of academic discourse by its label of SPN, and through that label, the author should invite debate over the very notion of text as representation of truth (Nash, 2004). And, according to Dolby-Sahl (1985), it creates a “procedural safeguard where researcher can claim a reliable methodology without compromising any ethical concerns” (p. 55).

By using the SPN of my experience as a lesbian mother of a child with a disability and a graduate student as a location for applying my chosen theoretical lenses, I will help illustrate to the reader the ways in which truth becomes an impossible concept, one that changes dramatically with the application of different perspectives. Much like Robert Nash's (2004) description of one of his students, I see this project as uniting theory with practice.

He [his student] was able to punctuate his philosophical investigations into the strengths and weaknesses of postmodern theory by referring often to both his personal family experiences and his professional work with students and colleagues. Postmodernism was more than an obscure philosophical system to Dave [Nash's student]. It was an actual way of being, something to be lived as well as theorized. (p. 106)

While this project is valuable to myself as an exercise in analyzing a period of time in my life, my SPN is also valuable to the reader's understanding of truth production, the various ways that a feminist disability studies perspective can help one understand how truth can be and produced, and how other graduate students may benefit from integrating their lived experiences into their graduate education. This becomes helpful to higher education practitioners and researchers as they seek to create pedagogy, policies, scholarship, and mentorship/socialization for graduate students who are navigating different stages of life. By understanding what my experience as a graduate student, with multiple identities was in while in the classroom, I hope to contribute to the field's understanding of the multiple and conflicting identities of graduate students and how to better integrate them into graduate education.



### **Narrative Methodology**

Far from representing the “ease of self-indulgence... an analysis of the generic conventions, themes and personal frames of reference” (Dolby-Sahl, 1985), I will argue that my story, by its very nature of being a postmodern feminist disability studies SPN, is useful to the field of higher education. My narratives presented in chapter 4 will be used as a model for how theory can become practice as “time has traditionally been incorporated into educational research as a variable to be controlled, managed, or manipulated for the purpose of advancing instructional objectives...educational studies of time are rooted in the modernist conceptions of segmentation and linear progress” (Slattery, 1995, p. 612). My narratives do not adhere to that process and instead progresses and regresses to rewrite truth that felt real at one time but later became false through nothing more than a change in perspective, or an increase in one aspect of my student identity over the other.

These shifts in my perspective of truth as explored in chapter 4 become particularly valuable when thinking about ideas that have a great deal of social meaning tied to them: family, doubt, loss. How one constructs the truth of such weighted subjects has functioned differently over time. As Hillyer (1997) notes when discussing Jill Sager’s writing about her child with a disability,

She [Sager] used repeated retellings of her stories to protect herself from her emotions, keeping the stories vague so that she could be distant enough from the feelings to survive. And yet, with each retelling she creates an opportunity to remember the feelings, when she has distance enough and support. (p. 36)

Here Hillyer notes the impact of the retelling of stories and the way in which truth is constructed as both protection and a memory. This gives the story told by one person a life outside the bounds of which it was created. Hillyer (1997) asserts that the conscious reader of biography “must simultaneously respect the woman’s own words, recognize the biographer’s or editor’s relationship to those words, and honor herself as reader. In doing so the boundaries of correctness, both academic and political, are likely to be transgressed” (p. 40).

Trauma or grief is a location where storytelling has a specific engagement with truth beyond relating a description of events. Marie-Luis Gaeten’s (1989) study of German women’s autobiographical accounts of the Nazi Germany furthers this idea as the women she studied “use memory to avoid understanding the past, to falsify it” (p. 55). The women Gaeten (1989) studied cooperate with “the social production of memory as a legitimizing ideology for a social order based on forgetting...[the women] internalize this system of amnesia upheld by the society in which they grew up” (p. 57). The pressure of family members to not discuss their grief over disability may be similar to the pressure minority groups feel to present in ways that counter negative stereotypes or assumptions. This pressure can “distort their narratives as it increases their pain...to disguise the pain denies the human connection, whether the disguise is meant to satisfy the demands of scholarly objectivity or those of political activism” (Hillyer, 1997, p. 42).

As Hillyer (1997) states, this illustrates how “to remember what society has insisted we forget is both an affirmation of self and an assertion of political competence” (p. 37). Sharing autobiography, or the telling of one’s story, particularly one that contains the less celebrated human emotions, is an act of political assertiveness. Hillyer makes the

argument that our stories have meaning outside of the individual seeking to understand themselves. This is because these stories are “based on the insights we did not want to have, because knowing produces grief and requires action” (Hillyer, 1997, p. 37). This project is both the telling of stories and an academic action.

### **Methodology**

I will use a number of artifacts to inform my narrative project. The first is the simple communication between myself and others regarding the birth, and subsequent development of my children August and Greta from April 23, 2009 through April 23, 2010. This is in the form of emails (mostly between my partner and myself) about the events, and our feelings about them, during this time period. All of these records, as well as text messages sent and received during this time, inform my narrative and will be quoted within it. To document my mindset and feelings during the time I will rely on entries in my personal journal as well as other non-academic (meaning not the result of assignments) writing.

Further in January of 2010 I began coding the notes that I took during all classes from this time period to May of 2011. I used the code “CP” written in the margin of my notations to denote times when I was triggered to think about Greta’s diagnosis, health, future, etc. These instances will be featured prominently in my narrative as they illustrate the amount of time I spent thinking about disability in the classroom, as well as my ability to rapidly shift identity from student, to a student preoccupied with doubts, and to a student consumed with feelings of loss.

Finally I will draw on medical records from the time period of August 23, 2009 to July 1, 2011 of both myself and my daughter. I will use pseudonyms for any medical

personnel and will avoid including any identifying features or descriptions. These records not only verify the dates and times of my narrative when my identity was that of a mother of a child with a disability first, they also help the reader understand the medicalized model discussed above and my struggle with a system that was at times liberating and at other times limiting; allowing my narrative to move in those contradictory spaces explained above. I spent considerable time with this material while constructing this project reflecting on the feelings and emotions each piece artifact or remnant made me feel and then constructed the narratives in through their various lenses based on these feelings. At times the feelings of family were foregrounded most strongly, and at other times loss or doubt were felt most strongly. These emotions helped guide the constructs that created the narratives of chapter 4.

All narrative material will be informed by the vast postmodern feminist disability studies scholarship I have reviewed in chapter 2 and as a SPN piece of writing will blend both academic work with narrative stories about my experience. My SPN project will create space for not only postmodern feminist disability studies to play out in the real world, but also for my experience to be considered valuable in making recommendations for how this framework can further the work of higher education scholarship to honor this type of authenticity and more importantly, to create pedagogies that allow for the lived experience of graduate students to inform the work of the classroom.

Each narrative, with its clearly outlined construct (family, doubt, loss) will cover the same period of time but will present different aspects of my graduate student identity that were most prominent under the chosen construct. As mentioned previously this method does not produce one true story as a culmination, but rather uses my experience

to illustrate the complexity of truth. Though many aspects of the three narratives will be telling the same story, the same moment even, by switching the focus of my graduate student identity in those moments I hope to offer the higher education community a glance into the complicated way in which graduate students navigate the learning process.

### **Scholarly Personal Narrative Framework**

Being that SPN is a relatively new method of research some of the assumptions, methods, and analysis look different than other more traditional research methods. Perhaps the most important distinction is the key terms of importance to SPN as they guide the work of SPN. In a work of SPN; vigor, subjective experience, personal testimony, perspectives, introspective questions, universalizability, personalized experience, plausibility, honesty, coherence, and illustrative embedded references is the language of research (Nash & Bradley, 2011, pp. 82-85). These are different than the typical research guidelines of traditional research such as; experimental design, evidence, prior research, data, interviews, samples, validity, replication, limitations, and objectivity (p. 81).

While these two lists do not necessarily contradict one another, they do promote the production of different research. SPN values vigorous writing that takes risks and can be both “expressive and emotional” (Nash & Bradley, 2011, p.82) and scholarly at the same time. Writing that investigates and presents, with analysis, the inner life of the writer by providing personal testimony that is influenced by the writers own perspective (p. 83). This is a constructivist approach to research where the researcher “constructs as much as describes, the phenomena being studied” (Nash & Bradley, 2011, p. 83). Rather

than interview questions, the SPN researcher asks introspective questions guided by the needs and judgment of the writer. Rather than trying to measure the success of a SPN project through replication, SNP asks the researcher to consider universalizability, or more specifically, can the researcher connect with common existential themes...that touch us all?" (Nash & Bradley, 2011, p.84). Similarly, the SPN researcher acknowledges limitations by highlighting that the research is based on their specific experience, and thus SPN research must be plausible, honest and connected. Finally, while some SPN research eschews the concept of literature reviews all together (this project clearly does not), the style does support embedded references that support the emotion or feeling intending to be conveyed (p. 85).

### **Summary**

This chapter has outlined the research design of this project. It has provided support of the importance of storytelling and how influential it can be to learning. This chapter has also provided the methodology of this project, to offer the reader three narratives covering the same period time but with different aspects of my student identity being the primary focus (family, doubt, loss). This project will draw on personal communication, coded notes during the time period discussed, and also medical records and reports. While there are ethical considerations of the a project such as this, the previous section provided a postmodern explanation for how I can navigate these and will also address these limitations in more detail in chapter five. The following chapter will provide the findings of my project, or more specifically, present the three narratives described in chapter three.

## Chapter 4

### Prologue

I was a working mother, a mother who not only worked but who also attended graduate school as well. I knew who I was and I knew what I wanted. Prior to the fall of 2008, my role as a student of a higher education administration graduate degree had been mostly unmarred. I had spent my time in the classroom making distinctions between myself and others, between research that mattered and research that did not. I was not here to complete the requirements K-12 administrators had to meet to remain licensed. I, and other higher education students in my classes, viewed their presence as weighing down the pace and making the depth of the classroom shallow. I cared deeply about students, those I considered *mine* by virtue of being their advisor in my job in higher education administration, and even those I passed by everyday walking across campus. I was also a feminist mother. I could distinguish myself from other students in hundreds of way, but perhaps most important to me was that I was a feminist, lesbian mother who already worked in higher education and *just* needed those three letters ('p', 'h', 'd') after my name to begin my promising career.

I valued my family, a family I felt I had built, believing that myself and my partner, Shana, were the roots of our family tree and that all who would come after would grow outward from us alone. I valued my theoretical foundation as a feminist woman and a lesbian woman with a firm commitment to social justice. I eschewed the myth of meritocracy publically, but somewhere inside I often felt if I worked hard enough I would build a life for myself and my partner and our then 2 year old son Jackson built entirely on my hard work. I knew life was complicated, I knew compromises needed to be made,

but I was not accustomed to making them. I believed in reality, in right and wrong, in yes and no.

I offer this description honestly, aware that I do not necessarily come off as easily likable, to begin this narrative of 2 years in my career as a graduate student. During these years, my twin son and daughter were born and I began to understand reality as fragile and experience learning in differently. Using the lens of family, doubt, and loss, I tell will tell the story of these years three different times.

### **Family**

#### **Fall 2008**

**September.** The day I discovered I was pregnant, it was in my typically neurotic fashion. Having been trying unsuccessfully to conceive for just a few months, I forced Shana out of bed before dawn to squint with me at a slice of paper, no larger than a postage stamp, which I had liberated from its plastic holder to see better. It was nearly translucent and I was certain there were two pink parallel lines present (indicating a positive result); you simply had to hold it up to the sun to really see. I neglected to explain that this test was 12 *hours* old (they become invalid after 10 *minutes*) and that I had fished it out of the trash where it was hidden because I knew I should not be taking a pregnancy test this early in the process, as even the most liberal timelines suggested detecting pregnancy this early was impossible. By the time I confessed my actions from the night before up to the past 5 minutes, our 2 year son Jack had toddled out of bed and joined us in the sunshine.

Wordlessly we dressed for the day, the unspoken was that immediately after we dropped Jack at preschool we would be raiding the shelves of the closest drug store for



more tests. Having had some early hopes dashed before by my eager assertions in previous months, Shana was slow to trust the reliability of the dried up old test and found my giddy enthusiasm grating. She shooed me out of the car once at work with a bag of newly purchased First Response pregnancy tests clutched in my hand, dismissing my assertion that we should instead go home and celebrate our good news.

A few minutes later in a grubby bathroom stall, I sent her a picture from my cell phone: two bright pink lines. I met her at the car 5 minutes later, using one of my coveted personal days to take every possible pregnancy test on the market, joyously hugging and clutching each other as test after test produced two lines. We called ourselves *officially pregnant* when the fancy digital test wasted no time in producing the word “PREGNANT” in the plastic window. We ate cake for dinner and sat outside long after Jack had gone to bed watching the sun set across the September sky and marveled at how this day fell just a few before Shana’s birthday. We laughed as I secretly slipped into our house to stuff all the positive pregnancy tests into a wrapped box and present it as her birthday gift. We held hands feeling drunk on love and let the mosquitoes bite, oblivious to their sting in our blurry and blind happiness. Here I was, having it all.

Green with nausea I sat through my classes and tried to glow. I was proud and considered myself a consummate professional as I discretely vomited in strategically placed trash cans in restrooms and guzzled ginger ale during my evening classes. Crammed into a beyond-capacity classroom learning about higher education policy, my table mates eyed me suspiciously as I nibbled saltines. This would end, I reasoned; I remember being sick from my first pregnancy and knew this would stop but when it didn’t I missed a class, then another, then another. I felt like a failure and composed

lengthy emails trying to blame anything except this absolutely female failing of *pregnancy*. I could fix this momentary lapse of being a consummate professional student later, I would explain and rebound my efforts, and this would be a situation of temporary weakness I reasoned.

**November.** The day I discovered I was having twins was with an atypically banal fashion. Heavy with an already protruding belly and snappish from the nonstop nausea that plagued me incessantly, Shana, Jack and I set out on to my 12 week ultrasound appointment. Considering ourselves pregnancy veterans, we ran errands before the appointment and ascribed no magic to the date like those other silly women we scorned who adorned their email signature with fetal due date tickers. We didn't expect magic, we expected affirmation. Instead we were met with something in between: twins.

Was I shocked, certainly? Overwhelmed, a bit? But mostly I felt vindicated! I quickly emailed the instructor of the class that so far I'd had abysmal attendance in and told the professor that I'd been ill not because I was a weak pregnant woman but because I was carrying twins! I didn't realize until that moment that I had carried the fear of being perceived as weak. The professor's quick response promising me that we would work together to summarize the missed classes assuaged the worry I had only begun to acknowledge existed. I work late at night to make up the work I've missed and manage to pass and even smile for the class photo a classmate requests on the last day, I go home and sleep for 16 hours.

### **Winter 2009**

**January.** This pregnancy is difficult. It is hard to admit this to myself, but night after night I sink, out of breath, into a chair that nearly explodes under my girth. I give

up appearing graceful. My strategy had been, as with past classes, to work hard and make every possible effort to be a dutiful and diligent student. I volunteered to do all course presentations first, hoping that, while elephantine in February, I would most likely be present, whereas with a due date of May 9<sup>th</sup> pushing projects later in the semester was asking for trouble.

**February and March.** I spend the majority of my free time perusing the internet for pregnancy tips with twins and decided to mentally file away the terrifying tales and keep the two most pertinent pieces close to my mind: expect twice the effort and twice the wardrobe. Both were true. My mind was racing during every class and focusing on everything but the content of the course. I wanted to portray the superwoman who could do anything but increasingly found myself snapping at fellow students who wanted to tell me about the miracle of homebirth. I was embarrassed of my giant stomach and the way in which everyone from the students to the instructors would watch the twins pitch and twirl against the fabric of my blouse. After one memorable class where I spent the second half counting contractions and promptly drove myself to the hospital during break, I had to admit I could no longer keep up the pace and needed to stop attending class. I wanted my family, even my then tiny one of my partner, my son, and myself, to be proud of me and I still clung to the hope I could fix this damage to my reputation as a student after the twins were born. The driven professional in me felt a loss, but the mother knew best. There came a time to focus my energy on other things, and perhaps, I reasoned then, growing two infants was enough work for one woman...at least for a while.

**Spring 2009**

**April.** On April 23, 2009, baby A and baby B were born. I was induced at 36 weeks and 4 days and pulled off the natural delivery of both twins despite baby B turning breech, requiring 25 minutes of various medical interventions to turn her around. I waddled into the hospital that day knowing they would be born, yet it was still a surprise to see them. Baby A, named August (Gus) was born with a tuft of white blond hair and skin so fair it was nearly the color of eggshells. Baby B, named Greta, was born with a full head of dark curly hair and skin the color of gingerbread. He was 17 inches long, and she, nearly 22. They didn't even look related, let alone like twins.

It felt as though I did indeed have it all. I had impossibly passed one of the two courses I was enrolled in and received an incomplete in the other. True, I was accommodated; I didn't climb an invisible ladder of success whose rungs only became visible with my masculinized ambition. But I was comfortable in my feminist success. I read ahead, I turned in work early, I summarized classes I missed, and I was a competent student using the flexibility of higher education to progress, leaving no gap.

In a photo taken of us leaving the hospital Shana, Jack, and I, posed behind the twins, strapped into their mammoth car seats in which they were barely visible. A few hours before, a team of doctors had come into my room to inform me Greta had failed her hearing test in her left ear. The senior physician, a person I've never seen and have yet to see again said, "99% of the time it is just amniotic fluid in their ears, we'll schedule a follow-up for you in a few months." I took this news in stride, I believed in the power of statistics. If graduate school had taught me anything it was to believe in the power of numbers.

Once home, I became acutely aware that I was now, for 12 weeks, just a mother. Not a student, not a professional. It was just me, Shana, one toddler, and two infants. Jack suddenly seemed too large, too dangerous to be near such tiny creatures. Everything in our house seemed different with the twins there. All at once, the pack-n-plays set up in the dining room, the tandem swings, and bouncy seats and cribs that had lain untouched for months, came to life.

The calm of those first days was unsettling. I checked my email more than was normal and after the third electronic admonishment to stop answering silly questions and enjoy my family I did. I had expected bedlam with newborn screams echoing off our walls and days upon days of no sleep. There were tears, and I became well acquainted with late night television, but it was eerily manageable. When I was still pregnant, I worried constantly about the introduction of not one, but two, new lives into our already pretty happy family. All those hours looking up information on twin births, all the things that could have gone wrong: micro preemies, the NICU (neonatal intensive care unit), preeclampsia, gestational diabetes, breathing problems, sibling rivalry. I had been certain I would dodge fate's unsteady hand, if only through the power of research. And yet, somewhere in the darkness I allowed myself to think these bad thoughts, but knew I could face whatever happened if only I could be *prepared*. An assembly line of bottles stretched across our counter top and each color-coded basket contained the correct assembly of items needed for each day.

But Jack loved them (calling them both "Greta") and insisted on holding them for a few minutes before growing bored and running off. They were both born healthy and never even visited the NICU, instead they roomed mostly with me in the hospital. I was

able to produce enough milk for both of them, although Gus never quite got the hang of nursing. As the dogwood tree in our backyard bloomed giant white flowers and as the scent of lilacs floated through the windows, I allowed myself to breathe a sigh of relief.

