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Valanced Voices: Student Experiences with Learning Disabilities & Differences

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Valanced Voices:
Student Experiences with Learning Disabilities & Differences

by

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A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts
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Abstract

This feminist oral history project located at the intersections of disability, feminist, body politics, and educational theory presents an analysis of three individual student narratives about their experiences with learning disabilities and learning differences (LD/Ds) at the high school and university levels. This thesis introduces students’ accounts of their daily lives, pasts, personal views, experiences, and memories about having learning disabilities and learning differences into the existing scholarship on LDs and reveals how students’ narrated experiences might shed light on the ways in which education might be reformed to better meet the needs of students like them. In response to these oral histories, I recommend a more distinctively holistic approach to intervention for students with learning disabilities and differences and introduce regime theory as a potential approach to educational reform to improve circumstances for marginalized individuals in the U.S. educational system. Adopting a broader, more universal model would result in more comprehensive and effective training for professionals to prepare them to more quickly and accurately recognize patterns and trends (such as the growing number of LD/D diagnoses over the past decade), and disability in education being reframed, reimagined, and handled as a social issue, a repairable condition in need of attention and resources.
Chapter 1. Introductions

1.1 The Project’s Evolution

The first major intellectual turning point in my undergraduate education occurred five minutes into the first meeting of an advanced feminist theory course. The professor began class by briefly introducing herself and her scholarship. She then stopped talking and drew the class’s attention to her arm. She waited. She plainly stated that many people would call her “deformed” since she did not have ten “normal” fingers and one of her arms ended just below the elbow. After pausing, she explained that upon seeing her arm strangers often rudely ask her questions about it and find it acceptable to stare at her because of her bodily difference. The professor then asked us to think of words that people use to offend one another when they do something incorrectly. We came up with a list of words that included: “lame,” “stupid,” “retarded,” “pathetic,” and “dumb.” We were then instructed to examine our list and report any patterns that we saw. Our discussion led us to realize that the majority of the terms that we came up with were those most often used to describe physical or intellectual disabilities. As a class we learned from the activity that offending someone means calling them inferior, and the easiest way to call someone inferior is by calling them disabled.

Though I began this thesis as a general thematic analysis of narratives on disability and education\(^1\) it quickly transformed into an oral history project located at the intersections of disability, feminist, body politics, and educational theory. That which

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\(^1\) My original plan was to conduct a thematic analysis of several interviews on disability and education. I
began as a general exploratory study of how undergraduate students feel about disability and education rapidly developed into a feminist exploration of a few case studies. Instead of a project that aimed to identify themes that emerged in my interviews in efforts to explain the nature of the students with disabilities, this thesis evolved into an analysis of students’ individual histories about their daily lives, pasts, personal views, experiences, and memories about having learning disabilities and learning differences (LD/Ds).

The students shared with me their memories and stories about what it has been like for them to have LD/Ds. When the interviews slowed down at point, I used my interview guide to generate conversation but for the most part the student narrators decided on where the interviews went. The oral histories that I gathered centered on what it was like for each student to learn with LD/Ds in high school and what it is like for them to currently learn at the university level. During every conversation the students told me about their specific LD/Ds, how their LD/Ds impact their academic experiences and life in general, and how they feel about those influences. Some of the most engaging, rich conversations addressed what the student narrators would tell other students with LD/Ds to help prepare them for what college and high school might be like for students with LD/Ds. The narratives transformed into feminist oral histories because their stories were those that had never been shared in such a context; like other feminist oral histories, these interviews featured voices that had been historically left out of the record. In line with feminist oral histories, these narratives also included students’ recommendations about what specific ways high school and university educators, administrators, and loved ones might more effectively facilitate learning for them as well as students like them now and in the future. At those points my thesis developed into a distinctively feminist project that
politicized the personal and that took personal experiences of “difference” that were discussed at length to an action level. By way of feminist oral history, this thesis exemplifies how the personal narratives of students with LD/Ds can unveil what needs to be done in educational practice and policy to better meet the academic and personal needs of students with LD/Ds.

The current burgeoning demand for research on disability and learning correlates with the increase in numbers of learning disability diagnoses over the past decade. For instance, according to the Centers for Disease Control and Prevention rates of Attention-Deficit/Hyperactivity Disorder (ADHD) have increased an average of 3% per year from 1997 to 2006 and an average of almost 6% per year from 2003 to 2007\(^2\). Individuals of all ages in all academic and employment environments are influenced by how they learn and by how their learning is responded to by those with whom they interact on a daily basis. I chose to gather oral histories from university students from quite different walks of life in order to represent the diversity of individuals with, and their experiences of LD/Ds at the high school and university levels. The students with whom I spoke differed from one another in terms of age, academic year, gender, and place of origin, but they were similar to one another in that they were what we might call “success stories.” These students with LD/Ds were among the few of all students with LD/Ds who made it to college, who had to learn how to advocate for themselves, who had certain privileges and opportunities to seek out accommodations for themselves. It is important to note that the group of students with whom I spoke both exemplifies the how diverse students with LD/Ds are

\(^2\) CDC Attention-Deficit / Hyperactivity Disorder (ADHD) Data and Statistics in the United States. 
http://www.cdc.gov/ncbddd/adhd/data.html
but also represents those who succeeded, those who made it through the educational system albeit with negative as well as positive experiences relating to their LD/Ds.

I chose to focus on three of the six interviews that I conducted; narrowing my analysis in this way gave me the freedom to delve deeply into the narratives and gave me the chance to present each student narrator as the multidimensional individual that each was. The three narratives that I draw from were those that most clearly exemplified how learning disabilities and learning differences can be analyzed at the theoretical intersections of disability, feminist, and educational theory. More particularly, each of them brought something different to my analysis. Ben’s stories were saturated with rich descriptions about what it is like to experience a process of becoming disabled in various ways. He described experience after experience of taking on and redefining disability, coming to terms with his disabilities, and negotiating what it means to navigate the world with a “disabled” body and mind. Laura’s oral history stood out in that it was a story about a non-traditional student, a woman who returned to college later in her life after a long period of drug and alcohol abuse that resulted in her experiencing memory and processing difficulties in academic settings. Finally, Julie’s narrative was a story about a girl whose learning problems had, for the most part, remained unidentified until she took it upon herself to seek out help, resources, and accommodations for herself. The three narratives that I present here emerged from the six as uniquely intriguing; the stories seemed to speak to one another and resonate with one another; as a collective, they brought to light how disability cannot be examined in isolation. Individuals experience disability socially and emotionally as well as educationally, and their experiences with their LD/Ds cannot be separated from their experiences as women and men nor from their
experiences as individuals of different ages nor from their experiences in different locations. While compelling and diverse, their stories were a mere sliver of the intriguing ones that I heard throughout the interviewing process.

Ultimately, the variety of discussions in which the student narrators and I engaged brought to light how influential educational policies and practices are to individual students who have LD/Ds. Oral histories on LD/Ds such as the three that I present here have the potential to lead educators, administrators, and even policy makers to recognize and work to improve how students with LD/Ds are considered, taught, and accommodated at all educational levels.

Like a reader forever changed by a story, I am forever changed by the moments that I shared with the individuals who shared their oral histories with me. The students I interviewed are far more than mere characters in the story that unfolds in this text. The memories, feelings, opinions, frustrations, and significant events in the lives of these individuals emerged as multidimensional manifestations of how disability is experienced in United States education. These rich manifestations morphed my thesis into a text characterized by intellectual cohabitation and interdisciplinary imperative. Both voices and theoretical bodies of literature sinuously blend together in the writing that follows for, in order to collect voices that have been historically omitted from record, I found it necessary to interlace the students’ narratives with feminist, disability, and educational literature. These bodies of knowledge seemed essential in this analysis. They exemplify the ways in which identity, experience, and intervention relate and can be concurrently explored in efforts to create the lasting sociopolitical change I aim to accomplish through this feminist oral history project. More specifically, my feminist objective is to refer to
these students’ experiences in order to reveal current problematics, inconsistencies, and shortcomings in the ways in which the U.S. educational system meets the needs of students who have LD/Ds.

Feminist academic work uniquely requires the writer to interweave politics with poetry. Many feminist scholars strive to demonstrate how one’s individual experiences, one’s worlds of meaning and perspectives, and one’s daily encounters and range of choices relate to power and how those dynamics might be reimagined and transformed. While endeavoring to demonstrate how power systems are constantly at work in our cultures, societies, and communities, feminist researchers and writers face complex junctions of interconnected wires tangled into heaps. For me, breaking free of these confines has meant having to understand and generate intellectual cohabitation, the ambiguity and fluidity necessitated by and expected in feminist, interdisciplinary research. I find it crucial to begin my own research from a place of recognition of my positionality as a researcher as well as the roles that I play in my own research. Similar to how my life experiences are fundamentally connected to what I learn and reflect on in my research, my voice is infused with the student narrators’. The analysis that unfolds in this thesis is therefore a collective accomplishment and serves as an example of how feminist research might be conducted with the aim to politicize the personal through oral history telling, narrative analysis, and, subsequently, offering action plans to change the status quo for historically disregarded or omitted populations.

This exploration collects and analyzes individual undergraduate students’ oral histories about what it has been like for them to learn with LD/Ds at high school and university levels. Gathering and reflecting on undergraduate students’ personal accounts,
views, and feelings about disability and learning uniquely reveals the complex ways in which education happens for such students in high school and college. The oral history analysis that I present here illustrates how, in what circumstances, and when particular individuals make meaning of their identities in relation to their specific, and often multiple LD/Ds. I describe in the chapter that follows where my research fits into existing scholarship on disability and education.
Chapter 2. Review of Empirical & Theoretical Literature

2.1 Background & Significance

One might typically assume that by calling my thesis “feminist” I mean that it only deals with women, girls, or the construction of gender. In actuality, this project is qualifies as feminist because it is aimed at establishing, protecting, and advocating for equal opportunities for marginalized groups of individuals. In this case, the marginalized group is that of students who have learning disabilities and learning differences. Since the late 1960s when the Women's Liberation Movement emerged in the United States, Women’s Studies and feminist theory has developed and served as the prominent educational arm of the women’s movement. Since then feminist theory has offered its students the chance to discover and develop tools for action, i.e. both activist and academic strategies, to be used to help students identify and resist systems of power and privilege that have historically marginalized, silenced, and oppressed particular populations while empowering and privileging others. Tenets of feminist theory have inspired students over the generations by leading them to recognize the importance of raising consciousness about diversity, difference, oppression, and power structures. Recognizing the origins of, and ways in which inequality plays out in society in regards to sex, gender, race, and disability leads feminist scholars and students to better understand how personal, everyday choices and actions can lead to more macro level sociopolitical change. Feminist theory is thus the jumping off point for my thesis. It incites, specifically, intellectual explorations like mine that are located at the dynamic
intersections of feminism and education. Social justice oriented research like this feminist study can drastically transform the lives of millions by leading to critically needed educational reform. Integrating students’ voices into the mix also qualifies my scholarship as feminist. This project advances social justice by recognizing individuals who have been omitted over time as essential agents and resources in the historical record; it, therefore, aims to give voice to historically silenced populations. The voices of the student narrators are indispensible, because progress in educational issues surrounding learning disability is impossible without their inclusion and integration. Current and future teachers, administrators, and students can greatly benefit from students’ perspectives and views on what it means to have a learning disability or difference in high school and university settings.

Feminist educational research centered on students’ personal accounts of experiences with learning differences and disabilities is quite limited. Much existing scholarship on LD/Ds is specifically educational literature that concentrates on the experiences and opinions of educators, administrators, and parents of students with LD/Ds. Instead of studies focusing on students’ accounts of their own experiences having LD/Ds, studies appear to focus on and analyze the accounts of individuals who hold influence and power in the students’ lives. Theirs are the opinions and pieces of advice that seem to be most often taken into account and, consequently, become permanent parts of the historical record. The research that I offer here contrasts with this scholarly trend by highlighting students’ perspectives and experiences. In so doing scholarly endeavors like mine aim to pave the way for future research intended to fill the existing void in scholarship on students’ experiences with LD/Ds. My particular research questions about
learning and disability led me in multiple directions when I went searching for literature relating to my project. Thus, I begin this chapter by interweaving feminist and disability theory to introduce the theoretical frame with which I analyze the oral histories at the center of this project. I proceed with a review of existing scholarship on disability and education to illustrate the need for future research on students’ perspectives on experiences of disability and education.

2.2 Feminist Disability Studies

The struggles for the rights of individuals with disabilities are intrinsically connected with the struggles for the equal treatment of all groups of oppressed people. Thus, since the goals of disability theory align with those of feminist theory and Women’s Studies there is great potential when research is conducted at the intersection of these intellectual approaches. Drawing from the social model of disability, the impaired body and mind are disabled in our society through their being treated as deviant, inferior, and damaged (Oliver, 1996; Hughes & Paterson, 1997; Shakespeare & Watson, 1997; Oliver, 2004; Thomas, 2004). I argue that such social and political mistreatment of students with disabilities extends, quite evidently, to education in the U.S. (Corbett, 2001; Gay, 2002; Cole, 2006; Knoll, 2009). Students with LD/Ds are not always taken into account and thus their needs are not always met since they are considered different from “normal” students who do not have what might qualify as a learning disability or learning difference. While educational inequalities often relate to students’ race, gender, and sexual identities, I argue that they are absolutely tied to how students learn, any health conditions that may influence students’ ability to retain information in particular
circumstances, and students’ past personal experiences that might impact their academic performances.