### **Summer 2009**

**June.** Gus got acid reflux. Here it was, finally, the source of that nagging feeling I had akin to waiting for a shoe to drop, or so I thought. He screamed mercilessly for hours on end after eating. We tried every medication, every trick, every remedy, but the only relief we had was tightly strapping him into a constantly moving baby swing to sleep. This produced a metronome-like clicking punctuated by his sharp intermittent shrieks night after night. During his hours awake he had to be bounced by one's foot at maximum speed in a baby bouncer. It seemed he had to be moving at all times, and yet hated riding in the car. After a horrible trip to the zoo where Gus screamed for over 65 miles, we became shut-ins.

Dark circled grew around my eyes and Shana and I began to snap at one another. "Did you give him his medicine?" she'd ask accusingly as he spit up through his nose causing him to choke and gag and begin to whimper. "Of course I did!" I'd snip back, "here give him to me, you're not bouncing him hard enough." All the while, peaceful Greta slept in a little Moses basket, swaddled in a green and orange blanket that made me think of Princess Tiger Lily from *Peter Pan*. She looked on at Gus screaming and squalling with a moderate expression of disappointment regarding his lack of proper infant decorum. Jack had become terrified of Gus and his extreme fussiness and instead preferred to have Greta visit him in his room where we placed her into her baby seat as

she sat rapt, while he showed her books and performed plays for her, nearly always smiling and wanting more.

**July.** Every pediatrician's appointment looked the same. We tried to convince our doctor that Gus has some kind of pediatric personality disorder that made him scream 85% of the day, and she would say it was colic and would pass with time. On several visits, I remember her holding Gus, clad only in a diaper, beet red from screaming, as she slowly examined him looking for a possible cause for his rage. I have no memory of her holding Greta. I know she must have, but I can only recall seeing Gus wiggling in her arms. She liked to joke that boys were horrible infants, but just wait until Greta was a teenager, *then* we'd wish we'd had all boys. I found her extreme perkiness and penchant for stiletto heels annoying, and her dismissal of our fatigue with such a difficult infant even more so. But by now I had devoted the same energy to being the consummate professional mother, as I had student and worker so I only agreed.

Greta, despite her pleasant personality began to generate her own concerns. Shana noticed that she, even at 4 days old, kept her tongue permanently stuck outside her mouth. She looked like she was waiting to catch a falling snowflake. I remember Shana telling me she seemed different than our other babies. You could lift Greta up by armpits and her legs would stiffen so woodenly that she could practically stand on her own. I wanted so badly for things to be okay after all the worries of pregnancy and the drama of one colicky infant that I just dismissed her concerns, citing that all babies were different and this was our easy one, let us not borrow trouble I thought.

**Fall 2009**

**August.** Summer passed and fall took hold. I foolishly returned to work and classes and the results were predictably disastrous. That is, I resembled something out of a bad Hollywood film about those silly women who think they can have it all. Dark circles ringed my eyes and I pumped milk with an electronic (state of the art) pump carefully plugged into a bathroom wall socket. I had such trouble prying myself away from my former position as mother extraordinaire, I found myself fumbling with my coursework.

I remember the first day of a class devoted to the professoriate. We were instructed to draw life maps on large scrolls of white paper. I scrawled a series of poorly rendered pictures of myself. One of me working at a computer, one reading a book, and then, large and thick at the edge of the paper a stick figure of myself holding two babies with a giant question mark above my head. I was so far into the thick of juggling work and school and mothering that beyond just living the present, I could not see any future, whether good or bad. I still had it all, I reasoned to myself, as I continued to pump breast milk in bathroom stalls; I just could not have it all at the same time. Tucked safe in my feminist ethic of self-care that equated success with happiness, I pushed through to the middle of the semester, ignoring the work piling up on my desk, the readings I could half understand under the intellectual drain of exhaustion. Time could cure this I was sure of it, I just needed a little more time than I had originally estimated.

**September.** Holed up in our house one particularly dreary day, we decided to feed Gus and Greta baby food for the first time. Gus took to the smashed avocado like a professional, devouring an entire half and looking around greedily for more. Greta turned her face away at the spoon; she even struggled against it. A few weeks later,



Shana called me into the kitchen where she was feeding Gus a jar of peas. “Watch,” she said pointing at Greta. Greta tried to eat a spoonful but her tongue thrust from her mouth, pushing the food away and causing it to pool under her chin. I tried to feed her with the same results. “I don’t think she’s ready for solids,” I reasoned, but Shana’s eyes were filled with worry.

I barely remember this lost fall of managing two infants, returning to work, and returning to being student. I realized with some concern that my calendar was slowly getting gobbled up by the demands and the needs of these infants. Although constantly drowsy from my lack of sleep and physically depleted, I one day thought about Greta’s failed hearing test and the follow-up appointment that was never made. I called the pediatrician’s office and after two or three telephone transfers, finally reached audiology where I was able to set up an appointment to do a more thorough test.

Greta looked different the day of the test. Shana had dressed her in a pink shirt and a denim skirt with silly, useless shoes. I was used to seeing her in warm pajamas or little zippered one-piece outfits that said inane things like “I love kisses” and came from a giant box of hand-me-downs. I felt like it was the first time I was really seeing her, first at home and then at the audiologist’s office where I was able to see her through other people’s eyes. They looked at her longer than what felt comfortable, as though they were studying her. It was unsettling and kicked in that niggling worry in the pit of my stomach again.

I held her still as instructed, while they tested her hearing. They attached wires to her head that measured her brain waves at the recognition of sound. Her right ear was fine; the clinician turned the machine off after just a few minutes describing her hearing

in that ear as “perfect.” Her left ear was set up and after a long silent 15 minutes, the clinician said “you need to see another doctor, she’s not registering enough sounds.” It wasn’t news to me, I had been pretending to preen and coo over Greta so she would sit still, but out of the corner of my eye I was watching the machine click by producing sound after sound with no change on the glowing green counter mounted in the center. I called Shana from the parking garage, “she failed her hearing test again, and we need to see an Ear, Nose, and Throat (ENT) specialist.” “Okay.” Shana said, but there was coldness in her voice; we both began to entertain the notion that things just might not be okay.

Did I share this news with colleagues and fellow students? In bits and pieces I doled out the parts about ENTs, and non-stop screaming mingled carefully with amusing anecdotes to maintain the storyline that I was lucky. Lucky to have carried them so long. Lucky that they were healthy. Lucky. In return, I smiled politely through story after story of twins other people knew: their cousin, whose twins spent 45 days in the NICU; their sister, who was on bed rest her entire pregnancy. Even worse, I tolerated the daily intrusions of strangers who flocked to us in grocery stores wanting to know whether our twins were identical, to tell us, complete strangers, how they had always wanted twins. The world looked blurry through my gaze of fatigue, and these interactions passed by me like conversations with ghosts. And yet, ghosts whom I convinced with dedication that certainly these twins were the most exciting and amazing thing! Who was I to question what everyone else saw as a gift?

As they began to sleep more I began finally having enough energy to actually worry properly, and I took upon it like an escape. Additionally, I made giant binders of

Greta's mounting medical information and called the doctors who gave us appointments months away begging for an earlier slot. This, I thought, is what good mothers do; this is the magic that wards away the danger.

**October.** After securing visit to the ENT, what seemed like a few short days later, Greta underwent surgery to put a tube in her left ear. "It will drain the fluid from her ear, once we get that out, she'll hear fine," the kind ENT (who yelled mercilessly at his staff) said. After surgery, Greta was drunk on the gas they blew into her lungs and sick from the sedatives they pumped through her I.V. She slept, for hours, slumped in her car seat in a quiet corner of our house.

After Greta recovered from surgery, I took her for a follow-up appointment where her hearing was retested. She again failed the hearing test in her left ear. We were told Greta would have to undergo something called an auditory brain stem response (ABR) test that required her to be sedated and lie still while a machine produced different sounds and projected them directly to her brain via electrodes and then recorded her brain's response (or lack of response). The sedative they gave her did not calm her but made her restless and frightened. The exasperated anesthesiologist insisted we cancel the test; it was too close to 5:00 to re-try with I.V. sedation. Arranging for someone to watch both Gus and pick up Jackson from preschool was so difficult that I begged the audiologist, desperate, to tell me if she could decipher anything from the small amount of testing she was able to complete. She said she had some information but we would have to talk to the doctor later, maybe tomorrow, maybe next week for him to explain, she was not "allowed." We left, angry, with an exhausted Greta whose forehead was covered in red patches from where the electrodes tore off her skin.

The ENT (who still yelled at his staff) was baffled at the few numbers the giant machine had produced during the few moments Greta was still enough for any data to be collected. Over the phone he asked me to come in and see him. I sat, with Greta on my lap facing him, and asked “do we have anything to worry about here?” He sat down, rolled his seat closer and said “yes.” He wanted her to undergo genetic testing. He said her ears were low set, her eyes had epicanthal folds, her tongue protruded from her mouth. He said there were a number of genetic abnormalities associated with this set of traits. He promised to get in touch with our pediatrician to urge her to write the referral for the necessary tests.

I was so hungry for a break from feeling like a failure at home that I clung to education like a life raft. I was still making progress in my doctoral program I reasoned, I was certain I could make it to that glimmering finish line. Maybe now instead of sprinting, I would be limping my way there, but I would not fail; I was certain of that. In addition to the class that began with my artistic rendering of my maternal and professional incompetence described above, I was also enrolled in a course that examined work and family. The irony was not lost on me that I spent the majority of this class conducting internet research on Greta’s symptoms, too consumed with my own family to effectively argue when the professor insisted work was only labor for which you were paid and families were only biologically made. I had to conserve my fight for other locations in my life.

At Greta’s next pediatrician appointment, Shana brought with her a jar of food and tried to get perky pediatrician to watch how her tongue thrust the food out of her mouth. Perky just laughed at our worries and said “I have no concerns about Greta.” I

cannot explain how difficult it was to continue insisting something was wrong with Greta. There is a strong motivation in society to insist your child is normal, exceptional even, not to constantly look for flaws and deficits. By bucking this social convention, Shana and I were treading dangerously close to bad mother territory. Vague remarks were made in Greta's medical notes about this phenomenon: "parents seem overly concerned" remarked perky pediatrician in her dictated narrative following this appointment. She also noted "she [Greta] has a high-pitched voice that is described to be extremely annoying by parents" written after a conversation where I explained that Greta's high pitched screeching made Gus cry. I do not recall using the word "annoying" but I do not deny it either. Was it so wrong to have become, after hours of wailing from all corners of our home, annoyed?

**November.** But whether annoyed or not, we got perky pediatrician to finally write us the lab slip for the blood test that would take 4-6 weeks to come back and would locate any genetic abnormalities. In reviewing the notes regarding this test, perky pediatrician had written "screen for mosaic down syndrome and other explanations for child's dysmorphia," so it seemed we were not the only ones taking note of all the difference written on Greta's body.

It took three tries and two different hospitals to get her blood collected. We ended up in the hands of a sweet, but swift, pediatric nurse who finally got the needle in. We drove home with Shana yelling at me, "why did you let them stick her three times, you should have just demanded the pediatric nurse right away?" I shook silently in my seat, crying and sick with guilt. I know Shana was just scared. I didn't yet know what it meant to demand things of medicine.

**December.** By now, the semester was coming to close. I was finishing work for both my classes and my final paper for the class in which I had earlier produced the life map required a more detailed future plan. I wrote that I wasn't sure that I would be able to continue being a student anymore. I was bracing myself for the worst, padding my cell in preparation of devastation. I could now see a future and it looked entirely unfamiliar to anything I had ever known. Was it back logged sleep deprivation or a premonition? Either way, I wrote a depressing paper where I was encouraged to think about my future. I was specifically short-sighted, for fear of putting dreams out for the world to read that might never, could never, be realized. I wrote awkwardly, "Though I fully intend to continue on my career and education track, a recent family health situation has made me ask the hard questions...what if I never finish this PhD or even this semester?" (Jennrich, 2009, p.7). I guarded my aspirations as though they were something that could be stolen. I used this paper again after it was handed back, as a piece of scrap paper to quickly jot "9:00 Greta appt.," marking yet another venture to perky pediatrician's office. That my papers would now be seen as scrap seemed to perfectly describe how quickly my dedication to my role as a graduate student had shifted from dogged dedication in September to distinct defeat in

**December.** I had to plead my case for a 'B' in the work and family class because I missed too many classes. It was a tone I was becoming more skilled at being able to strike. Much like the forced exuberance with which I used to talk with strangers when the twins were newborns, this type of interaction required a script as well. First, I would listen to the things I had done wrong (missed 3 classes when only 2 absences were allowed, did not contribute enough to class discussions). Then I would thank the speaker

profusely as they stated without conviction that I was a good student but needed more focus. I would cock my head at an angle that indicated sympathy and arrange my face accordingly as they told me about the person in their family who has a disability of some kind and how they turned out just perfectly despite doctors insisting they'd be better in an institution. I would smile in a kind and agreeable way that made them understand that I also knew that Greta would be just fine, and that whatever happened I would always be her biggest supporter. This last piece is important as you have to be careful not to appear the least bit bitter about the situation or fearful of the future; you must seem confident that whatever life decided to throw at you, you will take it and make the best of it. I wish I could say I did not have to repeat this conversation over and over throughout my career, but I include it here specifically because I did it so much it became a performance for which I had perfected. It sounds manipulative, but this is how I completed yet another semester of graduate school, and would complete several more.

At home the strain of the constant screaming from Gus and the parental anxiety around Greta was starting to take its toll on Jack. I am certain he noticed our preoccupation with Greta, our conversations in hushed tones, and the meaningful silence between us as well. Jack seemed to inhabit a love similar to that described in Judith Butler's 2002 essay *Doubting Love*,

Love is not a state, a feeling, a disposition, but an exchange, uneven, fraught with history, with ghosts, with longings that are more or less legible to those who try to see one another with their own faulty vision. (p. 63).

His three 3 year old mind processed change as danger; he stepped carefully, and I became the first recipient of what I now know to be his fake smile. A smile that communicated a

desire for me to be recognizable again, that made me compulsively run my thumbs over his smooth face, straining with my finger tips to communicate my presence. “I’m still here Jack,” I wanted to scream, but was I really? It was clear he loved me but also clear he was seeing me through the faulty vision of a child trying to reconcile his protector becoming his destroyer.

The stress made me snap too quickly at him, “Jack just let Gus have it!” I’d shout when he protested to the grabbing of one of his favorite toys. It made me overly permissive as well. Too tired to argue, each night I built him a *dinosaur nest* (pile of comforters arranged in a vaguely circular shape) on the floor of our living room where he would sleep open mouthed, basking in the glow of the endlessly looping dinosaur movie he insisted on watching, surrounded by bowls of melted ice cream I dished out at 3:00 AM while I slept on the couch beside him.

Half rotted leaves flew upward, caught in the brisk wind and plastered themselves to our windows. Fall slunk away and winter came upon us. But it was Christmas! Despite being atheist/agnostics, we celebrated Christmas down to its bones. There was the typical giant tree, matching Mr. and Mrs. reindeer salt and pepper shakers, a looping illuminated swath of evergreen garland circling our staircase that were decorated by five matching stockings. In each room, some holiday cheer was placed. We made cookies and spent hours punching out Santas and snowmen and trees and candy canes. Shana and I held frosting contests, coloring mountains of white icing in different hues and painstakingly brushing the icing onto each cookie only to have Jack devour them and erupt in a sugar inspired grin announcing us both the winner. It was a shallow attempt to



right the leaning ship that had become our lives; Shana and I figured, if Christmas could not fix things what could?

I began drinking wine at night, to “calm down.” Sometimes it made me brave enough to ask Shana what she thought about Greta. “She’s probably fine,” she said. But viewing history on our computer and her absence in our bed at night told a different story: pages upon pages of websites, blogs, and message boards all devoted to mosaic down syndrome and various genetic anomalies. Sometimes Shana was the one to ask me, usually calling me over to the computer screen to look at rows of children’s photos, “does Greta look like them?” “Sort of,” I said just wanting to get back to watching “It’s a Wonderful Life” or writing Jack’s Christmas list, refusing to look at these smiling children and even consider that Greta could be like them. I was ashamed of my instinct to turn my face away and make these children disappear. I allowed Shana to be the student, my inclination toward research to dissolving into a preoccupation with family centered activities. Shana, though, was methodical, reading article after article. At night, she paced the house until the medication given to her by her doctor to help her sleep finally let her rest.

When Christmas day actually came, our fears over Greta lay like a dead body we all politely ignored, stepped over, walked around, for the good of holiday propriety. Each toy was lovingly placed under the tree and wrapped to induce maximum excitement for Jack (the twins being only 8 months old, were content to eat wrapping paper and fight over ribbons). The precision and sudden confusing rage with which I removed the decorations on January 1st marked my desire to escape this whole frustrating worrisome situation, like I could pack it back into a box and store it in the garage.

**January.** It was Gus that led us to a revelation about Greta. As I waited for a medical test for him related to his bent neck (torticollis), I played with him using a little plastic ring that linked toys together. I watched him pass it from hand to hand and realized that Greta did not do this. Quickly I texted Shana, “can Greta pass toys from hand to hand?” A long delay and then the return text, “no, she won’t use her left hand at all!” As soon as Gus completed the CT scan and was pronounced fine, I rushed home to find Shana sitting with Greta, mountains of toys surrounding her. “Look Jess, she won’t open her left hand!” How had we never noticed this before, I wondered? Shana’s desk, askew with the monitor on her computer tilted at a violent angle and the keyboard dangling, produced a photo slideshow of all photographs taken of the twins and in each and every one Greta’s left fist is clenched in a tight ball. I ran to the phone to call our pediatrician’s office and was forced to leave a message with the nurse. Perky pediatrician herself called back to say that Greta needed an MRI. When I asked about coordinating it with the other failed ABR hearing test so she would not have to be sedated twice, she said we could not lose time waiting for that. While I wanted the MRI, I was almost glad we would not have to wait. The beginning of the semester was looming ahead and I tried to imagine myself juggling these new medical issues that seemed to be stacking up faster and faster during the academic semester and knew I would fail. I asked what could be causing her hand to be stuck in a fist and she rattled off a list of conditions, none of which I understood or had researched, “try not to worry so much!” was her farewell.

Things seemed to move fast, to spin out of control. Shana yelled from her seat at the still impossibly angled computer, “she has what’s called thumb in fist posture!” I

asked her to find out what type of things it was associated with. Long minutes of her fingers clicking over the keys and she then said, “cerebral palsy.” “Greta can’t have cerebral palsy, Shana!” I said thinking of children strapped into wheel chairs unable to move, to speak, lolling with their head tilted to the side and drool pouring from their mouth. “Well, sometimes it is an injury to the nerves in the arm,” Shana said after more internet searching. That’s it, I thought. Just as with Gus’s torticollis, Greta probably just injured her arm during her difficult birth. Still the words CEREBRAL PALSY could not be erased from my mind, blinking like a blinding neon monstrosity I could never disconnect.