This project extends the social model of disability to education as it seeks to lead to more thorough, nuanced understandings of how students with LD/Ds are disciplined, subjugated, and mis/treated not only because of their LD/Ds but also because of other aspects of their identities. This project therefore recognizes how each of us has multiple and ever-changing identities that deeply influence how we navigate the world, and, in this case, how we experience education. Ultimately, this project is an identifiably feminist disability study since it seeks to both recognize and critically analyze disability as a major category of otherness. Feminist disability studies scholar Rosemarie Garland-Thomson (2001) explains how disability studies examine the disability identity “in the service of integrating disabled people more fully into our society” in ways similar to how women’s studies expand the lexicon of what we imagine as womanly in order to better “understand and destigmatize the identity of “woman” (4). Uniquely, like the social model of disability, feminist disability studies interprets disability as “a cultural rather than an individual or medical issue” (Garland-Thomson 5). Like feminist theory, FDS insists on “examining power relations rather than assigning deviance when analyzing cultural representations of oppressed groups” (5). In a broader sense, FDS brings disability studies and women’s studies together to argue that “cultural expectations, received attitudes, social institutions, and their attendant material conditions create a situation in which bodies that are characterized as both female and disabled are disadvantaged doubly and in parallel ways” (4-5). I explore in my analysis this last point in depth as the oral histories that I gathered illustrate quite well how multiple aspects of someone’s identity
can doubly disadvantage them (i.e., where LD/Ds meets gender, sexual orientation, age, and other disabilities).

In the words of feminist scholar Diane Price Herndl (2006), as women, “while we are not all marked by physical invalidism, we are all marked by cultural invalidity; we may not be invalid women, but we do have a certain solidarity with them” (3). In line with Price Herndl’s argument concerning necessity of being able to recognize when disability, or invalidism in this case, is “a useful or necessary strategy of subversion” (3), I assert that while each of us might not claim a disability identity, it is crucial to recognize how research like this has the potential to improve education for all students. I aim to exemplify how using a both disability/feminist theoretical lens to analyze and determine how we might reimagine education in ways that will improve the learning experiences of students both with and without LD/Ds. In the spirit of feminist scholarship, the oral histories that I present here offer the reader varying contexts through which I indicate how power functions. Concurrently, I reflect on the ways in which the student narrators constantly make meaning of their LD/Ds, how they construct and reconstruct their LD/Ds identities depending on their social and educational surroundings, and what recommendations they offer to reform pedagogy of students with LD/Ds. These students’ oral histories therefore “ground” the often impenetrably abstract theories that I refer to in this study by providing concrete, real-life examples. The narratives illustrate the need to connect the theories from which I draw to educational policy and practice that can cause lasting and innovative change.
2.3 Empirical & Theoretical Literature

For the last twenty-five years, a key topic in special education has been, “the integration of children with special educational needs in ordinary schools” (Avramidis, Bayliss, and Burden 2000b, 191). Integration refers to externally made decisions about where particular children should be placed. Therefore, integration denotes a process that does not imply or require the restructuring or altering of educational environments in order to accommodate the needs of what could potentially be a small number of students with significant disabilities (Fish, 1985). The more novel term “inclusion” has been used more frequently and come to signify a shift in how disability is contended with in classroom spaces. Inclusion has been gaining popularity in these debates and discussions since it implies the restructuring of mainstream schooling so that each and every school can “accommodate every child irrespective of disability (accommodation rather than assimilation); this approach ensures that all learners belong to a community” (Fish 192).

This linguistic shift signifies a more general commitment giving all students more equal access to education. Restructuring schools to become more inclusive and effective for all students regardless of disability is an admirable goal, though problems arise if teachers are not sufficiently prepared or trained to meet the needs of all students, namely those with disabilities.

Much research on education and disability is comprised of surveys looking at teachers’ attitudes about what it means to be inclusive when it comes to disability and education. One recent U.K. study focused on student teachers’ attitudes towards the inclusion of children with special educational needs in the ordinary school (Avramidis, Bayliss, and Burden, 2000a). Findings showed that respondents held positive attitudes
toward inclusion in general, but their perceptions of how successfully they could teach “included” students dropped significantly as the severity of children’s specific needs increased. Respondents felt that children with “emotional and behavioral difficulties” caused their teachers more concern and stress than children with other types of special needs (Avramidis, Bayliss, and Burden, 2000a). This study’s findings bring to light student teachers’ attitudes about their levels of comfort teaching students who have particular disabilities alongside students without disabilities, and the more severe the students’ emotional and/or behavioral difficulty (assumed in this study to be related to their particular disabilities), the less secure the student teacher felt in their instruction of said students. If teachers, and student teachers, do not feel sufficiently trained to meet the needs of students with disabilities, and the trend is that more and more students with disabilities are entering “mainstream” classrooms, great difficulties are bound to arise.

The same year another study by Avramidis, Bayliss, and Burden (2000b) explored the attitudes of mainstream teachers concerning the inclusion of students with special needs in ordinary schools. These results showed that teachers who have experience implementing inclusive programs had significantly more positive attitudes about inclusion in general than teachers with less or no experience with inclusion. Professional development and training greatly increased teachers’ positive attitudes and made them feel more confident in meeting the needs and requirements of students who have disabilities. Examined in conjunction with findings from the former study, this study’s results illustrate how increasing teachers’ awareness about disability in general (through improved training, greater exposure to people with disabilities, and more experience with students with disabilities) can have a significantly positive impact on teachers’ attitudes
about, and instruction of students with disabilities. Research studies like mine are useful in that they have the potential to raise awareness about the experiences and attitudes of students with disabilities as well as their feelings about how they are treated by teachers and peers at the high school and university levels.

Another study, Cook’s (2004), revealed that teachers in schools that were inclusive had more feelings of concern about “included” students with disabilities in comparison to their feelings of concern about nondisabled students. At these schools, teachers who did not have assistants were more likely to report that they have experienced feelings of rejection when they think about the included students in their classrooms (Cook, 2004). These findings bring to light how teachers in inclusive classrooms who have thorough training in issues of disability and assistants develop more positive feelings about students with disabilities than those lacking sufficient training and assistance. From these studies it is evident that there is a great need to raise awareness about students’ experiences with, and feelings about, having a disability and learning in educational spaces. Since existing research (such as the studies cited above) overwhelmingly focuses on the views, experiences, and perspectives of teachers, further studies must be conducted on how teachers’ attitudes about students with disabilities correspond with the learning experiences of students who have disabilities. My study on students’ narratives about their experiences with their teachers, attitudes about disability and education, and reflections on what it means to have a disability in learning atmospheres epitomizes these necessary efforts to raise awareness about classroom experiences of students with disabilities.
Cook, Semmel, and Gerber’s 1999 study measured special education teachers and principals’ attitudes about including students with disabilities in general education classrooms. Data showed that while principals felt strongly that “students with mild disabilities improve their academic achievement … when [they are] placed in the optimally effective environments of general education classroom with [needed] services,” special education teachers did not (Cook et al., 1999). These findings reveal the need for further research to be done on the discrepancies between the attitudes of those who “determine school policy and school-level resource allocation [i.e., principals] and [the attitudes of those who have] the most training and experience regarding the instruction and management of students with mild disabilities [i.e., the special education teachers]” (Cook 200). Divergences in these populations’ attitudes can be extremely problematic for students with disabilities. Since the on-site teachers have significantly more direct authority in their classrooms than educational policy and decision-makers have, when teachers are not sufficiently trained and feel uncomfortable teaching students who have disabilities, those students could suffer grave consequences. While it is beyond the scope of my project to address this in my study, further research must be conducted on potential reasons for and influences of attitude inconsistencies among education providers, policy makers, and administrators.