A few days later, perky pediatrician called us again, this time with the results of the complicated blood test that checked for mosaic down syndrome. She said, not without a detectible note of annoying certainty, “the test is negative, Greta does not have mosaic down syndrome.” I expressed thanks and was happy that on an ordinary Tuesday afternoon when I should have been at work but instead had stayed home, afraid for some reason to let Greta out of my sight, that fear had been put to rest. But my mind still wouldn’t let go; what about her hand? Something was not right.

We had an appointment with a geneticist a few days later. It seemed silly now as we knew that Greta’s entire karyotype, or map of her genes, was perfect, but we went anyway. The day before this appointment, Greta had a seizure. She was in my lap and Shana was playing with her camera. Greta began to look upward and jerk her arms stiffly towards her head where she’d hold them for a few seconds and then do it again, and again, and again. Shana caught it on her new camera. I called the pediatrician’s office

immediately after, they begrudgingly (even the office staff was tired of my constant calls and requests) offered us an appointment 2 days later.

At the geneticist appointment, two doctors looked her over. They asked what felt like millions of questions about everyone in my family, even making us bring pictures of them. They poured over the donor profile of Greta's sperm donor. It was all we had to represent 50% of her genetic makeup. The main doctor, who was the attending physician of the genetics department, was curt, never once smiling or showing even a trace of interest in Greta. He coldly measured all her limbs and body parts. We had brought our laptop and tried convince him to view the footage of her seizure, but he said he wasn't interested. He diagnosed her with hemi-hypertrophy (meaning one side of her body was bigger than the rest). He sighed audibly when I asked him to spell it so I could get more info and barked "don't go looking around on the internet it's not a big deal." Shana and I doubted this diagnosis and asked about her hand, forever clenched in a tight fist. Casually, while leaving the exam room he said over his shoulder, "that's probably brain damage from when she was born" and with that, he was gone.

Brain damage? What did that mean we both wondered? At the time, I had no idea that cerebral palsy is an umbrella term for damage occurring before, during, or after birth, and that it could manifest in a number of ways. My outdated mental images of children in wheel chairs began to be replaced by new pictures Shana pulled from the internet and forced me to view. Pictures of kids in walkers, balancing on balls, wearing brightly colored leg and hand braces all described in pastel fancy fonts to be miracles and gifts from god. Most were extreme preemies who survived against all odds and who had matching sweater families who all ran 5Ks for the cause and supported the troops.

Turning slowly around our house, I used my bulky woolen winter sock as a skates and spun fast enough to make myself dizzy, trying an old witch trick to see the future. Nothing was revealed but our faces superimposed on all those terrifying websites leaving Greta's characteristic smile in perfect place.

The following day at perky pediatrician's office, Shana forced her to look at the footage of Greta's seizure and before the clip had finished playing, perky pediatrician was on the phone with the university hospital securing Greta admission and lining up a visit by the attending neurologist. Shana, Gus, Greta and I, all piled back into our van and drove to the hospital. I knew the hospital from only the emergency room. Jack fell and bumped his head as an infant. He dislocated his shoulder as a toddler. He split his chin on a slippery sink- the accidents and calamities of childhood. I did not know this hospital, with an entire floor of sick children and colorful murals painted on the walls.

All the nurses wore cartoonish scrubs and Greta's bed looked more like a cage with long metal bars all around it. We shared a room with a tiny baby born very prematurely to a teenage mother. Her entire family filled her side of the room and through the curtain they blasted car races and repeats of *Law and Order*. Greta's size and relative health made this baby seem all the more sick by comparison. The neurologists came. They had already seen the video (Shana had wisely placed it on YouTube, as the wireless internet of the hospital was unreliable) and it began to garner an alarming number of hits from medical personnel passing it around. They wanted an MRI, to repeat the ABR, and get an EEG, or electroencephalogram, to measure her brain waves during any seizure activity. All this, we were told, would happen the next day.

Shana had to pick up Jack from preschool and I was left alone with Greta in her giant cage. I chose to stay behind, alone in her room, when the nurses insisted on putting in her I.V. I could hear her screaming from down the hall no matter how hard I jammed my fingers into my ears. I watched the floor warp and thought how wonderful it would be to just slip through the linty linoleum and disappear. I had handed her over to be hurt by strangers with the hopes that I could rescue her and she wouldn't remember me as one of the many faces of those holding her down and hurting her. I slept beside her that night on a broken chair/cot with chiming monitors ringing all night long.

The next day came; Greta was NPO, the abbreviation of *non per os*, or nothing by mouth. This meant she couldn't eat or drink anything, creating one very crabby baby. Her MRI kept getting pushed back, one hour, two, then finally, in a blur, a team in white coats came to get her, promising to reunite us in time for her EEG. Jack went to preschool. Shana had secured a babysitter for Gus, paying twice our normal rate and allowing our seemingly sweet college babysitter to take Gus back to her house for convenience. I knew so little about her that I didn't know if I could trust her driving, or her roommates, for all I knew they were sitting around blowing marijuana smoke in his face. Yet I let him go, wanting, maybe even needing, Gus gone so we could sit in the silence and wait.

When the nurse came back to get me, Greta was disoriented from the medication and mewling pathetically like a cat. She didn't seem to recognize me and flopped listlessly as they glued 25 electrodes to her head ignoring her cries when they poked her too hard. The nurse walked me back to our room, but instead of the double room with the tiny preemie, we were moved to a large white sterile room of our own. Doctors were

hooking up a video monitoring system as they explained that Greta would need to be monitored by the EEG for 24 hours. Every time she had one of her seizures, we were supposed to press a button that would mark the spot on machine recorded her undulating brain waves non-stop. This meant our interactions would be videotaped too. Greta's head was wrapped in layer upon layer of gauze with long trailing multi-colored wires flowing from her head to the machine. So heavy was this set up, she could barely lift her head.

It wasn't long after we got settled into this room that the neurologist, an enthusiastic older Indian man, and his assistant, a less enthusiastic middle aged white woman came to get us. They had the results of her MRI and they wanted to show us something. In his thick accent he beckoned to us to "come and see, come and see." We started to leave then stopped; what about Greta, we couldn't just leave her alone. "You go," I said to Shana, trying to convince her it was my altruism toward Greta that motivated me to stay when actually I was scared to death at what they wanted to show us. "You should both be there," the assistant spoke monotonously from the side of Greta's crib where she was listlessly scraping a toy past the bars on her crib, "I'll stay with her." Greta didn't protest when we left the room, a fact I marvel at still today, that she stayed, happily, with this complete stranger in this foreign setting watching us go with her beautiful, but impression-less, face.

We did not walk far, maybe just across the hall. We were brought into a dim room, intensely overheated, just behind the bustling nurses' station. "Look, see," the neurologist began pointing to two images on a screen. Already, I could see the blotches, the blotches of pure black on one image. I gripped the back of the one of the leather rolling chairs scattered around the room with my hand, dug my fingernails into its flesh,

trying to support myself as I felt unsteady and sick. “Here,” he began, “is a normal brain,” pointing to the unmarred gray photo of two identical hemispheres, and “here,” he continued, “is your daughter’s brain.” “You see the black marks? That is the damage.” I swayed a bit, recalling inexplicably the advice of my despised grade school gym teacher telling us to never lock our knees when under great strain. My knees locked anyway but the unconsciousness I had hoped it would induce did not occur. “It is an old stroke,” he said. He was so convincingly chipper when he continued, “happened a long time ago, never again” that I almost wanted to feel happy too. Then the images on the screen were gone.

“What does this mean?” Shana asked. “A little physical therapy, and maybe she’ll walk late, when she’s three; but she’ll grow up and nothing but a little limp no one will know,” he answered. “I don’t think her cognition will be affected,” he continued. “How will we know?” I barely whispered. “Time,” he called over his shoulder, and was gone. Somehow we were back in Greta’s room, though I don’t have any recollection of walking back. Somehow we were alone. I know neither of us cried, even Greta who greeted our return with a signature smile and went back to banging plastic objects against her prison walls.

Shana called people, friends I think, to pick up Jack because soon enough Jack was there, with our friends, and Gus too. Shana sent me home with a friend to pick up some food, change my clothes, and bring back Greta’s special chair so she could sit up, as the heavy gear still strapped to her head was making her miserable. I drove home and came back with everything but the seat. Fueled by our friend’s inane chatter about why she is afraid of hospitals, I had run through our house grabbing random items in a hurry



to get back and get her to shut up. Shana was mad about the seat, but she was gratefully kind about my forgetting it. She sent me back home to shower and try again. It was clear that even after the MRI confirmed this old damage to Greta's small brain, we would not be released until tomorrow when all testing was complete.

Back in our house, everything looked out of place. It was obvious Shana had been letting Jack and Gus rule the roost these past few days while I camped beside Greta. Odd toys and strange blankets were strewn in unfamiliar places. I showered and felt nothing, not the beating water, not the cold from the tile, nothing. I remembered the baby seat this time. I called my parents who had been alerted that Greta was in the hospital and had been waiting for a follow-up report. I repeated tonelessly into the phone. "Greta had a stroke, they say she'll be smart still. I guess we need physical therapy. I don't know when we can come home." I spoke to my father, a man also of few words. I was thankful my mother, whose talking knows no bounds, did not answer as he mercifully let me go quickly recognizing I did not want to talk. It was January 14, 2010. My winter break from school was set to end in just a few days. While other students rested, spent time with family, and attended parties to ring in the New Year, I watched our family get shattered into thousands of pieces and wondered how I could possibly put them together again.

Back at the hospital Jack had climbed into Greta's crib with her and was making her laugh. Gus began his typical fretting and whining and Shana knew it was time to go. She whispered to me, "Don't talk to anyone about this on camera." Always smarter and shrewder than me, Shana already sensed the hesitancy on the part of doctors to answer our questions about why this happened. She feared I would ask too many questions about

why this happened and set off red flags. As it turned out, I didn't even need to do that much, the medical machine put in place to assuage parents and get them to stop asking questions had already kicked in.

"Why did this happen?" I asked a young resident just coming to do some vital checks.

"Well, he said looking over her file, "she was born before 37 weeks, infant's brains are more delicate then." "When did this happen?" I asked the neurologist coming to tell me Greta seizures were not harmful. "Shortly before, during, or after birth," he said coldly. Gone was the enthusiasm of yesterday. He authorized Greta's release thrusting a two page print out copied from a medical journal about benign myoclonic infant epilepsy, the diagnosis Greta was given when leaving the hospital. To him the brain damage was not something he wanted to talk about, just her seizures, which now having proved to be nothing more than her brain misfiring over the damage, was no longer of interest to him.

Nurses came to scrub the electrodes off Greta's head using nail polish remover. Her scalp bled and she cried as I held her begging them to hurry up. I made a follow-up appointment with perky pediatrician for a week later, and with that, we left. Shana pushed Gus in one stroller. I pushed Greta in another. Jack walked holding my hand while swinging it back and forth, squeezing it tight with his tiny fist. Exiting the doors of the hospital, we were an entirely different family than we were when we entered.

At the follow-up appointment with perky pediatrician, Shana and I had broken our stunned silence and we fired question after question at her. "Why did this happen?" we asked. "I don't know sometimes these things just happen," she answered. "Was it something from her birth?" I asked, "too much Pitocin [a medication used to induce labor that I was given large amounts of], the stress from being turned around, something?" I

nearly begged, wanting so badly to know what happened. “What does this mean for her future?” we asked. “Greta will be fine, I’ve already referred you to First Steps, the early intervention system in Missouri. She’ll just have to make her way a little differently in the world. I know a kid with a much larger stroke who is doing just fine now.”

“So, does she have cerebral palsy then?” Shana asked. “We don’t like to make that diagnosis until age two,” she answered. I didn’t even have the energy to ask why. I packed up our things slowly, not wanting to leave, not wanting this to be true; as if by staying there, we could delay the inevitable of leaving with no answers with nothing changed. I don’t know what I had thought would happen; that she would tell us something different, that this was some mistake. All I know is that I had hoped for a miracle and got the ordinary slap of freezing winter wind in my face instead.

We ate lunch at a tacky family restaurant afterwards, ordering burgers the size of our heads and letting the twins nibble french fries. I cried all through lunch. Shana seemed perplexed. She wasn’t surprised by Greta’s MRI and wasn’t surprised by perky pediatrician’s summary either. Her trusty internet research had been right all along. I kept thinking back to when I was pregnant and Greta and Gus floated inside me, rustling my belly like a bag of kittens. What if her stroke happened when I was in the shower, tying Jack’s shoe, typing a pointless email, enduring an extra-long meeting, in the middle of class even? How could a moment so important just pass us by? It seemed the more I fell apart, the more determined she became to stay put together.

Let’s face it. We’re undone by each other. And if we’re not, we’re missing something. If this seems so clearly the case with grief, it is only because it was already the case with desire. One does not always stay intact. It may be that one

wants to, or does, but it may also be that despite one's best efforts, one is undone, in the face of the other, by the touch, by the scent, be the feel, by the prospect of the touch, by the memory of the feel. (Bulter, 2006, p. 22)

What did I expect, that love, that the unconditional hallmark version of maternal bonding thrust at us from every corner of Western society, would be enough? This sadness felt like a betrayal and, as my meal congealed into an inedible mess, I packed these thoughts away, deliberately shutting the memories of *before* into a category of my brain I was no longer allowed. I had to move forward even, if I was undone by the weight of this grief.

Winter vacation was almost over; I was slated to begin two classes in a few short days. In light of my spectacular failure last semester I had begged a faculty member from the department where I was employed to allow me to complete an independent study with her. Knowing how unstable I was, she kindly granted me the permission to do so. The other class was a qualitative methods course that I began with the dedication and enthusiasm I had approached all of my other doctoral coursework, hoping I could shut everything out when I was in the classroom. I was also hoping that a topic as technical as methodology may give me a buffer from the worry, but I simply could not summon my same dedication.

### **Winter 2010**

The classes were the same, but I had changed. It seemed like every appointment with the early intervention team, so crucial to Greta's acceptance in the program we were told, conflicted with this methodology meeting time. I missed class after class and was finally forced to break down and tell my instructor about Greta in a repeat performance on the demands of parental obligation interfering with my classes from last semester. I

felt as weak and as incapable a scholar as last semester, but this time I did not care in the same way. The desire to want to do well, to prove that I belonged in graduate school were there, but had been dulled so I no longer felt the same shame as the previous semester, rather I viewed this pathetic academic performance as my new normal. The frazzled parent in need of accommodation was now a role I needed to perfect to survive the rest of this degree program. I knew I must embrace the change from promising young scholar to struggling mother, or walking away from graduate school all together. I chose to stay, in no small part because the financial investment was all the more important now that my family would likely need even more support.

**February.** In the methods class, we were asked to write all important thesis statements, topic sentences, and identify the problem we planned to solve with our research, I instead wrote pouty unusable prose. Scribbling questions such as, “What is the point of making up questions that I never want to answer?” “Is higher education only for the perfectly abled student?” or even worse, “Can a mother adjust to different expectations for her children?” and “Can trying hard enough fix anything?” I was lost in magical thinking that I could feel a haze spread over my vision as the PowerPoint slides passed by, absorbing none of the information and merely trying to survive the hours of the class before running for fresh air. Often, I didn’t even make it that long and disappeared into a bathroom stall until an hour had passed without my noticing and I plodded back to my office to pretend to do my job for another few hours before I could go home.

My independent study was faring much better. Like a good student, I decide the cure to my misery must lie in some theoretical tincture: an academic’s cure for a broken

heart. I look into disability studies and try to shift my paradigm away from normal vs. abnormal, try to stop thinking in terms of abled and disabled but rather in the language of body variety. I failed. Not the course, for which I received an ‘A,’ but on shifting my way of thinking. The professor working with me, who is also my department chair and thus my boss, pulls me into her office and says that I can’t continue to keep my heart divorced from my head and while she liked my paper what she really likes is reading our family blog where I discuss my fears, frustrations and hopes for Greta. Similar to the previous semester, I engage in thinking about whether I can continue to do this degree program. I allow myself to think about what work would look like that would allow me to integrate my full self as a graduate student mother of a child with a disability? It is compelling enough to forgive myself for the terrible showing in methods and continue moving forward as a graduate student.

After a lengthy approval process, Greta began early intervention services that recommended weekly speech therapy, physical therapy, and occupational therapy. We started with an evaluation of her skills. A physical therapist with a wide genuine smile and a careful methodical hand assessed Greta’s skills and made recommendations for how we could get her to roll over, sit up unassisted, and use her left hand. We asked her when, or maybe if, Greta would walk and she thoughtfully said she did not know. Unlike the doctors who poked and prodded, she stroked and smiled and taught us to stretch Greta’s muscles. I felt I had to be there every week, at every appointment. She laughed when Greta “cheated” by using her right hand to snatch at blocks placed strategically to inspire her to use her left hand. She liked Greta, she liked Gus, and I think she liked us.

The first time it snowed, we flung the window in Jack's room wide open and let him reach out to grab handfuls of the stuff. Gus, held by Shana, planted his hand in the cold white blanket of snow and wailed at the surprise of the cold. I held Greta in my arms and uncurled her tight left fist, letting her fingers brush the cold snow. I smiled at her surprise and even laughed as she exclaimed "oh!" with a mixture of shock and delight.

**March.** As winter began to fade, a rare warm day found us walking to the park for the first time in months. We put the twins in the baby swings and let Jack run from slide to slide, crazy with spring fever. Earlier that day, I had taken Greta to an appointment to get her fitted for leg braces. After driving past the location twice, I finally found the tiny office where the best expert in orthotics in the area, was housed. She made casts of both of Greta's legs and then packaged them to be sent far away and turned into plastic contraptions with straps and Velcro buckles. I got to choose the colors. I chose bright purple with green spots. I wanted them to look cheerful, colorful, enticing, so Greta would wear them.

**April.** It was her birthday when I picked up the leg braces and tried them on her for the first time. Sweat dripped down my forehead as I tried to wedge her left foot, which, like her hand, remained perennially curled in a tight ball, into the smooth unyielding plastic. "You'll get the hang of it, it just takes time." the specialist says. How much time I wonder; how could anyone get used to this? I am instructed to have her wear them all the time, taking them off periodically to check for blisters. The purple I chose clashes with her pink party dress. I debate taking them off before the party, embarrassed for her...of her? Which is true, I do not know.

Greta and Gus's birthday party was held at a local pizza place, which has a back room big enough to accommodate the large number of people we invite who do not come. It is also a benefit for Greta, to raise money for the co-pays and other things insurance doesn't cover as our family has been slowly sinking into financial ruin; a thing that a year ago would have caused panic, but instead now induces amusement. It must be a joke that we are expected to care about money and bills at this particular point in our lives. We sing *Happy Birthday* and eat cupcakes while the twins sit on the floor on top of a large blanket that absorbs their smears and spills and the remains of their half-eaten cupcakes. They bat at the floating balloons and cry just in time for us to leave.

In the car on the way home, I note the time passing at the exact moment she was born. I feel my mouth forming the words to tell Shana this but stop myself and gaze out at the sunset instead. I'm unable to form the right sounds to say what I feel; which is love of this crazy family, and sadness at such a wilted birthday party, and fear of the days to come and the unknown future, and wonder at how all these things can be held in my mind in one minute slipping past silently in the green light of our car's digital clock. That night putting Greta into her pajamas, she looks at me with what I interpret as an uncharacteristic intensity. She keeps staring directly into my eyes. I whisper "happy birthday," and then quieter "I'm sorry," but from the look of her face it is not enough. She wants more.

### **Doubt**

#### **Spring 2009**

**April.** A thunderstorm gathered at 6 AM on April 23, 2009, as I departed to the hospital to begin the induction of labor for the twins I was carrying. My partner, Shana,



took pictures of me on the front porch to document my elephantine size. Looking at those photos now, I looked scared but excited, like right before you crest the hill of a roller coaster.

This wasn't an easy pregnancy. Easy by twin standards yes, but I worried incessantly about all the bad things that happen to twins. Outwardly I displayed a calm confident demeanor but inwardly at each early contraction, at each pull of a muscle, I pictured tiny babies hooked to wires relegated to Neonatal Intensive Care Unit (NICU) cribs for months. Even worse I perused the internet finding story after story of women carrying twins and one, or both, just inexplicably dying. Pretending to do work at my desk where I worked as a student affairs professional, I instead read horror stories and had to spend inordinate amounts of time in the bathroom to cry for the strangers who faced such unfathomable loss. Each week, I ticked off the calendar that brought me closer to safety, or so I told myself. So when at my 32 week OBGYN appointment, my doctor told me she wanted to induce me on April 23rd, at only 36 weeks, I was surprised and a little disappointed. I was engaged in a battle with my body to see how far I could push it and I was winning, and here the doctor just wanted to end the race? I pushed the doubt aside, certain others must know best.

Believing in the knowledge of others was not new to me. I was an expert at self-doubt. At this time in my life I had successfully convinced myself, as well as my graduate school professors, that I was a competent and confident student. Only I knew that the judgment I reserved for the K-12 Master's students was a way to hide my fear of being exposed as an imposter. That the distinctions I made between myself and others served as a way to hide self-doubt. I worried from the moment I confirmed I was

pregnant, and certainly at the very instant we were told it was with twins, that I would not be able to maintain this façade any longer. I made valiant (to me), but likely pitiful (to everyone else), attempts to keep up with my coursework while pregnant; and while I somehow managed to finish the semester preceding this April induction date, it was not without a significant addition to the doubt I had in myself.

April 23 came and the twins were born. I congratulated myself after their difficult delivery that I had them both naturally. I had become obsessed with this after reading that a natural birth would get excess fluid out of their lungs and make them able to breathe on their own. Shana had joined me in the delivery room, which was actually an operating room just in case. I lost count at 25 when I tried to number all the medical staff moving around the room. She took pictures of Gus, crying immediately with what we would soon recognize as his characteristic pout, and Greta, awkward and startled, moments after they were born. When she brought them to me, wrapped in hospital blankets, I didn't know who was who. These mirrored strange creatures thrust to my face, I wanted someone to take them away, afraid I would drop them as I shuddered and shook on the metal table.

It was wrong to feel this way, a cursory glance at any Hollywood or reality television drama teaches you how to behave, to heave sobs of happiness and unite as a family while swirling violins signal the end of the scene. To be fair, I had done this before and the confusion I felt was similar to my first son's birth. I find birth the closest thing to magic I've ever seen: another person where moments ago there was none. But there was a plastic quality to this moment, as though I was paying extra attention to document it later for others. Was I a typical modern women refusing to live in the

moment? No, something more dangerous, my mind nagged, something keeping me alert and untrusting.

All day, my doctor had harangued me, threatening to leave at 5:00 if I hadn't had the babies yet, abandoning me to the random doctor rotation who would just cut them out without so much a thought. Somehow I managed to get close; 6:35 and 6:58 respectively. But rather than a rush of adrenaline, or a feeling of relief at the pain and the worry being over, I felt sick in recovery. With the room spinning, I told the nurse I didn't think I could get up. She, concerned, felt my abdomen, and in doing so, blood began pouring across the sheets. Quickly a doctor was called to add more stitches to my battle wounds; it was only 20 minutes after the twins were born and my doctor was already gone home and I was being yelled at by a stranger to be still against the un-anesthetized pain of her clumsy needle.

I called my mother, who had been practically glued to my sister-in-law's bedside as, she too, was carrying twins, who would be born just a few days later. I told her I was fine, the babies were fine, everything was fine. I did not know why it felt like a lie.

Left alone the next day, I was startled by a nurse banging into my room wheeling the twin's portable isolettes that looked to me like infant sized Tupperware. I spent the day restlessly napping and rushing to their side at each grunt and cry. I had forgotten how loud newborns were and needed to relearn how their mewling and bleating rarely correlated to actual needs, but I doubted my ability in the face of such expansive human responsibility. Shana was home with our two year old Jack, coming and going when she could while Jack was in pre-school. Finally it happened; they both began to cry at the same time. I panicked and tried to hold one and soothe the other. Their crying

summoned the nurses who came and took them away. I was glad to see them go and fell immediately into a deep and dreamless sleep. I barely remember the doctors coming into my room to tell me Greta failed her newborn hearing screening; all I really heard was the main doctor's assertion that 99% of the time it was just fluid. I was sure that figure seemed right when I repeated it to Shana and she grudgingly agreed that fluid could be a likely culprit. Perhaps she could sense my desperation that we believe in the statistics, which grad school had prepared me to worship accordingly, despite our doubts. I was afraid to shatter the precarious illusion of ease we had smugly congratulated ourselves on creating, as though daring to doubt out loud whether it was really fluid or something more serious would make it so.

When we were discharged from the hospital, I wondered how on earth we could care for these two tiny infants; our older son Jack, and to be honest, ourselves. The first night home, I lay on the couch with each baby in a portable crib next to me. They woke up endlessly. Eating, crying, needing changed, spitting up. I, not entirely lucid considering my dependence on pain killers to get through the day, tended to their needs in a confused memorization of rote movements. The next morning Shana found me asleep with my arms around the plastic netting of their portable cribs pushed next to one another, my head resting on the hard plastic siding. Both twins were curled up, as close to me as possible, as if trying to push through the mesh to join all three of us back together.

"Greta looks funny," Shana said holding her out in front of her like a sack of flour. "What do you mean?" I said "Gus is the one who looks like Mr. Burns from *The Simpsons*," I replied, trying for levity. "No, not like that, look at her tongue," she said

thrusting her at me with stern seriousness. I took her and held her and looked. Her tongue was rough and dry from being pushed between her pink lips and exposed to the air. I touched it and it she began to fuss. “Well stop poking her!” Shana said plucking her from my arms. Still I thought it odd. “We’ll ask the doctor tomorrow,” I said.

Our pediatrician was the lesser of the evils we had encountered within the medical system. She “tolerated” gays, (“heck we don’t care if parents are blue or orange as long as they love their kids!” she said once failing to note that there are no blue or orange people, just gay ones like us), but she was competent enough to give us antibiotics when we needed them and referrals when we asked in the past. She irritated me though. Always impeccably dressed in trendy designer clothes and ridiculously insensible shoes and, perhaps worst of all, relentlessly cheerful. She didn’t seem like a real doctor, more like she was playing one on television. Nonetheless, she was our doctor and off to her office with the twins we went. She pronounced them both “keepers” (“as though there were another option,” I huffed under my breath) and dismissed Greta’s tongue as a personality trait.

**June.** When, months later, Gus began a constant symphony of screaming that scared even my mother, who claimed with certainty that my brother and I were the most challenging infants on the face of the earth, perky pediatrician diagnosed him as having acid reflux. We began dosing him daily with the most foul tasting and expensive medicine I’ve yet to encounter. It did nothing.

“We should stop giving him this stuff,” Shana shouted over the pandemonium of his screaming, “it doesn’t do shit.” I, always full of doubt, reasoned that maybe it did work; maybe without it he would be even worse. Shana said I suffered from fallacious

reasoning and thrust him at me to go outside and get away from the noise. I held him, sweaty and wiggling and screaming for hours, bouncing swaying, swaddling, shushing, and still he screamed until he was covered in red blotches and his eyes swelled nearly shut.

Greta was our good one, we joked. She rarely cried and when she did, instead of screeching like a wounded animal, as Gus did, she made a peculiar noise “mmm ghee...mmm ghee” she would seem to say. At night I wrapped her tight in her favorite blanket, nicknaming her Princess Tiger Lily because of the appearance of her dark complexion against the orange and green blanket. She woke throughout the night, but so much less so than her brother it seemed like she slept all night by comparison. But when she woke, she nursed so slowly that I would have to jiggle her awake to get her to finish in an hours’ time. She was prone to making a loud gasping sound in her sleep causing me at first to rush to the side of her basket to make sure she was breathing, and later to ignore it having grown accustomed to the sound. Sleep deprivation and perky pediatrician convinced me I should ignore what sounded like a drowning victim struggling for air.

I added it to the list growing in my head. Sticks out tongue, makes strange sounds, nurses slowly, failed hearing test. Her tone was different too. The morrow reflex (a newborn reflex where infants startle and throw their arms and legs out when laid down on their back) was especially pronounced. Over and over, she would jerk and attempt to steady herself on the entirely stable changing table as though on a tilt-a-whirl in her own body. When you picked her up, she stuck her legs out straight as arrows; it seemed she could nearly stand up at just a few days old.

Although these concerns did not go unnoticed, they took a back seat to the sheer survival skills needed to live through this life. After a particularly disastrous night when Shana took over care of the twins and shooed me off to bed only to have me find her red eyed and crying in the morning, we decided it best I take the night duty full time. This left me alone most nights in the quiet house with only the television and two babies as my companions. By morning, I was so hungry for a human being I nearly tackled Shana as she came down the stairs like an over eager puppy. High on sleeplessness, starving for relief from the twin's endless demands, it never seemed a good time to talk about how strange I found Greta's slow methodical sucking and odd jerky movements. What would I say anyway, what exactly was I seeing?

Every day was a battle to fight and hopefully, a battle won. By nighttime we both nearly crawled to our respective sleeping areas, letting Jack sleep wherever he pleased, plying him with popsicles or chocolate milk in the middle of the night if only he'd keep quiet and not wake the babies. He began a habit of taking care of his dinosaurs as though they were infants. Wrapping hard plastic tyrannosaurus limbs in layers of baby wipes and setting them to motion in the babies' swings. It was endearing, and perhaps if we were different people, it would seem right. Of course, a boy would enshroud his beloved dinosaurs in the accoutrements of infant paraphernalia, a "little daddy." But it was startling to stumble upon ridged and garishly colored toys swathed in white cocoons swinging rhythmically. It was not until months later when the stupor of baby boot camp had faded we had a reliable schedule without spending every moment running for more bottles, more wipes, more diapers that we began to see clearly how different Greta was.

**Fall 2008**

**August.** Just as my vision began to clear enough to begin looking more closely at Greta, I returned to graduate school for two classes. One was about the profession of professors and the other devoted to studying current policy and trends regarding work and family. Both seem like excellent choices. While I should have acknowledged my natural leg up in the professoriate class, as I had been working for an academic department not just interacting with faculty but writing the policy for the construction of an academic department, I felt as though I should not talk too much. I left each class embarrassed, assuming that the professor and my classmates, think I am a know it all. One of my worst fears is actualized when we are asked to make a life map as an assignment in class. Each of us is given a length of butcher paper and markers and told to draw the map of our professional life. Classmates use multiple colors (with shading) and exhibit artistic talent far beyond my scope. Even worse, they all seem so self-aware. As they take turns presenting on what they have drawn, I am still trying to make sense of the monochromatic green disaster I have created on the paper.

There are no metaphorical mountains illustrating struggles I have conquered like my colleagues have drawn. There are no neat piles of books next to smiling faces. I create poorly drawn babies huge in my stick figure arms, a house, my partner, Jack, and various lines and arrows and question marks. My presentation is, if possible, even worse. Poor drawing skills aside, I simply cannot find the words to explain who I am, where I came from, and where I am going. I am trapped in the absolute present and exposed as having no plan, no confidence, and no courage to seize up life and pound it into the mold I desired. I begin to think of my role in graduate school as West & Zimmerman's (2009) work on performance, and begin to put on the clothing I know associate with the



performance of a *good* student, and the paint my face with the makeup I feel necessarily to accompany this performance. I am exhausted by it but afraid of what would happened should I stop the show.

At home I return to my vigil of observation. Gus, propelled by what I can only assume was rage, had learned to roll over at 4 months old. If left alone underneath one of the many brightly colored crisscrossing play mats intended in entertain infants, he would roll himself from one end of the room to the other. Greta did not roll across our floor. She lay beneath the fluttering toys kicking her right leg in a frog like motion of excitement, her left side still.

**September.** “Come here,” Shana called one night. She had been trying to feed the twins peas and while Gus devoured most of the jar, Greta could only attempt to open her mouth before her tongue would thrust the food out of her mouth and down her chin. “I think it’s too early for solids,” I said, but seeing her eat like that was frightening. She looked damaged, she looked like a child with down syndrome, she looked vacant. I walked out to our porch and cried. “I think there’s something wrong with Greta,” I said to Shana when she joined me, trusting Jack to entertain the twins where we could see them through the window, as they laughed at him in their identical baby chairs. Shana cried; I knew then she saw it too.

**November.** Perky pediatrician was less than pleased when, after several rounds of surgery to get Greta’s hearing fixed in her left ear, she was delivered a note by our Ear Nose and Throat (ENT) specialist urging her to consider genetic testing. She did not like to have her opinion questioned and stared at a nearly naked Greta who slumped on her examination table with our hands supporting her to keep her from falling backward and

startling herself over and over. She said “I have no concerns about Greta...but I’ll order the tests.” We felt sick, could this really be our life? A child with some rare form of down syndrome? We had opted for every prenatal test offered to us, never even bothering to have the conversation, knowing where we each stood as pro-choice feminists.

There is the world of medicine we previously knew and then there was this new one we were about to meet. In our old world of ear infections, stomach bugs, and colds, doctors were our friends, here to help and save the day. This new world was full of subtext. Where doctors gathered in groups to poke and prod at Greta, never saying a thing to us. In this world, we took Greta for a fancy hearing test requiring sedation. The anesthesiologist examined Greta prior to the procedure and frowned, saying to us, “What is wrong with her?” I was able to reply, “That is what we are here to find out,” but what I really wanted to say was “I don’t know, why don’t you tell me?” But in this world, doctors were to be feared, they held the power to give us answers or deprive us of them at their whim. It felt like walking from a bustling street into a deserted library. The quiet was its own presence.

**December.** The quiet between Shana and I was always present too: a meaningful look across the carpet as Gus rolled from back to front over and over and Greta merely languished on her back; an internet search of conditions that qualify one to receive social security benefits; prescription bottles multiplying on our shelves of medicine that promised to ease our nerves; wordless hours spent trying to get Greta to open her left hand, to eat solid food, to stop shrieking in happiness so loudly it reminded us a parrot in a pet store and made Gus cry, startled tears.

We did speak during this time, in emails and text messages, and stilted conversations on our front porch late at night. It was nearly Christmas and we would stand outside bathed in the light of our neighbor's holiday lights smoking sneaky cigarettes like teenagers. We never looked at each other, just gazed forward into the freezing darkness and wondered aloud how statistics could have led us so astray. Or I would email her an article about mosaic down syndrome detection in prenatal testing, or a link to a blog written by a parent. She would write back with a link to a medical textbook page illustrating the hand-in-fist posture Greta had that linked the condition to cerebral palsy, to birth asphyxia, to a perinatal stroke.

It was Shana's research, really, that led us to discovering the source of Greta's issues. One evening she called me during one of my last classes before winter break, leaving a breathless voicemail on my cell phone, that she had uncovered an article documenting the phenomenon of people with down syndrome being incapable of also having cerebral palsy. How true this article was, I still to this day, do not know, but I know it pulled us out of both/and and thrust us into either/or and it was the closest thing to good news we'd heard in months. It wasn't long after finding this internet gem that perky pediatrician called with the news that Greta did not have mosaic down syndrome and that we would really need an MRI about that hand.

After the less-than-impressive sharing of my professional life map in my professoriate class, I continued a spiral downward. In my class on work and family I uttered a loud and audible, "Fuck!" when I received a text message that Greta had failed yet another hearing test. I ignored the tapping of my professor's nails as I fumbled through my class presentations and had to resort to bargaining my way to a 'B' at the end

of the semester. I use Greta as an excuse. Of course it is true that I have been preoccupied with her health and the mounting evidence of something being very wrong with her, but I hear from the professor that I should not worry. All kinds of people with disabilities go on to do amazing things, she explained. I did not doubt this but I did doubt *my* ability to do “amazing” things and wondered if I should cut my losses and give up on this degree now. It, however, feels too late and so I plan to continue reasoning the winter break will give me time to unpack this mess of a family I have created.

**January.** What is it about the human condition that we can pass by all these brightly lit signs pointing to disaster and choose to not see them? A few days after the phone call assuring us Greta was genetically perfect came, Greta had a seizure that Shana recorded with her new camera. Still I reasoned that things would turn out fine. We showed the video to perky pediatrician expecting her to say again, for what felt like the millionth time, that Greta was fine. She did not. She excused herself, leaving the exam room door open a crack, allowing us to watch her urgently pick up the phone and both page the attending pediatric neurologist to the hospital as well as arrange for Greta’s immediate admission.

She came back into the room and told us to head to the hospital immediately where we would be met by a pediatric neurologist and get an MRI and other test right away. In our minivan, it was quiet. I could hear the crunching of the car’s tires over the uneven road littered with salt. For once, the twins did not cry in the car. Shana and I talked logistics, she would pick up Jack from preschool later. By then, we would have answers (it was still early in the day).

I ended up alone with Greta in an overcrowded room on the pediatric floor where she donned a peach colored hospital gown and I let them take her away so I wouldn't hear her scream when they put in her IV. I bent to the floor and whispered to myself that I couldn't do this; I wanted to run, to gather my purse and give up. I thought I could do anything, but listening to her far-a-way screams echoing towards me, I thought I could not be there. Not surprisingly, simply imagining myself fleeing from the sickeningly cheerful mural, past the nurse's desk that felt like a police station with its reliance on Plexiglas, and to the parking lot did not induce teleportation and I was there to comfort her endless sobs once they returned her to me. I sat up next to her most of the night, unable to sleep on the half chair/half cot the hospital provided. Greta slept in fits waking for good at 4 AM.