The studies mentioned above are a mere few of existing research projects centered on the intersection of disability and education. While qualitative scholarship on disability includes rich studies on special education, special needs, and inclusion (Ainbinder, Blanchard, Singer, Sullivan, Powers, Parquis, Santelli, &The Consortium to Evaluate Parent to Parent Support for Parents of Children with Special Needs, 1998; Allan, 1999;
Bratlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Pugach, 2001), there seems to be quite a dearth of narrative and oral history studies on disability and education. Educational instruction oriented studies (Snyder, 1999; Gay 2002; Mavropoulou, Nikolaraizi, & Seremetidou, 2008) and ethnographies on disability and education (Angrosino, 1998; Shuttleworth, 2004; Maret, 2008) exemplify existing qualitative research on the intersection of disability and education. While academic journals dedicated to disability and education exist, the articles that they featured focus on special education, psychology, allied health, social work, and psychiatry. Studies on disability and oral histories that I found were published in special education academic journals and were thus oriented toward teachers and administrators, focused exclusively on the lives of disabled women (Broun & Heshusius, 2004), or took the form of biographies or conversational interviews that appeared as accounts of life events in an individual’s life or as oral histories of institutionalized individuals such as those in corrections settings (Anderson, 2005; Rouverol, 2003). I found no existing studies that were described or qualified as feminist oral history projects centered on education and learning disabilities. Personal student narratives about their experiences with disability in various learning atmospheres have remained untold; feminist disability studies oriented oral histories about learning disabilities and differences are virtually non-existent. The oral histories that I present here serve as mere jumping off points for future research on students’ attitudes, experiences, and accounts about what high school and college is like for students with LDs and learning differences. This research aims to begin filling current gaps in the existing literature in women’s and gender studies, educational research,
disability studies, and sociology by offering scholars one analysis of oral histories narrated by members of this under-examined population of students.

My analysis is inspired by the transformative possibilities of combining feminist, disability, and educational theory. Disability scholar Mark Priestly (2003) and feminist disability scholar Rosemarie Garland-Thomson (2003) provide solid frameworks from which I begin my analysis. Priestly explains his life course approach concerning, first, how disability “affects people of all generations and at all points of life course transition” (1) as well as how a critical, social interpretation of disability necessarily shifts the focus from the individual who has often been interpreted as having a “problem caused by impairment” to the social circumstances and processes that disadvantage, and thus disable individuals in different ways (12-13). In conjunction with Garland-Thomson’s feminist disability studies approach, Priestly’s social model of disability serves as an entry point to an exploration of disability as socially produced. Garland-Thomson’s work on disability (2003) proved uniquely useful as it led me to recognize and analyze how theories of the body, the body’s lived experience, the body’s materiality and politics, and its relation to subjectivity and identity (9-10) emerged in the oral histories that I gathered. Body politics theory in general also played a major role in this project since I illustrate with that literature how the narratives exhibit disabled bodies and minds as being relentlessly subjected to Foucauldian discipline (1979). In this thesis my goal is two-fold. First, I strive to extend Garland-Thomson’s claim that the gender, race, ethnicity, sexuality, class, and ability systems “exert tremendous social pressures to shape, regulate, and normalize subjugated bodies” (10), and second, I attempt to reveal how this pressure, discipline, and subjugation manifest uniquely in educational spaces. In so doing, I aim to
exemplify Priestly’s point that disability is, in essence, a “social problem caused by social processes” (13) and, even more importantly to my study, this social problem is one that is intrinsically tied to what students with LD/Ds experience in the U.S. educational system academically as well as socially and emotionally.

The analysis that I develop in this thesis interlaces feminist theory with disability studies to set the theoretical scene to transform pedagogy. As Garland-Thomson (2003) explains, “even though disability studies is now flourishing in disciplines such as history, literature, religion, theater, and philosophy in precisely the same way feminist studies did twenty-five years ago, many of its practitioners do not recognize that disability studies is part of this larger undertaking that can be called identity studies” (1). Furthermore, disability studies and feminist theory can benefit from one another. Just as “feminism has expanded the lexicon of what we imagine as womanly [and] has sought to understand and destigmatize what we call the subject position of woman […] disability studies [has] examined the identity disabled in the service of integrating people with disabilities more fully into our society” (Garland-Thomson 2). I extend Garland-Thomson’s perspective to education by exemplifying how disability and feminist theoretical analyses of students’ oral histories can instigate needed educational reform and advancement in the U.S. In the chapter that follows I temporarily step away from the literature to detail my research design, methods, and methodological framework within which my research lies.
Chapter 3. Description of Project, Methods, & Methodology

3.1 Why Feminist Oral History?

Oral history, in the words of feminist scholar Kim Golombisky (2010), “records and preserves the spoken memories of ordinary people for posterity” (111). Participants narrate their own stories by taking the lead in the oral history journey while the researcher takes on a role quite different from that of the traditional qualitative researcher/interviewer. Since my research goal was to gather and analyze students’ perspectives, memories, experiential accounts, attitudes, and reflections about what it is like to have learning disabilities and/or differences in high school and college, I chose to collect oral histories by conducting individual, open-ended, in-depth conversational interviews in which the narrator narrated his or her own stories and determined the direction of the conversation, the length and pace of the interview, the emotional tone and intensity of each conversation, and the experiences they felt comfortable sharing with me. I did not limit my project to students who have been diagnosed with specific learning disabilities since I found it important to let students identify, for themselves, whether or not and why they felt they have LD/Ds. The loose interview guide that I developed helped me remember to touch on certain major topics in which I was interested; I limited those topics to ones about which I was sure I wanted to write in the thesis that was to

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3 I recruited participants through the students with disabilities services office. Therefore, in order to qualify for services each student respondent had to have an official diagnosis of some sort and have decided to disclose their disability to SDS in order to receive accommodations; these two characteristics differentiate my respondents from other students with LD/Ds. Additionally, while some of their diagnoses were the LD/Ds about which they spoke with me, not all were.
come. Despite the fact that I touched on the same major topics in each interview, every oral history took on a life of its own.

My dedication to remaining completely transparent with every individual who participated in my research project, my asking open-ended interview questions to give participants the chance to develop their own narratives, and my concern with being accountable to and with each individual qualify my oral history method as feminist. Accountability was particularly important to me as I recognize how prevalent issues of power, epistemology, and privilege are in research. I aimed to balance as best I could the inherently unequal relationship between me, as researcher, and the student narrators by doing my utmost to keep my voice, interpretations, and reflections on what they were sharing with me to a minimum throughout the interviewing process. In the spirit of feminist research, I attempted to stay as self-reflexive as possible by reminding myself of the ever-present power differentials between the student narrators and me.

In line with Koni Benson and Richa Nagar’s scholarship on feminist oral history and ethnography (2006), I designed my research to be transparently collaborative. Since my project combines “insights of different persons, places and research contexts” and has the potential to “play a critical role in generating new dialogues and knowledges across socioeconomic, geographical and institutional borders” (Benson & Nagar 584), the kind of research that I conduct is collaborative. While we may have shared the agenda of gaining wider public audience for marginalized voices, the student narrators and I began and closed each interview by openly discussing how the oral histories will be used, why I was researching learning disabilities and differences, the plans I had for the thesis and the oral histories, and how involved in the project each of the student narrators wanted to be.
after the interview’s conclusion. Throughout each interview, the narrator set the pace, chose the stories and memories that they shared with me, and decided when to proceed to the next topic. I began and closed each interview by explaining that, as narrators, each of them had the option to be as involved or as uninvolved in the research process as they wanted. We discussed how I found it important that each narrator be aware that they held the power to edit, add to, or retract any part of the record that we co-constructed during our interview. I also explained how they could request copies of anything that I had access to at any point in the research/writing process. This exemplified my feminist belief that authority should not remain exclusively in the hands of the researcher.