When Shana came the next morning with Gus, I belatedly remembered his physical therapy appointment for his bent neck (called torticollis) and rushed across town where I slumped, too tired to even feign that I was listening, as the physical therapist moved him into one uncomfortable position after the next until he became inconsolable and I was allowed to leave. His physical therapist never asked why I was dressed in wrinkled clothes with un-brushed hair and black smudges around my eyes that occasionally leaked tears onto my collar. I think about her now and wonder what it would take for me to pretend I did not notice a woman in the state I was in. Would she be fired if she asked if I was alright? Is there social code that teaches us to ignore these awkward interactions? The truth is, I'm pretty sure she never liked either of us, Gus or myself, much anyway. Whatever doubt I had about the efficacy of this therapy was set aside and based on this soul crushing interaction, I never return.

Shana called me while I was in the parking lot packing Gus into the car to return to the hospital to tell me we were being moved to a new room. Greta was going to undergo a 24 hour EEG, where she would be videotaped at all times. Her MRI and a repeat of her sedated hearing exam were scheduled for later that day. We called our babysitter, the poor thing, she had been hired to watch two cute twins a few hours a week and quietly walked into a disastrous family drama that frequently had us returning from outings red-faced and teary eyed instead of smiling and holding bags of groceries. She took Gus away, to her apartment, where he was likely passed from roommate to roommate and perhaps wondered where his mothers had gone.

The sedation was awful; it always is. They made her drink a terrible tasting liquid the consistency of maple syrup and the color of cough drops. She coughed and sputtered as we forced it down her throat drop by drop. Luckily this poison acts quickly and in a few short minutes, she went from squalling drunkenly in my arms to being a dead weight. I laid her onto the gurney, knowing I would not see her again for hours. Instead of hugging her, tracing her chubby cheeks, or whispering mother's prayers into her ears, all I could think to do was turn away as she laid so impossibly still that she looked dead.

Where did we go during these tests? I have no memory of what filled the hours between her being wheeled away and the nurse coming to drag me to the basement of the hospital where Greta was sluggishly lashing out as technicians cemented electrodes to her head from which flowed red, yellow, and white wires. "She woke up once," the nurse tells me as we both watch in detached fascination at the horror scene before us, "during her hearing test, she started to cry but I just rubbed her back and she went back down." This news is good to me as I worried she would again fight the sedation hard enough to

ruin her hearing test but it forced me to imagine her alone, lost, confused, and drugged, with only a nurse in garish cartoon scrubs to console her.

The team of technicians were almost finished and Greta was almost fully awake. I tried to both hold her and give them access to her head. She looked awful, large red patches on her cheeks, unevenly opened eyes, slack jaw, and drool pooling down her arm. Her head quickly became so heavy with medical equipment, she could not hold it up. She looked like some kind of baby Frankenstein when I brought her upstairs to her new room. Shana and I watched them connect the wires to the computer beside her bed that broadcast both her brain waves and recorded her every move. We thought the hard part was over.

When the neurologist came back with his student buzzing behind him like a bee and beckoned us to another room, it took longer than it should to explain why we could not leave Greta alone in her giant metal crib. I wanted to stay with Greta, they scare me, their teeth seemed too long, their coats too white, and I actually put my hand on Shana's back and shoved her towards the door. The student, a middle aged woman who seemed the antithesis of student, finally agreed to stay behind at the direction of the chief physician. She was visibly disappointed to not be able to check this particular item, "breaking bad news to parents," off her checklist.

In a stifling hot room lined with computers, two monitors were lit. "This," the neurologist gestured to the first screen, "is a normal brain." Shana and I looked at it dutifully. "And here," he pointed at the second screen, "is your daughter's brain." It was like he was playing some sick "what's wrong with this picture" game except it was obvious, nauseatingly obvious, as large black blotches marred the image on screen two.

“It’s an old stroke, probably occurred sometime shortly before, during, or after birth,” he said happily. He was happy to have solved a medical mystery, which was maddening but technically good news, because it was clear her seizures were simply her brain misfiring over the damage, not causing new damage, not something to be needing to be controlled, not something dangerous...anymore that is. To him this picture was good news, to us, the end of normal as we knew it. We were told that because of the location of her stroke, only her left side would be affected. She might not walk until she is three. She will need physical therapy and occupational therapy. She may have trouble hearing on her left side, may have trouble seeing. When she gets older maybe she will have a limp, something she can hide so no one will know (he emphasizes this: *no one will know*). We were told walking is a finite skill, once you can walk, you can walk. Somewhere, our intellect told us this was not entirely true but we listened like good mothers and nodded along. The optimistic part of me that over the remainder of the year will grew smaller until it shrunk to the size of a pebble wanted very badly to believe him.

After this news, neither Shana nor I cry or are visibly upset. I am sick though. I feel like emptying the contents of my stomach and sleeping under a thick comforter for 3 weeks. Instead, we are forced to play super-mommies for another 24 hours until Greta is released. Each of us takes turns shuttling home, eating food and calling family, always aware that while in Greta’s hospital room, our every move and sound was being recorded. I remember robotically calling my parents to tell them what the neurologist told me as I careened our van down a rain slicked street and I wonder now whether my father, who answered the phone, or my mother, who I spoke to several hours later, ever considered



hopping into a car and driving the 8 hours to Missouri from Ohio to help cushion this blow? When exactly does a child stop being yours to fix?

Once finally home, we are left feeling empty. We thought we had the answers but really we just were given the question. More questions fly between us than ever before. At the follow-up appointment with perky pediatrician, she tells us Greta will be fine, that she has referred her to the state early intervention services, that Greta will just have to “make her way” a little differently in the world. We shoot questions at her so rapidly she quickly becomes defensive. “Why did this happen, was it because she was only 36 weeks, was it all the Pitocin was it because she was a twin, was it because I worked too much?” Silently I think, was it the 25 minutes after Gus was born when doctors and nurses pushed and pulled at my stomach, leaving finger streaks of blood across my abdomen instead of just cracking me open and getting her out that forced a clot to her brain. But all we got was shrugging, “sometimes these things just happen,” and the distinct impression that to be so upset over such a small thing as a stroke that only affected one side of her body, was, if not silly, then perhaps self-indulgent. After all, she knows of a boy with a much bigger infarct (the term for infant stroke-the first time we heard this term) and he was fine! I ask her what “fine” means and she just sighs and asks “anything else?” We ask her whether this means Greta has cerebral palsy and are told that doctors do not like to make that diagnosis until age 2, but yes she does. I wonder why 2? Is there some miracle that happens before the age of 24 months that can somehow reverse permanent brain damage? Shana tells me later, in the car, that they like to keep litigious parents at bay as long as possible. Always the family researcher, she knows that medical records get “lost,” doctor’s “forget,” all it takes is enough time. And,

she cynically reported, any type of financial services require a real diagnosis and we didn't want parents flooding the system now, do we? She bends towards bitter as I spiral into more doubt thinking surely there must be a way to explain this whole thing away, but I know she's right, she usually is.

My classes resumed and I return to the classroom a distracted student, more lost than the drunken freshmen bouncing their way from one overflowing lawn to the next. What could educational leadership and policy analysis possibly have to offer someone like me now besides a route to a better paycheck? My ambivalence is clear and my department chair, and boss, throws pity on me and lets me take an independent study with her. I proposed a topic related to disability studies and she agreed, perhaps seeing that in my desperation I could not force myself to disengage from the topic of disability. My other class is not as simple: qualitative methods taught by a new assistant professor, who seems as entirely impatient with the topic as I am unmoved. I worry whether I can continue as a student, but realize, with even my pathetic math skills, that to keep the towering student loans at bay, I must. I miss class after class, it seems that, without fail, all of Greta's medical appointments are scheduled for Tuesdays. I often arrive late, leave early. I assume the professor thinks I am above the class, given my stony silence and roving attention, but truthfully I desperately need the training and stay up late at night to keep up with the readings, somehow managing to fit my life into the practice research questions.

**February.** When it becomes clear I cannot keep up, I email him a typical graduate student email that I would mock with other faculty in the department in which I worked, telling him about Greta, about the appointments, about the importance of me

being there because the doctors do not listen to my partner and do not really consider her to be Greta's mother. I leave out that I cannot stomach sitting so still at the round tables of the classroom while he lectures. That I cannot let my mind wander, back in time to imagine a way out of this diagnosis. Nor can I allow my mind to wander to the future, trying to see Greta as an adult. My mind constantly conjuring images of her curled tightly, she in a wheelchair, drooling, her mind lost and my heart broken, demolishing my concentration on the subjects taught in the course. I don't tell him I spend most of his class fighting back tears and writing awful research questions like, "how does an intelligent and educated mother allow her family to be destroyed by her bad decisions?" or "what does it feel like to be a bad mother?". This could not go on. He, like many in this story, pitied me and allowed me to miss classes and turn papers late.

My new job quickly became navigating the medical world in which we were thrust. There is a difference, I soon learn, between medical doctors and therapy providers. A physical therapist came to our house and assessed Greta's abilities. She apologized over and over for having to give her "passing" grades for tasks, even, though she was only completing them with one side of her body. She promised to include a narrative in her report explaining the high grade so disparate with her lack of function. It is the first time I realized that Greta needed to fail the tests, that the worse she did the more services she would get. We were encouraged to dramatize her seizures, go back and note every little deficiency, from her hour long nursing sessions to her inability to roll over. Everything wrong about her performance on this planet so far is needed. This hurts, and I am surprised by that.

Never braggarts, we did not have experience touting the brilliance of our first child to anyone who would listen like so many parents do. In fact, we were more likely to just chuckle at his accomplishments and joke at his developmental mishaps. But to actively dredge up every undesirable and deficient aspect of your baby filled me with such sorrow, the cultural whiplash was often paralyzing. I wasn't trained to do this as a mother; I was trained to do the opposite. It felt traitorous to Greta; I had trouble looking her in the eye. I worried she could hear us, understand us. Later when she grew up, she would stumble upon these reports with sentences like "mothers reports child unresponsive to toys," "mother reports delayed reaction to images and sounds" would cause her to recoil in horror like a kid stumbling upon his parents making love. This didn't feel like advocacy, it felt like betrayal. We were "undone" (Bulter, 2002, p.63) by the doubt of making decisions, nearly constantly on behalf of her.

The activism of my academic training typically revolved around student development and was framed as empowering and, while often motivated by pain or anger, was a solution. At this time, activism was not a solution so much as a requirement. We yielded to being parents who not only had to choose the color of their child's socks, but also made decisions about Greta's future, seemingly every day. We struggled with the ethics of such decision making and were left to do so alone, the medical community far removed from helping us make decisions. I told Greta's story to doctors and therapists, hoping that I was doing so fairly and accurately, reminded of Butler's (2002) warning that love can potentially ignite this proxy relationship that I found so fraught, but that doubt was to be expected.

“[W]e must recognize that ethics requires us to risk ourselves precisely at moments of unknowingness, when what forms us diverges from what lies before us, when our willingness to become undone in relation to others constitutes our chance of becoming human. To be undone by another is a primary necessity, an anguish, to be sure, but also a chance--to be addressed, claimed, bound to what is not me, but also to be moved, to be prompted to act, to address myself elsewhere, and so to vacate the self-sufficient "I" as a kind of possession. If we speak and try to give an account from this place, we will not be irresponsible, or, if we are, we will surely be forgiven. (p. 65)

Slowly we began to understand what disability advocacy looked like, at least according to the websites we visited, the blogs we read, and the books we purchased. You are encouraged to fight for every drop of state or federal services or your child will not progress. All of them stressed early intervention as the key. But I wondered, the key to what? Most of the things we read focused on children with autism, with down syndrome, with genetic or congenital illnesses. These kids seemed capable of anything, just ask Temple Grandin, the spokesperson for functioning autism. With enough therapy anyone could be fixed. But what about Greta? Experts say that infants' brains are plastic, that they can make new connections by passing those long stretches of damaged highway in their brain to forge new roads. And yet, all my research efforts never located anyone with cerebral palsy who really *recovered*. In fact, research threw me into frightening spaces where statistics like 50% of children with cerebral palsy were diagnosed with mental retardation, and that another 30% were behind in school due to audiological processing disorders, speech impediments, and the general *perception* of

stupidity served to them by society they held them behind. And didn't I fit into that group too? Wishing that I could change time to change her? If Greta's own mother wanted her to be different, to be normal, how could I expect anything different of the world? I was her first betrayal.

**March.** As we slowly eeked out a schedule of therapy and doctor appointments, after firing, or in special needs speak, "revising our individualized family service plan to reflect parents' wishes", a number of therapists became our rag-tag team. At the core was our physical therapist, the original young woman who had come to our house and apologetically assessed our daughter as a failure, despite technically passing tests with one hand. It turned out that even the strict guidelines set up to qualify or disqualify children based on boxes checked had room to acknowledge Greta's inability to use her body like other infants. Pregnant, this therapist arrived with stunning cheer to be screamed at by Greta for an hour a week. She had suggestions, she had energy, and she had ideas. We listened, at first. I stood over the two of them pen in hand, poised to take notes on position and exercises we should do. I did them too, for a while. Until I couldn't take Greta screaming, couldn't touch her like a clinician to feel her muscles tight like stones under my hands, couldn't bear to see her fall over and over again. I think I am doing the right thing but am always doubting myself. Thinking of Eva Feder Kittay's (1999) work on disability and maternal labor, "professionals also sometimes expect parents to carry out often complex and time-consuming instructions that are unrealistic" (p. 171) I wonder whether any of this will even help.

The only routine I kept was her stretching. At night, drowsy from her last bottle and my warm cradling, I would gently peel the fingers of her hand open, massaging them

and begging them to listen to my ministrations. I would bend her tightly curled foot, rubbing the sole and pushing her toes flat. It was secret therapy; I stopped if she squirmed or protested. I brushed her bare body with a surgical scrub brush to encourage the movement of her limbs, which did nothing of note besides inducing a round of giggling and smiles, thinking I was playing a tickling game.

When a huge snowstorm hit, we went upstairs to Jack's room and opened his window to touch the perfect white blanket upon our roof. Jack gleefully made handprints and I added claws to his indentations to make them dinosaur tracks. Gus reached out to touch the bleached down and howled in surprise at the cold. Greta, I held in my arms, struggling to get her into a place where her body could make contact with the frozen surface. I reached her left hand out, uncurling her fingers to help her complete this task, squeezing her body far too tightly out of fear that she would cry, out of the pain of seeing her try so hard to do so little, out of fear that I was doing the wrong thing, forcing her this way.

**April.** While winter seemed to crawl by, spring took us by surprise and it seemed, without warning, we were looking at budding tulips and being awakened by birds chirping. I never was able to make up for the fumbling start in my qualitative methods course, but out of kindness the professor allowed me to write my final paper late and receive an incomplete to allow me a few extra weeks of time. I wrote something, goodness knows what. It was probably a train wreck of disjointed research but he gave me a 'B' anyway. His kindness made me feel, if possible, worse. I doubted how I could continue as a graduate student in this program with such an incomplete knowledge of something as integral as methodology. Before I began the familiar ritual of making

promises to myself to study independently over the summer, I took the ‘B’ and slunk away into the intoxicating sunlight of spring. I had accepted the doubts I held about my inadequacies at the beginning of the year and now I found that giving up on the perception of myself as a “good” student only stung for a moment.

The second course I had been working on that semester, the independent study about disability studies, was going slightly better. I needed a mirror, a reflection of someone, anyone, who looked like myself instead of being constantly faced with the perception of inadequacy. I particularly connected with Barbara Hillyer’s 1993 book, *Feminism and disability*. She writes,

But what of people who cannot “produce” by societal standards, or at least do so too slowly when judged by organizational time? The work ethic pronounces that hard work will produce results. But if a person’s brain is injured or the body cannot be “cured”? No amount of work will produce the results that society acknowledges is productive. In our society, the fall back prescription for this dilemma is that someone else must assume that individual’s burden of productively. (p. 68)

Not only did this resonate as a severely exhausted student who felt like a complete failure, but it felt empowering to see that the work that had been added to my load was not imaginary. However, it was clear to me then that it also was not going to go away.

It was important to me that I maintained the appropriate social behaviors of those in my classes and I worked to mimic those. I reflect on Freidman’s (2003) work on gender and autonomy and its connection to graduate student socialization, “Nearly all of us remain, through our live, involved in social relations and communities, at least some



of which partly define our identities and ground our highest values” (p. 104). While not necessarily very close to my graduate student colleagues, I did not want to be singled out as that student. The one with problems. Being above average age and having young children made me enough of an anomaly, but I worried about losing credibility amongst them just as I worried about losing credibility from my professors.

As the twin’s birthday approached, it coincided with me picking up the brightly colored leg braces created for Greta back in March. What did I expect, that these braces would just look like cheerful and extra-large shoes? That the purple and green polka dot pattern would transform them from a marker of disability to a jaunty accessory? They looked awful, they held her legs stick straight from under the knee to her ankle, where they bent at 90 degrees. They required long purple socks to prevent blisters and heavy black orthotic shoes, made to look like patent leather Mary Janes. Instead they resembled Frankenstein’s clunky boots. It was already hot in Missouri, between the plastic of the braces, the fiber of the socks, and the weight of the shoes, Greta’s face poured with sweat and her hair curled in the heat.

I made it home after picking up her leg braces just in time to shove both her and her brother in their birthday outfits and head to the local pizza place that housed their party. Shana had been there for a sometime setting up. One look at Greta in her pink party dress embroidered with a cupcake bearing a candle with the number “1” on the front combined with her awful braces peeping out from beneath the dress and Shana’s face fell. Quietly, she unloaded the dozens of cupcakes I’d made the night before, most of which would end up in the garbage, uneaten by absent guests.

The party guests were a strange mix, friends from my job, friends of Shana's she had met, and the parents of a small child a year older than the twins, who for lack of better words, were Shana's former employers. When I was pregnant, Shana tried to generate income by making a small childcare company. The company never took off, aside from one child who stayed with Shana as her care provider for nearly one year. The child's mother, a lady of leisure, fired Shana over email the day we brought the twins home from the hospital afraid Shana would be spending too much time with the twins and not enough with her daughter. I am still unsure how she got invited, but there she was, picking at a veggie pizza, holding her still clingy daughter and conversing with her surgeon husband.

I couldn't stop looking at this family. Our twins were seated on a blanket mashing cupcakes between their chubby fingers and playing with toys when this mother walked up to me and announced her second pregnancy (20 weeks along and barely showing). She told me she was planning to have a home birth. I was supportive in a general way, but gestured vaguely to the scene unfolding on the blanket saying "things don't always go as planned." I ask myself now, what did I mean? That we were surprised by twins or that Greta's birth caused her injury? I still am not sure. I know that felt angry with this woman, angry at her perfect family, and what seemed to be a perfect life. I should know better, I reminded myself then (and now) that looks can be deceiving but even though I doubted my right to be rude I still indulged in it. She replied, "Well I have midwives who will help. They would never attempt to deliver a breech twin, especially with an overweight mother," as she stalked off. It wasn't so much being called fat by someone who refused a cupcake for fear of harming her gestating fetus with the sugar, it

was the implication that I had done this to Greta, that I had taken risks, that in her eyes, and by now what felt like everyone's eyes, I was to blame. This was the reward for the wayward cruelty and envy I had indulged in. Shortly after this conversation, I left the party taking joy in allowing Jack to help me pop each carefully inflated and color coordinated balloon loudly with a the tines of a plastic fork. I was being petty and throwing a grown up temper tantrum, why not have my three year old join me?

Was the guilt I felt I carried in secret so obvious to everyone else? I had doubted every single moment of my life from the minute we decided to try for a second child to the color I chose for Greta's orthotics. Doubt was my new religion, replacing ignorance and the egotistical surety that things would turn out okay. This mother's rude comment only solidified my guilt so that when I changed Greta into her pajamas later that night, it was with love but also a sense of requirement that I whispered "happy birthday," but it was with tears and horror that I whispered, "I'm sorry," never having understood what sorry meant until that moment. Greta looked back, blinking her long-lashed eyes, thinking what, I will never know.

### **Loss**

#### **Spring 2009**

**November.** Waves crashed on the beach in my mind. With each landing, they licked at pieces of a carefully crafted sand castle, causing the walls to crumble, the towers to fall, leveling the palace to the ground. The sea carried away my carved grains of sand where they receded into the ocean, lost forever. I could feel myself, the person I knew as myself, disappearing too.

This is what I pictured as I lay upon a recliner in a darkened room and received the news that I was carrying twins. Families were built for four. Everything was suddenly too small, our house, our car, my salary. Or conversely too big: the price of daycare, my dreams for my career, Shana's plans to go back to graduate school. It was with the dizziness of stepping off a tilt-a-whirl that I left that room to go home and somehow reframe this as anything but a mistake.

Shana and I sat together, pushing close two oversize chairs from our dining room, while our 2 year old son Jack slumbered on the couch in the next room. Verbally we began making lists. "No one will expect us to be perfect now, I mean 'they have twins!' people will say, 'give them a break!'" Shana began. "I have a lot of time off saved up at work in case I have to go on bed rest," I followed. "We need to buy a new car anyway; the lease is almost up on the Jeep (the car I drove)." Shana added. "We can make them wear stupid matching outfits!" I said, causing us to start laughing and coming up with sillier and sillier ideas, like naming them Luke and Laura, or Roy and Joy, or telling people they had different fathers. And just like that, my castle was being rebuilt with a new nursery in the back tucked away safe from the incoming tide.

**March.** But it wasn't safe. As I grew and grew and grew, getting things done became so much harder. "Possibility is not a luxury; it is as crucial as bread," stated Judith Butler (2009) and I watching helplessly as possibilities disappeared from my life (p.9). Previously reliant on my role as a good student and professional employee, I watched in my dissociated state, as I begged out of commitments, stepped out of classrooms never to return, reasoning that when I could come back to myself, the self I

knew, I could repair the damage I had done. But I knew, the possibilities were no longer endless, that way thinking had been lost.

**April.** Coming back to myself was harder than I had thought possible. The twins were born in late April, shortly after finalizing my plans to complete coursework early for one of the classes I was enrolled in and receive an incomplete in the other. I felt I had lost control of my ability to stop my body from intruding into my identity space. The classes themselves had become unbearably painful to sit through. They required a half day of recovery time the next morning just to recoup some blood flow to my legs and feet. The eyes of the other students bore holes through me, while I tossed and turned in the cheap plastic seats and the twins took turns trying to punch their way free. Worse than knowing how foolish I looked to them (foolish to be attempting to continue graduate school and not just going home like a good lady in waiting), I felt foolish too. Had I been asked, I would have said, and at least halfway believed, that I would be back, that things would be fine, but my identity as a professional and successful student was lost to me.

I loved the twins fiercely and could, through perhaps the combination of baby magic and sleep deprivation, see all that I had gained alongside those things lost. I would have called our family, with smugness, lucky. I would blow Gus's white tuft of hair, so similar to dandelion fluff, and watch him wrinkle his nose. I would hide behind our couch and pop up over and over just to watch Greta's giant gummy smile.

I still could hear the surf pulling my castle into the sea despite the volume with which I cranked pop tunes to drown out the tandem crying. Shana held Greta, peering into her face and declaring something wrong. I scared Greta so badly she cried herself into hiccups when I startled her coming around the corner. In the sleepless nights, I

jostled Greta awake to nurse, so slow she was to finish a feeding that over an hour might pass. Both the twins hated the car (a shock after having Jack love it so much as an infant that, at times, it was the only way for us to get a break) and so we were often trapped at home. We tried, unsuccessfully, one fancy twin stroller after another to find a model where Gus could not pull out handfuls of Greta's hair and where she would not slump to the side and get tangled in the canopy. Time, we reasoned, would reverse these losses.

### **Fall 2009**

**August.** Unfortunately, time was not going to slow down for us. Before we had established any type of routine or gotten our feet back under us, I began another semester at graduate school and also returned to work. I was enrolled in a course titled, The Professoriate, and we made maps of our lives as graduate students in one of the first classes. Before the twins were born, I could, if not lie, then at least bend the way I represented the truth. I knew what instructors wanted to see. Perhaps some neatly illustrated adversity overcome through the use of mentorship, or advising, or scholarship. My former self, who felt lost to me, could have produced a life map like that easily. Instead, I created scribbles of green with arrows and question marks and two lumpy babies weighing down my illustrated arms. I used the class break to pump milk in the bathroom and realized if I were to run into my lost self on the street, she and I would pass each other by with perhaps only a momentary shock of recollection. The self I knew was made up of reflections of me by others. Those mirrors began to show me as desperate, flailing, and mock-able I parted ways with my former self and stopped expecting her to return. As Judith Butler (2004) stated in *Precarious Life: The Powers of Mourning and Violence*:

When we lose certain people, or when we are dispossessed from a place, or a community, we may simply feel that we are undergoing something temporary, that mourning will be over and some restoration of prior order will be achieved. But maybe when we undergo what we do, something about who we are is revealed, something that delineates the ties we have to others, that shows us that these ties constitute what we are, ties or bonds that compose us. It is not as if an “I” exists independently over here and then simply loses a “you” over there, especially if the attachment to “you” is part of what composes who “I” am. If I lose you, under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who “am” I, without you? When we lose some of these ties by which we are constituted, we do not know who we are or what to do. On one level, I think I have lost “you” only to discover that “I” have gone missing as well. (p. 22)

Without the parts of me that once made up portions of my identity, the ties to the others in one’s life Butler alludes exposed my inability to know myself in the new space.

My other course was an elective on work and family in which I spent most of my time wondering about whether the professor thought I was a good enough worker or had a good enough family. Our texts were outdated and built on a capitalist model of work and a heterosexual model of family. The old me would of objected, advocated that the devaluation of unpaid labor could be linked to women’s downfall and perhaps written my final paper on Haraway’s (1990) *A Manifesto for Cyborgs*, citing her argument that women have been “cannibalized...in the home, work place, market, public arena, and body itself” (p. 205). But instead I just thought these things and nodded politely, rarely

contributing to class discussions and, instead, sending text messages about Greta to Shana from my lap. I'm not certain which was worse, being viewed as non-participatory or taking the risk of being viewed as antagonistic. But I was incapable of doing the later so preoccupied was I with Greta's health.

She failed her hearing test at birth, something I was assured happens all the time. But when it became time for the retest, I held Greta still as the machine plugged into her ear and wired to her head to record her brain's ability to recognize sound sat stubbornly blank, refusing to display even a few small numbers on her left side, while her right side quickly zoomed to the thousands before it was disconnected. I tried to get some answers, asking all the typical questions of the audiologist. "What does this mean?" or "Can she hear at all?" but was told she really was just qualified to run the test not interpret the results. An ENT would help me understand better what was happening later.

**November.** After the ENT performed two surgeries (left ear tube, then a right ear tube and adenoid removal for good measure), he and I were still left staring at test results that insisted the same thing: Greta could not hear adequately out of her left ear. How much or how little she could hear was still, at this time, up for debate after a disastrous failed hearing test called an Auditory Brainstem Response (ABR) where she was given inadequate sedation and an anesthesiologist and an audiologist just shrugged when we asked the same questions what to do next.

**December.** The professoriate class I taking had now progressed far past art projects and was now asking us to write about our future plans. Before, having completed a similar assignment, I had carefully selected a job description and created an application packet, indicating that it would be my career trajectory. Now I stumbled,



firmly stuck in the present, and not able to envision the future without a horrifying vision of a child unable to function, a graduate school career growing dust, and a life littered with chaos appearing. Not only could I not adequately perform for my professors to obtain the grades I desired, I was beginning to have trouble convincing myself that things would be okay.

Struggling to perform the perfunctory behaviors associated with being a graduate student was alarming, but failing similarly as a mother was dangerous. With Christmas upon us and a break from coursework, I had dedicated myself to Greta's health concerns. It felt like I bullied genetic testing out of perky pediatrician at a December appointment where she looked at Greta, who sat slumped on her table and only reached to pluck at perky pediatrician's necklace with her right hand, declared her "a normal beautiful little girl" and handed over the referral slip I requested with a sigh. Shana had been researching some of Greta's symptoms and thought they fit into a genetic disorder or a brain injury, and at this time, the genetic road seemed most promising for a diagnosis. Perky pediatrician used to like us but it was clear we had gone from overly worried, to bothersome, to obsessed in her eyes. She gave us the referral to make us go away, but we lost the identity of good parents and now became a concern. Her every word and movement seemed to be wondering why we would not stop begging for trouble, why I would not take her pronouncement of "normal" and "beautiful" as the truth, instead of insisting on seeing problems where there were none.

While I was incapable of performing properly in academic and medical settings, I could lie to myself at times. When some time later I read Loinel Shriver's (2006) work of fiction about a mother dealing with the aftermath of her child's high school mass

murder and came upon this line: “we white folks cling to such an abiding sense of entitlement that when things go amiss, we cannot let go of this tortuously sunny, idiotically cheerful doppelganger of a world that we deserve in which life is swell” (p. 139), it resonated strongly with this time in my life. I felt entitled to a *normal* child and, as such, forced a giant Christmas celebration upon the family, saying all the while that we deserved it, when it was simply a way to fool myself into ignoring the terror that had affixed itself to my daily existence.

**January.** When the time came for Greta’s actual diagnosis, it was both dramatic and anti-climactic at the same time. She began having seizures that Shana captured on video, which we used to get admitted to the hospital. Perky pediatrician immediately dropped her “everything is fine” act when she saw the footage and moved so briskly to pick up a phone in the hall of her office and reserve a place for Greta’s admittance in the hospital that she terrified us. The fear gave way to anxiety and even boredom after we spent 3 days completing various tests and dealing with multiple nurses and doctors. So when, on the afternoon of January 14, 2010, a neurologist and his assistant beckoned Shana and I into a dark room to show us the patches of black that marred her brain imaging and were the cause of all these symptoms, we were unprepared for bad news. I mourned the lack of ceremony, thinking that when *normal* permanently takes leave of your life you should at least get to mark its exit. Instead we were left to roll the word “stroke” around in our mouths and choke on the diagnosis of “cerebral palsy” with no audience or witness at all.

**Winter 2010.** My former self was officially gone for good and I resumed classes in winter of 2010, a shattered and darkened new self, a self who I not only did not recognize

but did not particularly like. I was sullen and turned assignments in a qualitative methods course into ways to torture myself. Creating research questions that wondered how a person who gave their child a stroke could call themselves a good mother. I had become convinced that I had done something wrong to have caused Greta's stroke. I implored each physician I met, the number having multiplied to include numerous sub-specialties of pediatric practices, to explain exactly when and why this happened. The answers were always the same "shortly before, during, or after birth" and "these things just happen." I found these answers deeply unsatisfying.

Thankfully, my supervisor, and chair of the department where I worked, allowed me to complete an independent study that winter semester, so I could only humiliate myself in one class per week instead of two. All the better to have the extra free time, as my schedule quickly filled up with doctor appointments for Greta. I tried to find answers to a deeper struggle, my inability to stop wishing I could make Greta normal through completing an independent study on disability studies. I was able to produce the required paper, summarizing the theories and the explaining how through a shift of thought we could all stop placing people into categories of abled and disabled and instead see bodies as inhabiting a multitude of varieties. My department chair, who oversaw this work, said she liked the paper but wanted to talk about the blog posts I had been writing about my struggle to accept Greta's disability instead. She said I could not divorce my heart from my head and did nothing to stop my tearful confession in her office about how I was probably going to fail my methods class; how I thought I should drop out of school; how I had not completed a work task in weeks; and how, most importantly I did not care. Instead of being shocked, she nodded and said "of course you don't care, why would you

care about that now?" It was incredibly understanding, but also terrifying, as I then realized just how deeply lost I was and that I would likely never find my way back to being a model student and good professional worker. I had learned a great deal from the independent study, and while I was not able to embrace a disability studies way of thinking entirely, I did know that I had been swallowed up by those waves I imaged back in November and thrown back onto the shore as a different person, the woman I was having been lost at sea.

**April.** I did not fail my methods class, but did turn in work far below the expectations I had for myself and also required extra time. Still, I was grateful for the 'B' I received. As we planned the twin's first birthday party, I was distant and removed. With Jackson's first birthday came a huge party, color-coordinated balloons and decorations, a fluffy store bought cake. Instead for the twins I stayed up late the night before, making cupcakes that were significantly cheaper than an ornate bakery cake. I allowed my partner only one trip to a party store where I blindly pointed at pink and green plates and table clothes, not even trying to hide my disinterest. I dreaded the party and wanted to survive, it not experience it.

It was, however, not without love that I spent each night carefully stretching Greta's tight limbs as the physical therapist had shown me. I allowed tears to streak from my eyes and patter onto Greta's smooth skin as I closed my eyes and ran my hands over her body, trying to force the magic from my fingertips that would reverse time and stop the word, "stroke," from ever having to be uttered in our house.

It is late and past everyone's bedtime when the twins' birthday party is over. As I dressed Greta in her pajamas, I paused to look into her eyes. That night they reflected the

dark so much, they appeared like small black endless pools. “Happy birthday.” I say and meant it, wanting her to know that the tears I have cried are not for lamenting her existence but begging for her forgiveness. “I’m sorry.” I also said, wanting her to know that I am sorry I lost myself, sorry that she is stuck with this imposter mother who took my place; silently I promised to let her real mother come back should she ever decide to return from the sea.

## **Chapter Five**

### **Introduction**

My story is one of a student experiencing graduate school in way where my identity was fragmented. At times, I focused my identity specifically on family, while at other times I was mired in doubt about my abilities, or mourning the loss of my former conventionally successful self. In using my narratives to extrapolate about graduate education, I offer an example of how the lived experience of a student is inextricable from her classroom experience. This has potential to change how graduate education values different types of learning and how graduate education is structured.

In this chapter, I make broader use of the narratives presented in chapter 4 to connect to the research objectives of this project. I explore their collective meanings for higher education. I do this by offering a critique of graduate education organized by project objectives. I present recommendations for higher education from this project, as well as identify future research areas for the field. I detail the limitations of this project and discuss the benefits and challenges of using this particular research framework and methodology. Finally, I offer a conclusion that situates my experience within the larger context of higher education.

### **Research Objectives**

In this project, I had three main research objectives; I will synthesize them in this chapter. The first objective is to contextualize my valuable graduate school experience as a way to better understand the complexity of my graduate student life and perhaps the lives of others as well. The second objective is to assert that valuing the lived experience of graduate students in the classroom, and in all aspects of their education, is necessary to

create educational spaces that can better support student learning. The final objective is to deconstruct how I produced knowledge to position education as personal unrest.

### **Personal Contextualization**

In my narratives in chapter 4, I both struggled to conform to the dominant narrative of a good student, as well as exposed the artificiality of this narrative. This narrative is characterized by perseverance in the face of adverse life events, uninterrupted progress in degree plan, and separation of personal life from their academic life (Austin, 2002). While much of my experience may be applicable to learning writ large, I expose a specific tension between my whole self and my identity as a *graduate student*. Kezar, Chambers, and Burkhardt (2005) observed that “doctoral students sometimes experience conflicts between their own values and what they perceive as the phases and quality of life in the academy” (p. 276). These researchers were specifically studying graduate students’ perceptions of faculty life and found that doctoral students felt they were trained to separate personal relationships and individual interests from their work in the academy. This tension between personal and professional life was evident in all levels of students, and most strongly, for doctoral students. While my focus was not on understanding perceptions of faculty life, my experience also reflected this tension. In so doing, I provided a critique of graduate education that complicates the structure and purpose of graduate education, as well as upset the dominant narratives of what graduate students need to do in order to be successful.

There is evidence of this conflict in how I felt I was being trained. I discussed trying to hide my true fears regarding my ability by sharing only what I felt were “acceptable” reasons for missing my methods class. After missing numerous classes in a

qualitative methods course, I confided in the professor that my daughter was ill but I did not disclose that the pressure of sitting in class allowed my imagination to wander into bleak futures for Greta that made attending class unbearable.

While I was not told what I should discuss with my professor, my training (both formal and informal in watching other successful professors) was something I considered when discussing my difficulties in the classroom. It seemed to me then that honestly divulging these difficulties would have harmed my reputation as a student. As the demands of my life circumstances eclipsed my ability to attend to the attributes of a “good” student, it reinforced the aforementioned critiques of graduate education (Austin, 2003; Kezar et al., 2005). While I could have challenged the dominant narrative of a good graduate student by clearly explaining the difficulties I was having in the classroom space, I chose not to. I assumed that this type of personal information would not be received positively.

My roles as a staff member and graduate student instilled in me an increased desire to conform to the good graduate student narrative; in my job, I witnessed firsthand graduate faculty complaining about graduate students who did not conform to traditional expectations. I did not want to be “that” graduate student. While I do not know if the contents of my email about missing class, even with their omissions, harmed my reputation, I do know that I was not comfortable approaching that instructor for advice, mentorship, or other graduate student-related assistance. I perceived the email, as it was presented, damaged my reputation. If I had been more forthcoming, I believed the damage could have been irreparable. The narrative of what a good graduate student should be was pervasive and influenced how I chose to share information about my



identities, and more specifically, about the aspects of my identities that interfered with my ability to complete my coursework.

Austin (2003) found that graduate students must be able to interact and produce scholarship with those who hold different identities; yet, they are often not taught these skills. This includes cultivating collaborative skills with those holding different racial, economic, or gender identities, as well as those with different types of academic appointments. This suggests that graduate education must train students to appreciate the skills and potential of all individuals and not link intellectual capacity to job type or identity. Despite this call, my graduate school experience emphasized assimilating to a specific understanding of the academy where faculty were considered more intelligent than staff, and where, more importantly, the knowledge learned by life was lower on the hierarchy than the knowledge obtained in the classroom. I assimilated because of the messages I received. For example, my professional expertise was often devalued in my graduate coursework, which focused on scholarly knowledge not on knowledge produced by administrative staff (e.g., coursework on higher education functions, policies, and foundations were rooted in a faculty perspective). Similarly, the messages I received about motherhood emphasized being a caregiver who always puts her child first but did not bring her experience as a mother into the classroom. I was also not prepared for the conflict in my identities. I felt often that I had to choose which identity to try and conform to, feeling that I could not represent all aspects of myself for fear of harming my credibility or reputation.