My project epitomizes those that impart “new and sometimes unforeseen meanings to the collaborative [research]” (Benson & Nagar 584) in that the student narrators and I co-determined various dimensions of the research that we participated in together. These dimensions included the actions (such as emailing them transcriptions and/or copies of my thesis), writing, and follow-up processes. As I reveal in subsequent sections, research like mine takes on radically different forms of responsibility when considering analysis. This is due to the fact that such endeavors are “simultaneously accountable to the people with/for whom [they are] imagined and undertaken, as well as to multiple academic/institutional audiences who have supported or are invested in the [projects]” (Gluck & Patai, 1991; Shopes, 1984; Shopes, 1986; Kruzynski, 2003). My particular project is aimed at multiple audiences including education, disability, and feminist scholars; students with learning disabilities and differences; educators, parents, advocates, policy makers, and administrators. My project is consequently accountable to people across these diverse populations.
Oral history as research method helped me achieve my research objectives in two major ways. First, gathering oral histories about learning disabilities made it possible for me to participate in supplementing the scarce number of existing narratives pertaining to disability and education at the high school and university levels. While oral history research on learning disabilities exists (for instance, Walmsley’s 1995 study entitled “Life History Interviews with People with Learning Disabilities” and Gates & Moore’s 2002 study on the lived experience of a learning disability nurse), oral history research centered on feminist and disability theory are few and far between. The second way that oral history as research method assisted me in meeting my research goals was by permitting me to engage in identifiably collaborative feminist research. As Golombisky describes, in oral history, “what counts as history and who says it gets to count (much like what counts as news and who says it counts) is a moving target spanning everything from ‘great’ men and women to the man or woman ‘on the street’” (112). This democratic perspective concerning the importance of particular voices characterizes a feminist approach because it reinforces the idea that all voices are equally valuable and deserving of becoming part of lasting record. Golombisky describes how, while oral historians might find the realization that definitions of history are not set in stone to be disconcerting, oral history is liberating since one need not “be a celebrity to contribute to historical knowledge [nor have] a Ph.D. to become an oral historian” (112). Collaborative feminist oral history emerged as the ideal method for my particular project.
3.2 Methodology & Theoretical Frameworks

The methods that I employed both resulted from and gradually constructed the methodological and theoretical frameworks that inform my research project. The feminist orientation of my oral history method particularly parallels postmodernist ideas since power relationships are implicated among those accepted as legitimate oral historians, those considered reliable narrators, and whether or not what is recorded qualifies as history in the first place. Returning to Golombisky’s work, this postmodern perspective asks “who or what is being included and excluded from the historical record, and why” (113). My project centers on an analysis of narratives by three of the six students I interviewed at a large state university in the southeastern U.S. in 2011. The student narrators with whom I spoke must be recognized as the few among the already diminutive number of students with learning disabilities and/or differences who made it through high school and to college in the U.S. The record indicates that researchers have not conducted studies on the experiences of students with LD/Ds, and a natural consequence of that lack is that policy makers, educators, and administrators are not able to successfully meet the needs of these students. The feminist oral history project that follows demonstrates how much potential lies in research centered on students’ accounts of their own experiences with LDs and differences at high school and university levels.

Combining disability theory and feminist theory has the potential to greatly influence the educational experiences of students with a wide range of LD/Ds. I develop this argument throughout this thesis by suggesting that student subjectivity, personal experiences, and perspectives highlight the importance and impact of how the “disabled” mind and/or body is treated in educational spaces and how it might be reconceptualized
for the enhancement of those students’ learning experiences. Oral histories that narrate what it is like to have LD/Ds serve as unique exemplars of how the personal can be used to influence the political and cultural. These oral histories have the potential to enhance education for students with LD/Ds since sharing and reflecting on the narratives that I will gather can improve learning experiences for future students with LD/Ds by showing them that they are not alone. Additionally, this research can reveal to teachers, administrators, and parents what students with LD/Ds their unique, everyday experiences, and perspectives about how education happens for them as well as recommendations about how our educational system and practitioners might more effectively meet the needs of students with LD/Ds. This thesis has an identifiably feminist disability studies theoretical orientation since I view and interpret “learning disabilities and differences” as cultural and social rather than individual or medical issues. Consistent with feminist disability studies, I chose to focus my project on the ways in which power relations influence students’ experiences having LD/Ds. Refusing to assign deviance “when analyzing cultural representations of oppressed groups” (Garland-Thomson 5, 2001), or narratives by members of those groups, and insisting on examining power relations at work aligns my project with feminist disability studies.

Throughout this analysis I reveal how learning disabilities and learning differences are culturally defined and redefined in social settings, how students constantly make meanings of the ways in which their LD/Ds are “handled” by others, and what suggestions students have to improve the future learning experiences of students with similar LD/Ds. One of the major goals of this project is to positively transform the lives of students at all academic levels who have learning disabilities and differences. I
conclude my thesis with recommendations centered on personalizing pedagogy through transformations of learning atmospheres into spaces where students with learning disabilities and/or differences are empowered through increased access to accommodations that they need as well as through instructional techniques that align with their particular learning styles. Rethinking education for students with learning disabilities and differences means empowering students and inspiring them to challenge any disabling structures in their communities. In a global sense, efforts such as this can compound over time and result in a more inclusive, egalitarian academic future for all. Advocating for social change, being dedicated to personalizing the political and visa versa, and applying theory to action motivate me as a feminist researcher.

3.3 Research Project Design

Language

My choice to use vague language when referring to LD/Ds in my recruitment email and flyer to solicit respondents and during the actual interviews resulted in my receiving responses from students with diverse LD/Ds as well as quite divergent experiences. Each interview began with the student narrators explaining why they decided to meet with me and participate in my research. At that point the narrators and I discussed how they feel they qualify as students with learning disabilities and/or differences, and even during those moments, I chose to not use or define any terms if and when words pertaining to disabilities, impairments, LDs, and learning differences came up. This gave the narrators opportunities to use language that they felt most comfortable using. Each time the narrators used words or acronyms relating to disabilities,
intervention, accommodations, identification of students with LD/Ds, or special education I asked them to explain what those words meant to them; this allowed the students to narrate their stories with their own words and exclusively speak about topics with which they are familiar. Since the unique terms and definitions that emerged during each interview were rooted in the students’ experiences, they became essential aspects of their oral histories. That the students’ voices, their language, and their perspectives took center stage qualified this project as distinctively feminist oral history. My decision to limit my own voice and language during interviews stemmed from my feminist perspective that participants in any research endeavor should always have the chance to define, to give meaning to, the language that they use when they narrate their own stories. These voices were cultivated and inspired by their own lived experiences and each oral history emerged from each narrator’s individual linguistic style, voice, language, and meanings attributed to each term they used. I chose to gather students’ interpretations of topics relating to impairment, disability, learning disability, learning difference, special education, and inclusion because they are so deeply political and I include in my analysis how these students with LD/Ds feel about and make meaning of such terms.