I was surprised and then later saddened that I felt like I could no longer fit in properly. I described feeling, prior to having twins, as though any setback I faced would

be temporary. However, in coming to terms with the permanence of both Greta's disability and my need to modify my school and work commitments, I experienced it as a loss: a loss of self and a loss of opportunity that had previously felt was endless.

By following Austin's (2003) recommendations, I could have benefitted from bringing my struggles to the classroom, offering alternative ways to think about education based on these life experiences. However, I saw my inability to maintain my status as a "good" graduate student as damaging to my future, and thus, I needed to hide it. Austin's recommendations are quite relevant to my experiences. If I believed that graduate education allowed for diverse types of scholarship to be produced by those holding diverse or non-dominant identities, like mine of professional, mother of a child with a disability, and graduate student, my narratives might look quite different.

### **Lived Experience of Graduate Students**

In this project, I argue that the lived experience of graduate students must be included as part of the learning environment. Throughout the narratives in chapter 4, my experience of graduate education is inextricable from that of a mother, a professional, a person struggling with grief, and an individual trying to negotiate loss. The lived experiences I presented exposed the guilt and deception I felt in having to perform in alignment with the "accepted" behaviors of a successful graduate student (Austin, 2003). More specifically, the narratives showed that the compartmentalization of my identities left me feeling unsure of whether I could continue with my work, and if I should.

Stephen Brookfield (1995) noted that "...despite the opportunity graduate study offers for purposeful reflection on the nature of teaching, many teachers [pursuing graduate degrees] I speak to keep their lives as graduate students and their lives as

teachers neatly compartmentalized” (p. 53). My experiences are consistent with Brookfield’s findings; I felt that I must compartmentalize my multiple identities. Moreover, my narratives extend Brookfield’s point by exposing some of the consequences of compartmentalization. My experiences also acknowledge that graduate student lives are much more nuanced and complicated than just the role of teacher.

I experienced consequences that resulted from compartmentalization when I ignored my physical exhaustion and needs of my body to try and be as “normal” in class as possible. I ignored contractions and other physical complications of a twin pregnancy so I could be present in class. I also wrangled with the consequences of appearing in a way I felt was dishonest, or performative; I was not really present in class. In addition, I felt this strain when, rather than finding ways to integrate my family life and my graduate school life, I took great care to hide my family life. Any inability to do so was a failure on my part. I began to accept that I was unable to self-identify as a promising young scholar. Instead I became a student in need of constant accommodation.

Consequences were also extrinsic. For example, I lost points for participation when I chose to attend my daughter’s therapy appointments rather than class. While the most detrimental consequences were likely the damage to my self-image, I was unable to reflect on this meaningfully until embarking on this project. Beyond this project, there were opportunities to do this honestly during my time as a graduate student, but out of fear of rejection I chose not to explore them. My inability to self-reflect (Brookfield, 1995) was influenced by my own understanding of the “rules” of graduate school, combined with the socialization I received. As such, I faced the additional consequences

of lost opportunities to question, and perhaps dismantle, this life/class compartmentalization.

By valuing my own graduate student lived experience, and subsequently training instructors to do the same (Austin, 2003), the classroom can become a location for liberation and build opportunities for graduate students to mine their experiences in life to make deeper connections to the scholarship in the field. Graduate education as a place of liberation is akin to Paulo Freire's (1970) contention that good education allows the learner to act as co-creator of knowledge. The consistent confluence, present in all three narratives, of life outside the classroom intruding on life inside the classroom, serves as an example of how inextricable these locations are to my learning as a graduate student and the need for graduate education to be liberatory. Further, my narratives expose the complexities of graduate students' lives, which should be embraced by both students and instructors.

My narratives show how the performative identities that are required of students become complex and informed by many different life experiences and emotions. In my experience of graduate school, I navigated my social identities (lesbian, mother, professional) as well as worked — often clumsily— to integrate new ones (mother of a child with a disability). The narratives illustrate how, rather than articulate the learning that the richness of my lived experience presented, I went to lengths to hide these experiences. The narratives of what I thought it meant to be a good graduate student were so deeply ingrained that bringing the knowledge of my lived experience to the classroom would have been rejected. Yet, I have also acknowledged that it may have been embraced had I attempted to integrate my identities. As such, it is critical for

graduate education, from the classroom, to research experiences and mentorship, to explicitly include graduate students' lived experiences to create a more authentic and effective learning environment. My point emphasized the strong role that graduate students' lives play in their success, much like Tinto (1993) and Golde (1998) found in their studies of undergraduates.

Research on graduate education typically subscribes to persistence theories that contend that those who persist despite negative life events are successful and those who do not are unfortunate, but accepted, casualties to the structure of education (Astin, 1999). My narratives highlight the intense feelings of failure, and even malfunction, I felt at being unable to uphold what I interpreted as the required separation between family and the classroom. If I was not resilient, I should be a casualty. Moreover, should I have attempted integration, or found that to be a supported aspect of my education, I may have been better able to trouble the compartmentalization in my life. The suffering I felt may have indeed been a result of my unwillingness to ask for the assistance I needed or to articulate the new ways in which my life was offering innovative opportunities to think about my graduate education. However, the powerless (or those perceived as powerless) are afraid of freedom, or in my case, of seeking freedom (Freire, 1970). Thus, my inaction is not unexpected. The structural power as well as socialized expectations of schooling contributed to my reluctance to integrate my lived experience with my graduate work more often. Additionally, the scholarship to which I was exposed in my graduate coursework was largely devoid of personal experiences, which reinforces my fear of integrating my lived experience in my academic work (Nilson, 2010).

Navigating the integrations of identities and life beyond the classroom *in* the classroom “applies to all people, [but] does not necessarily apply to all people equally” (Strayhorn, 2012, p. 22). This means that students with complex identities, including those like me who have experienced significant personal challenges, may find it more difficult to integrate their authentic selves into learning spaces. Or, as in this project, may be reluctant to try to engage in identity integration whether out of fear of facing negative consequences or as a result of graduate training that did not support this type of integration.

More specifically, in naming educational spaces as locations in need of more inclusivity, I now reject the positivist or modernist paradigm, which suggests that there is an objective reality of graduate educational success (England, 1994). Instead, I argue for variation in how higher education defines a successful graduate student, and makes room for students with complex and complicated identities and lives.

While both modernists and positivists concern themselves with doubt, the problem with the modernists is that they are overly concerned with whether a decision is “right” and fail to consider the premises and/or assumptions by which they use to classify decisions as “right” or “wrong” (England, 1994). The postmodernist understands that “right” is contextually determined all the time and, thus, must allow for more diversity in what is considered to be a “right” or a good decision— it also allows for right and wrong to exist not as absolutes but as concepts with variance (England, 1994)

My findings also align with Smith’s (1990/2007) assertion that students’ identities matter and we must not ask students to place their identities and experiences outside the learning process. A requirement can be explicit (e.g., attendance, grading policies, peer

evaluation) or implicit, such as the existing culture of graduate education. I felt myself to be a failure while in graduate school because I could not mask my “true” identity at the time. This project connects to Smith’s (1990/2007) ideas about identity inclusion in learning, as it uses my graduate school experience as an illustration of some of the issues around graduate student identity integration. This project emphasizes the negative implications of removing the aspects of one’s identity that exist outside of the classroom. Zirkel (2004) found in her work on racial integration in the classroom that students with marginalized identities have fewer and less meaningful peer relationships, lower rates of achievement, and less investment in academics. These were also my experiences, and thus, likely shared experiences of others who held multiple identities.

As a result of using a postmodern feminist disability studies framework to think about higher education, creating the space necessary for graduate students to integrate their lives into their scholarship becomes more welcomed and accepted. Placing students’ lives outside the learning process risks losing certain contributions to knowledge by forcing students to compartmentalize their roles such as student, mother, partner, or professional. Projects such as this one, where one’s identity is foregrounded, offer ways for scholars to better understand the complexity of the graduate school experience and open new ways of thinking about subjects and subjectivities. For example, I struggled with not being present in my research methods course and composing research questions that related to my daughter and the cause of her stroke instead of those that related to my field of study. While the questions themselves were not particularly useful, integrating my external life into an education research project may have yielded prospective insight into how higher education as a field could assist

graduate students in better understanding their lives, while simultaneously shaping the field to be more accepting of integrating graduate students' lives. Should I have used that classroom experience as time to create scholarship that included what my experiences were outside of the classroom, I may have been able to better connect to the curriculum of the class to my lived experience. Doing so would have required me taking some perceived risks, but it also may have prompted earlier the process of identity integration for which this project advocates.

The potential messiness of straying from the organized classroom structure of graduate school that occurs when welcoming the lived experience of students should not be viewed as an impediment to the learning process, but rather an enhancement of it. While I did not provide many examples of this messiness in the formal classroom (as I more often hid aspects of my life from my instructors), the independent study I completed on disability studies, as well as the conversation with my former department chair who liked the writing that I did about my struggles as a graduate student mother of a child with a disability, serve as examples of times when the walls between life and classroom were dismantled and the results were compelling to my reader and motivating to myself as a graduate student. These examples support welcoming the potential messiness of moving away from traditional graduate study structure, as they offer models of what types of work could be created in less-conventional settings.

Using postmodern feminist disability studies as a research framework to contextualize my graduate experience justifies my use of narrative, as this particular framework values personal narratives and also encourages one to use life occurrences to make broader meaning for others. By advocating for integration of the lived experience



of graduate students throughout their education, this project also examines who is, and is not, allowed produce knowledge, which I explore further below.

### **Knowledge as Personal Unrest**

I advocate for considering research and work outside the field of education to better understand why the lived experience of graduate students is necessary to the type of multilayered learning required of graduate education. In valuing narrative work that is informed by theoretical lenses outside of higher education, specifically in this case, postmodern feminist disability studies, educators can find new pedagogical and epistemological tools to advance higher education as a field that values lived experiences. Baxter-Magolda (2004) suggested inclusion of lived experiences to further student identity development, and such inclusion could also serve as a potential location for creating new knowledge to further the field. The combination of postmodernism, feminist theory, and disability studies in this project serves as one example of how graduate student learning autonomy can be increased using theories created outside of the field of education.

Higher education theories do, increasingly, allow for students' experiences to be valid forms of knowledge production. However, as I suggest earlier, this requires influence from outside areas of study that value student knowledge production. For the purpose of this project, I would not be able to contextualize my graduate school experience as I did in my narratives without the influence of postmodern feminist disability studies theories. Education is unique in that it is a field dedicated to learning, and as such, must bend with the additional weight of new ways of thinking or risk breaking under the pressure to maintain the status quo.

Historically women, and by extension others with non-dominant identities, have been categorized as “unreliable knowers” (Mackenzie & Stoljar, 2000, p.185). Higher education has structurally “recapitulate[ed] the subjection to paternalistic tutelage John Stuart Mill sought to counter more than a century ago” (p.185), depriving some graduate students of autonomy. Or, said differently, by devaluing the knowledge of those with non-dominant identities; only specific groups of people with privileged identities are able to produce knowledge. Reflecting on my narratives, I found that I felt pressure to perform in ways that aligned with how graduate students were socialized to behave, and how those with privileged identities behaved. Referring to the specific way I navigated classes in which I began to fall behind, I did not challenge accusations from professors that I needed more focus. Instead, I agreed to follow the social norms of the graduate program. Further, I described attending to notions of traditional mothering, when during these exchanges, I acknowledged that I would love and support Greta no matter her needs. These interactions were noteworthy, and I repeated them over and over with little deviation. As previously noted, although I may have been met with acceptance had I tried a different tactic, I did not feel it was appropriate to do, given my socialization as well as my graduate student training, which I believed would discourage such approaches.

Just as we understand higher education to have changed over time from an opportunity only afforded to the elite to a much more accessible option for diverse groups to engage in post-secondary learning, so too must we understand that the structures that guide higher education still reflect that exclusionary history. In reflecting on higher education history, Kuh (2015) writes,

the dominant approach [in the mid-twentieth century] at the vast majority of colleges and universities was Darwinist; that is, the students who deserved to succeed were those who could figure out on their own how to adjust to and find their way through the institution (p. viiii).

And, while he notes change has occurred, he cautioned student affairs professionals to not equate an increase in student diversity with having overcome this past way of thinking. Rather he called “to make proper student-centered adjustments in policies and practices” to address continued feelings of alienation of students from non-dominant groups. (p. x). Despite this recent call, my interpretation of graduate education required me to adhere to the traditional narrative of a good graduate student discussed earlier and supported by research in the field (Kuh, 2002).

I further conclude that embracing the complexity of multiple, and often conflicting truths, as exposed through personal narratives told from different perspectives, can lead to complicating the way in which knowledge is produced in a higher education setting. Postmodernism specifically positions itself as an anti-theory of sorts (Nash, 2004). This conflicts with the purpose offered by conventional understandings of education; “purposeful action in educational administration is defined by a limited range of options defined by constrained intellectual/conceptual boundaries” (English, 2003, p. 12). As a result, a theory such as postmodernism, and specifically postmodern feminist disability studies, creates confusion within higher education as it rejects certitude (English, 2003). It concerns itself more with the questions than the answers and, as such, is not easily applied in administrative or educational settings (English, 2003).

### **Recommendations**

The theoretical framework and narrative method of this project illuminated some intricacies of graduate student life. As such, it provided groundwork for efforts to integrate graduate students' lived experience with their classroom experience. However, more research needs to be done in this area. Specifically, research needs to be devoted to how higher education as a system can better support the integration of students' selves into the learning process.

### **Graduate Student Lived Experience**

More work needs to be done to support the legitimacy of using personal narratives within scholarly work. There is ample evidence that this format is useful and productive, but it remains at the outskirts of acceptability (Nash, 2004). With more research using this type of method, the field can expand to include narrative work as an important contribution to scholarship.

Educators, such as faculty, staff, and those in the classroom, can engage in specific efforts to encourage integration of graduate students' lived experiences and classroom learning. For example, instructors can create assignments that ask students to think about how they learn and use examples within higher education scholarship to support drawing on students' lives as a component to learning. Additionally, instructors can communicate their willingness to work with students to integrate their lives into their learning to create spaces for diverse types of scholarship that incorporate influences perhaps external to education. Although much work has been done in the field in recent years to include scholarship external to education, it can still be regarded as secondary to scholarship that relies upon educational theories alone (Meirow, 2000; Nash, 2004).

**Policy and Practice**

When students are struggling with profound life events, institutions should be equipped to work with staff to address some of the students' needs. Accommodating the effects of life events on students' learning should also be integrated in graduate education policy. By providing overt procedures regarding accommodation and flexibility, graduate students will be encouraged to be more honest about the effects of their outside life on their studies. This reduces the shame and performativity described in my narratives and would help move graduate education to a more authentic learning space.

Relatedly, were flexibility and authenticity welcomed in graduate education, there would be a necessary shift in academic culture that would no longer pathologize the students struggling with life events as unable to meet the expectations of graduate education, but instead see them as sources for new learning. Further, by developing policy and practice that integrates flexibility and authenticity into graduate orientation, advising materials, and other procedural aspects of graduate education, these values would be embedded within the culture of higher education institutions. This would create higher education institutions that are prepared to be inclusive of graduate students' whole selves by institutionalizing the integration of students' lives into their studies through explicit policy and overt practice.

To accomplish this there must be several changes. First, increased communication amongst faculty and administrators who oversee policy creation and implementation will be required to allow for this paradigm to shift. Those involved with graduate education must communicate with one another so that students facing life events can seek services that support them as graduate students *and* as individuals, without

implying that it is impossible to be a person struggling personally and a scholar. Second, it requires graduate education to include examples of different types of learning and to employ faculty with specialization in this type of integrated learning. Professional development opportunities that teach faculty in graduate education the merits of diverse knowledge creation should be offered. Not all faculty or instructors will be experts in this work, but all faculty and instructors should have the tools necessary to guide students to those who do.

My narratives both expose tension between my graduate student life and what I believe are the expectations of graduate education. This complicates the efficacy of continuing to expect that graduate students lived experiences will remain separate from their learned experiences (Brookfield, 1995). There are a number of graduate programs that are working to incorporate new ways of producing knowledge (e.g., University of Texas at Austin, Michigan State), specifically with the mission of encouraging doctoral programs to categorize personal community connections as valuable and necessary work for new professors (Kezar et al., 2005). Relatedly, graduate education efforts that train future professors to cultivate a balance that attends to their personal life as well as their professional life illustrate a step in the right direction. Progress in this area is currently underway, and the potential for more inclusive reform is encouraging.

Those in the field of higher education could use my fragmented identity narratives as a way to better understand graduate students. In using my individual experience, faculty and other educators can see the complexity of my life. As a result, they may be more aware of the value of personal discovery and self-knowledge for all students within graduate education. Certainly there are aspects of the narratives in chapter 4 that do not

belong in a classroom, and yet, the existence of these events infected every aspect of my being. The deliberate effort of having to impersonate a “successful” graduate student could be used as rationale to expand higher education’s expectations of a professional student. Presenting a model to prospective and current students that includes vulnerability and authenticity would create an environment more inclusive of integrating graduate students’ many identities. In doing so, higher education will become prepared to deal with the complexity of human experience.

### **Critique of Graduate Education**

The following section will provide a critique of graduate education using the project objectives outlined above as a framework for this analysis. The three main project objectives overlap in how they manifest in this critique, often intersecting to create a synthesized criticism that includes aspects of each.

#### **Successful graduate students.**

Much of popular research about graduate education focuses most on how to best guide graduate students in their research efforts, specifically completing dissertations or other qualifying scholarship (Bolker, 1998; Peters, 1997; Sternberg, 1981). These guides adhere to the dominate ideas about graduate students’ lives and address issues such as procrastination and time management but, as a sub-genre of scholarship on graduate education, avoid dealing with life circumstances. For example, in a 2001 study by Nelson, Dell’Oliver, Kock, and Buckler regarding the coping skills of psychology graduate students, the researchers found that those who could use cognitive and behavioral efforts to manage internal and external demands causing stress were much more successful (p. 759). Emphasizing that successful graduate students are able to

manage external and internal stress creates the conclusion that those who cannot manage stress and require modification or additional help are then unsuccessful. Additional research that focused on time of degree completion also concluded that those students most likely to graduate in the shortest amount of time were those least likely to have non-dominant identities, experience stressful life events, or challenge accepted ideas within their field (Sheridan, P.M., & Pyke, S.W., 1994).