According to philosophy of education scholar Lorella Terzi (2005), disability in education has taken the form of a significant debate that has been characterized by positions that, on one side, see disability and special needs as being “caused by individual limitations and deficits,” and, on the other side, see disability and special needs as being “caused by the limitations and deficits of the schooling systems in accommodating the diversity of children” (444). Like debates on the social versus medical models of disability, debates about disability in education are complex, multifaceted, and often
profoundly political. I chose to abstain from defining terms pertaining to disability in education during the interviews in order to reflect on how these students think about disability and special needs in relation to the schooling systems, accommodations, and student diversity. Due to the complexities of polarizing debates on disability, the subjective and politically charged definitions of disability, and the varying perspectives that highlight possible discriminatory and oppressive uses of these systems of language, I chose to only use language that emerged in the interviews that I conducted.

**Case Studies as Exemplars**

The project that I originally designed centered on exploring how education happens for students with disabilities. For the purpose of this study I limited the scope of my thesis by focusing on particular kinds of disabilities since I was primarily interested in how education and disability relate to one another, how disability is experienced by students at the high school and college levels, and how particular disabilities influence learning processes and styles. I narrowed my objective by exclusively gathering narratives by students who feel that they have, or have been diagnosed with learning disabilities and/or have disabilities that result in their having learning differences. The open-ended approach that I took during the interviewing process resulted in each interview lasting significantly longer than I had expected, becoming emotionally charged at particular moments and in unpredictable ways, and concentrating on aspects of the students’ lives that I would have never foreseen.

My project rapidly transformed into an assemblage of exceptionally individualistic, emotionally rich, and extensive oral histories. After only a few interviews
I recognized that I would be left with far more data than I could analyze for originally planned project. There was such variation in the LD/Ds, ages, and educational levels (as well as such variation in the directions that the interviews took) that it became clear that my thesis was on oral histories of LD/Ds. I offer my analysis in two parts. The first chapter explores three specific oral histories through a body politics and feminist theoretical framework, and second examines the oral histories through an educational theoretical framework. The in depth analyses of the three cases present intricate, detailed descriptions of how disability has affected and continues to affect these particular students socio-emotionally, existentially, and educationally. I close by reflecting on how identification (as well as instruction) of and intervention for students with LD/Ds might be transformed in ways that enhance all students’ learning experiences.

As Feagin, Orum, and Sjoberg (1991) explain, “the [case study] researcher is a variable in the research design” (36). The data that I gathered led me to shift the focus of my project. I became a variable in my research design as I found this shift necessary to permit the greatest amount of reflexivity, collaboration, and critical analysis on what was actually gathered as data. Through this change in approach I exemplify what Feagin et al. describe, not merely in my role of stating the problem but also in my role as data collector and analyzer. Feagin et al. maintain that, “the only way some form of objectivity can be sustained is through critical reflection, through recognition of one’s position in the power structure and by the ideological context within which one carries out social scientific activities” (36). I narrowed the focus of my analysis to permit such concentrated self-reflexivity and critical reflection. In so doing, I intend to exemplify how a feminist researcher might successfully conduct research by constantly analyzing the
power dynamics and structures at work in the research designing, the data collection, and the writing and editing processes.

**Research Matters**

The students with whom I spoke had story after story to tell as well as experiences and feelings about which they had never had the chance to openly reflect in depth. The narratives took on lives of their own and turned into beautifully intricate and remarkably extended accounts of how education and learning disabilities and differences play out for these students. Disability emerged as an exceedingly fluid, multidimensional entity as the narratives revealed how complex having a learning disability or difference is; such an identity requires constant negotiation and renegotiation. Internally and externally, the students regularly defined and redefined their LD/Ds in educational spaces. The narratives went in countless directions but all included students’ stories about:

- How and when they developed their disabilities or disabling conditions
- Educational, social, and emotional experiences that relate/d to their LD/Ds
- What worked and did not work (and what currently works and does not work) for them academically
- Where, when (in what circumstances), and to whom they “come out” about their LD/Ds
- Experiences of self-advocacy and seeking accommodations they need
- How and when they initially realized they needed accommodations
- Resources they wish existed for students with LD/Ds
- Advice they offer other students about how to successfully “survive” high school and college with LD/Ds

Ultimately, the content of the narratives that I gathered has great potential to enhance what educators, scholars, administrators, parents, and students alike know about how students with LD/Ds experience high school and college. With data like mine to refer to, these individuals have the power to change the educational status quo for
students with LD/Ds. These students’ voices, memories, and reflections can, in this way, help create a brighter and more positive educational future for all students by helping enhance high school and university atmospheres, reform policies for students with LD/Ds, and improve teacher-training programs to enrich the experiences of all students.

In their work on inclusive education, Mickel and Griffin (2007) illustrate that improvements in and the reauthorization of the Individuals with Disabilities Education Act of 2004 (Public Law 108-446) have resulted in classrooms across the United States evolving into “inclusive learning environments where children with and without disabilities learn side-by-side” (1). In response to Mickel and Griffin’s (2007) finding that teachers-in-training often find themselves “unsure of how to address the needs of students with disabilities through the general curriculum” (1), there is a growing demand for research such as mine since it has the potential to better inform current teachers-in-training in the U.S. about how students with LD/Ds experience educational spaces and situations. More expansive and concrete understandings of issues that students with LD/Ds students face can more effectively inform educators on how to meet the needs and desires of their students. Personal student narratives about LD/Ds in educational spaces have remained untold, and thus their experiences have remained unexamined.

This project grew out of my desire to add to the existing record of students’ experiences with LD/Ds. More generally, I share Susan Wendell’s view (1999) that people with disabilities have a great deal of knowledge about aspects of bodily experience and should “therefore be major contributors to our cultural understanding of the body” (326). Feminist research that brings these voices and experiences to light is therefore essential, and, using oral history as method can be exceptionally powerful as it
can help develop feminist theory by contributing to social justice and facilitating understandings and coalition building among different marginalized groups (Reinharz & Davidman, 1992). By highlighting voices, perspectives, and views that have been historically silenced narratives have the power to change our perspectives, attitudes, and behaviors; more globally, narratives can cause positive transformation and macro-level change. This particular analysis reveals how individuals’ experiences illustrate the complex ways that having multiple disabilities impact one’s life. Through narrative, these individuals’ stories exhibit the transformative nature of personal narrative for both the person experiencing it first-hand and the readers experiencing it vicariously.