Similarly, graduate student supervision can be described as “a blend of academic expertise and the skillful management of personal and professional relations” (Ballard & Clanchy, 1993, p. 5). While each faculty member likely approaches graduate supervision, whether of an individual student or of a group of students in a class, differently, the largest trend that exists in the literature is a lack of specific training related to supervision. In the narratives, this style of supervision is evident when my formerly acceptable graduate performance began to decline and I was left to engage in specific behaviors that both assured professors of my ability to return to my former status and also conveyed my needs for accommodation. In reflecting on my inability to uphold the artificiality of graduate student social contract I wrote, “Before the twins were born, I could, if not lie, then at least bend the way I represented the truth. I knew what instructors wanted to see,” indicating that I was very strongly aware that I was violating the unspoken rules of good graduate studies but also that I was aware of what violating these rules may do to the perception of my ability to succeed.

The messages I received about the qualities necessary to succeed became strongly embedded in my identity as a graduate student. Even as I comprehended these attributes as performative, or at the least imitative, I still measured my success toward being a



“good” student against them. The inauthenticity may well be troublesome to many students, as the research suggests, but few, myself included, challenge established notions of “good” or “successful,” and as such they remain the dominant message graduate students receive regarding the attributes necessary to prosper in graduate programs.

In graduate study, our self-image as a competent learner is confirmed, challenged, or destroyed. As graduate students, we are brought face-to-face with the realities of power...No matter how congenial our relationship might be with an advisor, we know that the last resort, his word goes. (Brookfield, 1995, p. 52).

With conventional success (e.g., graduation, employment) hanging in the balance of graduate students’ acceptance of these norms, it is not surprising that most do not question the structure of the system, nor demand valuation of their lives.

### **Challenging structures.**

It is also a risk to the status quo and a potentially unwelcome challenge of “authority” for graduate students to question the structure of higher education. It is even a risk for professors and instructors to pose questions of their institutions and colleagues for, “they [those questioning the structure of graduate education] run the risk that colleagues will see them as engaged in an act of betrayal” (Brookfield, 1995, p. 236). In chapter 4 I describe confessing to my supervisor that I felt permanently unable to care about the content of my coursework. Her response, which was to acknowledge that I likely would not be able to continue approaching my education in the same effortless and accepting way I had in the past was alarming. “It was incredibly understanding [of my supervisor], but also terrifying, as I then realized just how deeply lost I was and that I would likely never find my way back to being a model student and good professional

worker.” The terror I felt reflected the training I had internalized, which asserted that should I be unable to maintain a performance of a “good” graduate student my future would be doomed. Though I wanted to change the academe, my experience, as well as the research, indicated that the academe wanted me to change instead.

However, by socializing graduate students in this way it limits education’s ability to grow and diversify. Graduate education must continue to value different types of learning theories as well as utilize ways of teaching that appreciate alternatives types of knowledge production. Baxter Magolda’s (2000) theory of self-authorship requires students to “construct knowledge by organizing and making meaning of their experiences, and that this construction takes place in the context of students’ assumptions about and creation of knowledge” (p. 4). Consistent with self-authorship, my identity as a mother, and the learning that took place when this aspect of my identity was in the foreground, was necessary to my individual learning as well as useful to my understanding of what knowledge and ways of learning were valuable. In chapter 4 as I discuss sitting through classes “fighting back tears and writing awful research questions like, ‘how does an intelligent and educated mother allow her family to be destroyed by her bad decisions?’ or ‘what does it feel like to be a bad mother?’ I am engaging in new ways of producing knowledge.

While certainly deeply personal, and likely not viable research questions, I was embodying the act of (trying to) make meaning of my experiences. As such, learning functioned as personal unrest, an important tool as identified by Baxter Magolda (2000) as well as Gunn (2004). Baxter Magolda’s (2000) theory of “self-authorship” is rooted in the realization that modern education requires higher education institutions to prepare not

just specialists of a discipline but independent thinkers capable of synthesizing data related to a topic from diverse fields and academic locations. Moving towards an intersectional understanding of students selves that acknowledges the interconnected nature of social categorizations such as race, class, and gender (Crenshaw, 1989) could allow for educators in higher education settings to adopt the attributes of “self-authorship” (Baxter Magolda, 2000) more fully. Additionally, there are messages that professors can give graduate students to make their intentions regarding accommodating beyond ADA statements clear. One way is to state in the syllabus the professor’s intentions that students communicate with the instructor should they have difficulty with assignments, whether for medical, or other issues. Instructors can further strengthen this position by verbally affirming this in class the first day and emphasizing that they want graduate students to succeed, in the broadest sense of the term, and that they are open to alternative assignments and to helping students integrate their lived experience in the classroom. By stating this it changes the environment and makes it safe for graduate students to reach out to professors to ask for assistance when faced with challenging life events.

For example, what if instead of hiding the research questions I composed and begging my way to a passing grade by creating something that adhered closely enough to the acceptable standards of qualitative higher education scholarship I instead worked with the professor to mine these questions and there implications for my scholarship? I could have potentially considered the questions potential for furthering my growth as a researcher who was allowed to document this dramatic change in how I was once able to learn? It would not have necessarily produced phenomenon scholarship but may have

reduced the shame of being unable to mimic the prescriptive role of graduate student presented to me and fostered a new appreciation for the potential of scholarship to accurately reflect my changing sense of self. It is supported by research that other students learn in this way as well (Brookfield, 1995; Ball, 2003; Mezirow, 2000).

Integrating life experiences with the material presented in the classroom moves a learner to new levels of understanding, and helps them to see different implications for the knowledge they receive.

Additionally creating graduate training that values students as producers of knowledge can potentially lead to an increasingly innovative and adaptable professoriate as these students go on to become professionals (Kezar et al., 2005). Gillett and Beer (as cited in Haroian-Guerin, 1999) suggests that educational work that draws upon personal experience is not only valuable to the field but that graduate students have a responsibility to engage in this work to “reconstruct, new ways to understand the customs, values, and history of their social groups” (p. 18). Considering the narratives of chapter 4, and specifically the section on loss, adopting the stance that graduate students should be renegotiating academic spaces to meet their needs supports the necessity of students to bring their whole selves to their work rather than segment their identities and experiences to fit the existing models.

### **Importance of student voices.**

Nash (2004) notes that increased presence of autobiographical, memoir, and ethnographic work in other fields has an important influence on legitimizing students' voices, “[these] initiatives enlarge the more conventional, positivistic research modalities...[and] are a necessary precondition for recognizing the unavoidable role that

the ethnographer's self plays in interviewing, analyzing, and generalizing" (p. 18). What emerges then is higher education as a setting that is on the precipice of change, with many (e.g. Baxter Magolda, Kezar) advocating for the inclusion of students' lived experiences. As such there exists a continued need to more purposefully embed self-reflection into the curriculum and the culture of graduate education.

The narratives expose the ways in which, as a graduate student, I felt it necessary to conceal the effect my external life was having on my ability to succeed. Why did I feel this was necessary? As detailed in the narratives, I was a conventionally successful student at one point. I followed the rules as outlined to me, whether through formal means such as syllabi, or through informal conversations. When I could no longer fit the image of a successful student as I understood them, I experienced self-doubt in my ability and felt I did not belong in graduate school. It was later when I found research that supported the claim that "the ultimate intellectual responsibility of the SPN scholar is to find a way to use the personal insights gained in order to draw larger conclusions for readers; possibly even to challenge and reconstruct older political or educational narratives" (Nash, 2004, p. 18) that I felt I could once again find a "home" in higher education graduate work. My self-doubt, combined with the lack of overt graduate program flexibility, insisted that I had fallen "outside the dominant research paradigm" (Nash, 2004, p. 19) yet I still felt that deep learning was taking place despite it being outside the classroom, or peripheral to the structure of my graduate education.

Looking at the narratives of chapter 4, specifically in the section on family, at first I sought graduate school as a refuge from the constant worry of my daughter's health. Later, in the narratives in the section on loss, I mourned losing the role of successful

student noting that it was more resignation I felt than sadness as I deeply clung to the traditional idea of what a successful graduate student should look like. Finally in chapter 4's section on loss I had accepted the permanent loss of my former successful self and firmly established my place, within my own mind and in my future research interests, as outside of the scholarship that dominated the field. Within the narratives there is evidence that flexibility did exist within my graduate program, and yet I viewed asking for them as exhibiting weakness.

The narratives of this project help illustrate that what was perceived, whether by me or others, as weakness had much more in common with authenticity. More broadly, rather than graduate students who need help in managing graduate work because of life events being seen as unable to meet the expectations of graduate education, they should instead be encouraged to integrate these different sites of learning into their graduate experience. Life events should be a source of intense learning that complements the learning that takes place in the classroom. This project serves as one example of how my life events can be transformed into meaningful sites for scholarly inquiry. Additionally, within chapter 4 I detail an independent study I completed where I was permitted to research disability studies and the new ways in which I was able to think about body variety as a result. Finally, serving as a more successful example, I wrote in chapter 4 how my supervisor found my writing about Greta to be the most interesting and authentic research I produced, reminding me that I could not divorce my heart from my head. This project is one example of how an authentic research approach may be applied.

This authentic approach to learning extends to teaching as well. Teachers are successful when they acknowledge the essential connection between the subject [one is

teaching] and the student, Palmer (1998) names this as integrity (p.13). “No matter how technical my subject may be, the things I teach are things I care about—and what I care about helps define my selfhood” (p. 17). Palmer’s explanation of successful teaching as a practice infused by authenticity that both educates others as well as enriches himself illustrates how valuing lived experiences, authenticity, and passion make for a more robust learning environment. Relatedly, as Palmer asserts that aspects of our selfhood show up in our research interests, it seems only reasonable to accept that graduate students’ lives include their work, and thus their work includes aspects of their lives as they study to become future professors or practitioners. No longer do faculty and students become entirely beholden to the “authoritative other,” but rather they are able to integrate the “subjective self,” ultimately encouraging the field to grow in new ways (Nash & Bradley, 2011, p. 57). Education then is a logical location for inclusion of authentic learning as its interdisciplinary structure (Klein, 1990) makes it adaptable to integrating students’ lived experience as well as including diverse areas of study. Higher education is unusual in that research and scholarship related to education, at its most simplistic, is dedicated to how we learn (Goodchild, 1991). As such, it is a potentially innovative location to practice new ways of thinking about how students learn as it is structured with the study of learning at the forefront.

### **Potential of authenticity in higher education.**

In this project, I used a postmodern feminist disability studies lens to frame my narratives. By using lenses outside the field of higher education, I hoped to dismantle some aspects of the graduate student experience that are accepted as routine or normal. Grimmet and Neufeld (1994) see three motivations of teachers: the traditional, the

alternative, and the authentic. When situated in the context of higher education, this suggests that faculty, and others with teaching responsibilities, are only motivated when what they do is rewarded and/or incentivized. And while educators are more motivated when they engage in work they see as rewarding, when their motivation is grounded in authenticity they do what is best to further the research potential of themselves and their students (p. 5).

This places authenticity, which supports the integration of lived experience with classroom learning experiences, as being a useful tool for providing better education. Using additional theoretical frames to examine higher education practices could be particularly useful in advancing pedagogy that is inclusive of graduate students' lived experience. By mixing theoretical locations, I tried to uncover faults in the foundations of graduate education. Chapter 4, buoyed by the theoretical framework described earlier, poses questions about the graduate student experience and the separation of selves necessary to succeed. Using narratives informed by theories outside of higher education frees the researcher to interrogate how learning occurs outside of the confines of conventional education research on the topic as it amplifies those aspects of education research that advocate for authenticity and change within the field. Through the use of research frameworks created outside of education this project attempted to further push through the discomfort of the academy (Gunn 2004) regarding integration of lived experience and strengthen scholarship that advocates making room for students' voices.

### **Creating new spaces.**

While my multiple, and occasionally conflicting, narratives exposed a life defined by fragmentation, the act of telling and hearing the stories provides an opportunity for



unification. All three unearthed elements of performance necessary to succeed: the family-focused narrative provided a portrait of a mother struggling to function as anything other than a mother; the doubt narrative uncovered the way in which my reality was defined by others' perceptions and my ability to cope when those perceptions changed; and the loss narrative detailed mourning of losing "normal" and losing my previous methods of dealing with adversity. Family, doubt, and loss were often in the foreground of my graduate student experience, and yet I remained a graduate student. As Jean Joyce-Brady (2004) details in her essay on being a mother and working in student affairs, her role as professional and her role as a mother fluctuated in dominance, but she found herself succeeding at both when she developed a "tolerance for that fluctuation" (p.122). Even when my narratives exposed my inability to keep up, or my preoccupation with health and disability, I remained an active graduate student. This was viewed, by many, as commendable and an indication of my level of perseverance. However, it felt at that even my apologies must fit into the accepted expectations of the contrite graduate student. The disclosures I made about my life and the effects it was having on my ability to succeed in my graduate program were calculated to elicit the responses I needed. Ball (2003) describes graduate education as performative in that it "requires individuals to set aside personal beliefs and commitments and live an existence of calculation" (p. 215). I similarly used tropes associated with resiliency in higher education to convince faculty that I could continue my work.

There is additional evidence that my life experience influence my graduate education. For example, a course on student identity models was something I could engage with prior to my daughter's birth with little intrusion of contradictory thoughts.

However, afterward I could no longer receive information about student development without considering the diversity of student abilities and becoming distracted by whether these models included her abilities. And, it did not feel possible to address my concern about including diverse abilities in identity models openly. Brookfield (1995) noted that students quickly learned “the lesson that it was dangerous to challenge the teacher” (p. 177). Further admitting to a preoccupation or distraction, as it were, would likely decrease my ability to be taken seriously in the future as “responses to deficiencies [of graduate students] ... were most likely to include terminating students and psychotherapy referral (Procidano, Busch-Rossnagel, Reznikoff, & Geisinger, 2006, p. 427)

The narratives, in totality, and as fragments, serve to remind educators that knowledge is constantly being acquired and affixed with values based on students' lives. What could be perceived as distractions to real learning, such as the themes of my narratives, actually provide examples of how organic learning takes place? Even when the requirements and rigmarole of graduate school were presented in various narratives as being difficult to manage, each narrative also depended on information gained in graduate school. More specifically, while I retell the pain of performing so poorly in my qualitative methods course, I still used the methodology of the course to help frame my life. Just as life intruded upon my classes, my classes intruded upon my life. I gathered information from the classroom to help understand my life circumstances just as I applied learning that occurred in my life within a classroom setting. It is in these complicated spaces, where life and classroom were competing for my attention, that learning took place.

The movement away from established places of knowing, and embarking on/engaging in research as a process whereby we are confounded and dislocated, where there are no easy answers or even ‘successful’ research outcomes, or where we fail to map the start and endpoints of our linear research processes, where we are unable to find language, may indeed be the very knowledge and ultimately the learning we require in representing ourselves. (Herising, 2005, p. 127 )

More specifically, learning is, and should be disorienting. Using multiple truths in my narratives functions to interrogate typical structures of knowledge production that rely on teacher/knower and student/learner dynamics. This criticism of formalized structures “serves the purpose of encouraging the important internal conversations that ultimately deepen and refine the ideas in an academic or professional discipline” (Nash, 2004p. 148). We should no more expect graduate students to stop learning in the face of disorienting information than we should expect instructors to avoid facing perplexing questions about accepted ways of thinking. The reciprocal nature of my relationship with graduate education created a hunger for academic and personal inquiry that was beneficial in both locations and I hope, beneficial to those reading about my graduate journey. It is important to note that this additional learning and new way of approaching scholarship would not have been possible without having the opportunity to embark on this project and think critically about the way in which my lived experience and multiple identities contributed to my knowledge and growth as a graduate student.

### **Research.**

More work needs to be done to support the legitimacy of using personal narratives within scholarly work. Specifically, research needs to be devoted to how higher

education as a system that can better support the integration of students' selves into the learning process. There is ample evidence that this format is useful and productive, but it remains at the outskirts of acceptability (Nash, 2004). With more research using this type of method, the field can expand to include narrative work as an important contribution to scholarship.

Educators, such as faculty, staff, and those in the classroom, can engage in specific efforts to encourage integration of graduate students' lived experiences and classroom learning. For example, instructors can create assignments that ask students to think about how they learn and use examples within higher education scholarship to support drawing on students' lives as a component to learning. Additionally, instructors can communicate their willingness to work with students to integrate their lives into their learning to create spaces for diverse types of scholarship that incorporate influences perhaps external to education. While much work has been done in this recent years to include scholarship external to education, it can still be regarded as secondary to scholarship that relies upon educational theories alone (Meirow, 2000, Nash, 2004).

### **Limitations**

Some of the limitations of this project have been addressed in chapter 1; however, it is important to note these limitations again at the culmination of the work. Scholarly personal narrative (SPN) is a method of research that relies upon the author as the lone interpreter. Certainly I used notes, journals, medical records, electronic mail, text messages, and other "concrete" evidence to document my narratives but artifacts are subject to my interpretation alone. While I present interrogating others' notions of

“research” as a crucial component of this postmodern project, it is still important to acknowledge that others may critique this aspect.

Further complicating my credibility as a narrator is my theoretical location. A postmodern understanding of truth requires that one accept there can be multiple and conflicting realities. This acceptance opens the door for readers to be skeptical of my narratives. How can I present three tellings of the same time period without losing trust? Reliability is taught as one of the tenets of good research (Creswell, 2009). The use of a postmodernist frame allows for reliability to become secondary to self-authorship, as scholarly personal narrative is informed by the lived truth of the writer, “what works best for the narrator and the reader in the never-ending quest to find and construct narratives of meaning” (Nash, 2004, p. 33). By framing the research of this project as narrative, there becomes less focus on whether I, as an author, am credible, and instead emphasizes whether the narratives as a documentation of one person’s experience are valuable to understanding the graduate school experience.

Finally, it is important to note that this is the narrative experience of one person. And, while I believe important learning can occur based on the experience of one person, readers may find the transferability of these findings limited.

### **Conclusion**

This project used personal narratives from a specific time in my graduate education to provide examples of why such narratives should be legitimized in higher education, why valuing the lived experience of graduate students is integral to higher education, and finally to complicate the current system of knowledge production. This project is an attempt to address the complexity of graduate students’ lives and makes the

case that this is necessary for higher education to continue to grow and expand in new ways.

As previously mentioned education is a unique field in that it focuses on how students learn. As such it is an influential location to shape the way in which other disciplines and fields approach learning. Educational administration governs the way in which scholarship is valued (Kuh, 2005). More specifically, higher education administration creates the policies that dictate what is valued in a program, a department, or even an institution. As such, it is necessary that higher education continue to expand its policies, practices, and theories to make room for graduate students to integrate their lived experience into their learning. This way of thinking creates emancipatory learning spaces where graduate students can engage fully in inquiry that is not limited by hegemonic barriers to their thinking, but rather open's the field to complex truths and diverse possibilities (Mezirow, 2000).

These areas of growth are needed as graduate education continues to adapt to the changing world in which we live. As more diverse students enter education graduate programs it becomes important that these programs allow for news ways of producing knowledge to, not only accommodate the needs of graduate students, but to also remain an influential and innovate location dedicated to truly understanding the depth and breadth of humans potential to learn and teach.

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## Vita

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