3.4 Guiding Research Questions

The students began their narratives by telling me about themselves. They usually started with their year in school, where they are from, and their academic and extracurricular interests. This general information allowed us to get to know one another a bit more and gave students the chance to set the scene by describing where they are in their academic careers. From there students backtracked to tell me about what high school was like for them in general. They often shared how they felt about being in high school, what the school itself was like, and what their peers and teachers were like. The students shared with me what worked and did not work for them in high school; these conversations usually stemmed from their descriptions of their favorite and least favorite classes and teachers in high school and in college. The students and I discussed the same topics about college that we did about high school; this helped me gather information about what worked and did not work for them at both academic levels.
Additionally, the students shared their stories and feelings about how disabilities were “handled” in their high school and college classes as well as whether or not students with particular disabilities were in classes with students without disabilities. The student narrators reflected on whether or not classes had different names depending on what kinds of students were in them and if any teachers treated students differently in response to aspects of the students’ identities; student narrators often connected disability with other identity categories (such as gender, sex, race, sexual orientation, or socioeconomic status) at those points in the conversation. The students explained to me how they feel about having students with particular LD/Ds being taught separately from students without LD/Ds as well as how they feel about the language used to designate those classes. At other points during the narratives the students described their interactions and relationships with their high school and college peers and reflected on how they socially and emotionally navigate and contend with their LD/Ds, to whom and in what contexts they feel comfortable discussing their LD/Ds, and why.

In addition to discussing their experience in high school and college, students shared how they feel about disability and education in general. They described the ways in which their LD/Ds influence their learning experiences and reflected on how other aspects of their identities might have impacted (and continue to impact) how they learned in high school and how they currently learn in college. Students also shared their views about issues pertaining to the treatment and experiences of students with “marked” bodies or minds. Most often students spoke about “being different” and feeling like “outsiders” or “others,” as well as feeling alienated by those feelings, because of their LD/Ds.
Each interview concluded with students reflecting on high school and college experiences having LD/Ds. These conversations led them students telling me how they wished high school and/or college had been, or could be, different for students with LD/Ds. Students shared their views about what they felt worked and did not work for them, why, and how education for students with LD/Ds might be altered to enhance their learning experiences in general.

3.5 Sampling & Recruiting

I recruited students with the help of the Students with Disabilities Services Office at the large, state university in the southeast U.S. where I conducted my research. The director was kind enough to distribute my recruitment email and flyer to all undergraduate students that the office was serving during the fall semester of the 2011/2012 academic year (please see recruitment email and flyer in Appendix A). In the recruitment materials I mentioned confidentiality and asked students to email me back if they were interested in helping me with my research. I attached the IRB approved consent form to my response email so that students could let me know in advance if they had any questions about my project. Once the student and I confirmed that they qualified to participate, and once they asked any and all questions that they had about the consent form and project, I asked the student to pick a location and time to meet for the interview. This allowed students to choose the physical places where they felt most comfortable speaking with me about personal topics.

While I planned to analyze between ten and fifteen undergraduate students’ narratives, only eight of the dozen students who responded to my email qualified as
potential participants. Respondents who did not qualify included students who were not enrolled full-time at the university, students who had not yet completed at least one full year of college, and students who were not at least eighteen years of age. One of the eight students who qualified failed to respond to the follow-up emails that I sent, and another did not show up for her interview. These unforeseen events led me to limit my study to six interviews each of which was approximately two hours long. A coordinator from one of the satellite campuses of the large state university was kind enough to help me recruit students at these campuses and I also chose to include one graduate student as a participant.

3.6 Informed Consent, Confidentiality, & Transparency

Once students who were interested in participating contacted me via email, I sent them another email that gave them a more detailed description of what I was interested in looking at in my research, how and why they were going to be audio-recorded, and the purpose of my project. I explained the purpose of the IRB-approved informed consent forms and that I chose to give them the paperwork in advance so that they would have time to look over and generate any questions before the interview took place. I let them know that I planned to bring hard copies of the consent form and recruitment flyer to the interview; this helped the students make sure that they had the opportunity to ask me any and all questions that they had before we began the interview. Before commencing each interview, I asked each student to sign and date the consent form signifying that they agreed to talk to me and give me permission to audio-record the interview. I explained that they had the right to end our conversational interview at any
point and for any reason without consequence and made sure that they understood that nothing that we discussed would be associated with their actual names or any other identifiable aspect of their identity. I explained my plan to use pseudonyms in the transcripts and final thesis, that all audio-records, transcriptions, and notes would be kept in secure locations, and that my data would be stored on a password-protected computer.

In the spirit of feminist research, I did my best to maintain my transparency at every stage in the research process. Before each interview, I explained to every student the audio-recording process and I showed them how the iPhone application and digital audio recorder worked. I explained that if they became uncomfortable at any time during the interview we could reschedule the interview and meet up another day or never again. During the interview I checked in with them to see how they were feeling. At the end of each interview, I let the students know that they should feel free to contact me at any time if they have questions or would like to change or add to what they told me during our interview. I also explained that I would be more than willing to set up a follow-up interview with them if they so pleased. Finally, I told each of them that they were welcome to copies of the transcriptions of our conversations and/or copies of my completed thesis. Overall, the students were surprised and welcomed these offers.

I kept electronic files of all interview data on my personal, secure, password-protected computer. Hardcopies of the transcriptions were locked a file cabinet that only I had access to and I kept all research records and original documentation of informed consent, as well as research authorization, in secured-access electronic files on my personal computer. I will keep these records for a minimum of six years after the final IRB approval period has expired.
3.7 Transcribing & Analyzing

I audio-recorded each interview using an iPhone application called iTalk and an audio-recording device that I rented from the university’s classroom informational technology services. During the interviews, I took brief descriptive notes about the students’ body language, significant responses to particular questions, and any and all recommendations that the students had for me. After each interview, I uploaded the audio-files to a secure computer/server, saved the files in two places to make sure they would not be accidentally deleted, and erased the files from the recording devices.

As I transcribed the interviews, I changed all names mentioned to pseudonyms and took note of any recurring themes that emerged as the interviews unfolded. I analyzed the interviews by interweaving existing literature on feminist theory, body politics theory, disability studies, and education with the narratives where it was most appropriate in order to make meaning of each oral history. The students and I communicated via email with one another to collaboratively decide on when and where (i.e., the date, time, and campus location) would be most convenient for them to meet for their interview. This collaborative scheduling process did not allow me to analyze each interview before the subsequent one occurred. Instead, I analyzed the interviews once they were all gathered.
Chapter 4. Body Politics & Disability

4.1 Once Upon a “Disabled” Body/Mind: Introducing the Histories

We are bound by language. Words spoken, written, carved, seen, and heard both limit and emancipate us. We are simultaneously imprisoned by and liberated from our uniquely individual experiences of our bodies and minds through how we describe those experiences to others, how we make meaning of what we feel and think. Early on, each of us is taught to communicate our thoughts with, and through, language. Each of us is urged to quickly learn how to express ourselves to one another using words, and we expand our vocabularies over time to more exactly, explicitly communicate our complex feelings and experiences. Language grants us relationship to one another, connection through empathy, and opportunities to mutually disclose and identify with those around us so that we no longer experience our realities in isolation; we grow through mutual vulnerability, through meaning making as we collectively story our lives. In any situation, our perspectives inform the language that we use when we make sense of our lived realities through narrative as our interpretations of our interactions are fundamentally made possible by our incarnations, our lived bodies. Making meaning of this mind/body liaison through our life storying is the jumping off point for the analysis that follows.

My analyses of these three students’ narratives focus particularly on how each of them makes meaning of his or her “disabled” body and/or mind. Examining these
boundaries through oral histories has the potential to expand current understandings of students’ experiences of disability in academic spaces as well as shed light on the lasting, and often detrimental, influences that policing artificial boundaries between falsely dichotomized categories have on individuals. I guide this phenomenological exploration through three oral histories and interweave feminist and poststructuralist scholarship that exemplifies body politics literature on the disabled body and/or mind.

The three distinct oral histories through which I present my analysis illustrate the complex interpretations and experiences of the disabled body and mind, particularly those that manifest in educational contexts. The first student narrator whose experiences I draw from is a twenty-five year old undergraduate named Ben⁴ who is studying education. Enmeshed in what turned out to be an extremely rich conversation, Ben and I spent approximately two hours talking about his experiences with multiple disabilities including an STBI (severe traumatic brain injury), manic depression, and ADHD (attention deficit hyperactivity disorder). Laura, the second person whose oral history I report, was a non-traditional undergraduate student who has been in and out of college for decades. During our interview, Laura explained her learning disabilities as a memory problem that she attributes to her age and former drug and alcohol abuse. As she put it, her entire story is colored by the fact that she has been a recovering alcoholic for almost thirteen years. In addition to her memory issues regarding her schoolwork, she also has a very hard time remembering when certain events in her life occurred. The third oral history that I discuss in my analysis is that of Julie, a twenty-one year old undergraduate student studying public health. Julie’s learning disabilities include dyslexia and ADD,

⁴ All identifiable pieces of information including the actual names of people and places have been replaced by pseudonyms for privacy and confidentiality purposes.
and her oral history exemplifies how the current, disjointed educational system can fail students with LD/Ds. I draw from Julie’s narrative to reflect on how a more cohesive approach to identification, intervention, and practice when it comes to LD/Ds might result in fewer students falling through the institutional cracks. I conclude my analysis with considerations of how students’ experiences might more effectively inform future educational policies, enhance practices, and increase available resources that can enrich the learning experiences of students with disabilities at high school and university levels. Julie’s interview illustrated of how and why students with LD/Ds remain unidentified for years and thus fail to receive interventions they might need when they need them. My second analysis chapter focuses on this and includes a discussion of how oral history research might lead to action, how identification of students’ issues, pressures, and experiences with LD/Ds can result in more effective practices of intervention, and ultimately how better accommodation and advancement might be achieved.

In the following section I offer examples taken from Ben and Laura’s narratives that illustrate the social and emotional impacts of having multiple disabilities. I aim to exemplify through these narratives how students with multiple disabilities navigate their worlds socially and emotionally. Concurrently, I reveal how sense making is a reiterative and fluid process upon which it is essential to reflect since disability narratives have the potential to lead scholars to currently uncharted lands in disability and feminist studies.

4.2 Socio-Emotional Impacts of Learning Differences and Disabilities

As both interviews reveal, Ben and Laura experience social situations in which they are forced to emotionally determine how, when, and to whom they discuss or
disclose information about themselves. The social and emotional are simultaneously experienced and lead to constant negotiations, and renegotiations, of their identities in relation to their disabilities. In both narratives, recurring instances in which the social and emotional connections to disability emerged were also the most salient. The “social,” i.e., the social influences and responses that Ben and Laura experienced as a result of their disabilities, seemed to be easily discernable while the “emotional” took the form of their reflections about how they respond in particular social settings. The social and emotional influences of Ben and Laura’s experiences with their LD/Ds serve as entry points into the analysis that follows.

Like a pebble’s impact on the motionless water, becoming disabled sometimes happens abruptly, often without warning, and has the potential to completely transform an individual’s life. Just like the rippling waves, becoming disabled or being diagnosed with a disabling condition can impact a person’s life in numerous, often overlapping ways that have enduring effects. Laura and Ben’s accounts of what having multiple disabilities has meant for them are uniquely pertinent to this discussion as they address gender issues alongside disability ones in educational contexts. Drawing from Michel Foucault’s work and feminist theories of the body I consider particular instances in these narratives in which Laura and Ben’s multiple disabilities socially/emotionally and existentially influence them.

Ben became disabled both gradually and abruptly. His life was transformed by a series of events that began when he was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) in first grade. Ben recalls being put on Ritalin immediately after his diagnosis:
I hated it. Like, you know, like, I was like, I didn’t ever get hungry. You know. Like I wasn’t eating. And… I was like a zombie… Like, some people like take Adderall and Ritalin and …well…they think it’s like speed or something? But… to me… to me? It…zoned me out. Yeah.

Ben took Ritalin every weekday from first grade to ninth grade when he decided to stop taking his medication because doing so made him feel better, physically. When he stopped his medication he felt more “awake” when he was around other people and his appetite returned:

I wasn’t a zombie anymore! Yeah! I could eat whenever I wanted, you know, like, um… my social skills improved! … Definitely! I felt like I could interact better, just… um, it was better for me! [sic]

Ben chose to stop taking his Ritalin from ninth grade until he graduated from high school because the medicine changed his personality. It made him feel “zombie-like” and less social around his peers. Early on in his life Ben explained that he intentionally refused to allow his ADHD determine how he interacted with others; he refused to allow his social life and sense of identity as an individual to be dictated by his diagnosis. Ben resisted this by refusing to take his “corrective medicine” in order to preserve particular aspects of his personality that permitted him to be comfortably social with his peers. Ben resisted against allowing his disability to define him.

Through her account of living with Rheumatoid Arthritis, scholar Andrea Avery (2010) describes negotiations that happen between people and their disability. Avery describes her personal negotiation with her disability as a dance. “Ultimately […] there’s a tango this disease has me doing. How much do I pull toward arthritis, how much do I
push it away? Do I claim the title of ‘disabled’ for myself, or do I reject it? If I claim it, is it permanent? Can I give it back?” (263). Finally, she asks, “Will I have to explain to more obviously disabled people why I label myself disabled?” (Avery 264). Early on in his life, Ben rejected the label and the identity of “disabled,” though his later experiences reflect similar tango-like relations with his disabilities. His attitude shifts after he is diagnosed with manic depression and experiences major, life-altering bicycle accidents.

In twelfth grade, Ben was working as a busboy in a restaurant after school a few times a week. He began working out a lot more than usual, staying up later at night, and for several weeks he found himself getting fewer and fewer hours of sleep at night. According to Ben:

No one really noticed it. You know, I didn’t really tell anybody? Cuz [sic] I didn’t- I was just like, “Ah! I feel good! I feel really, really good!” And then one day… I’m just like, “Oh my god… this is euphoric.” You know, like, euphoric feelings? And then, one night, while I was working, I was bussing tables, and …all of a sudden, I just went to the bathroom – and I had only had like 3 hours of sleep the night before – and I went to work, came home, went to school, worked out, and then went to work – and I was only working until 10…and then… like… I just started bawling my eyes out…you know…in the bathroom. And I was like, “What’s wrong with me?” You know … all of a sudden there was this shift in my- in my, uh, brain. I was just like, “Something’s happening, this is not right, you know? Yeah, something’s way off. [sic]

Ben explains what he did in response to this frightening, unanticipated experience:
And so, I walked out, and went to the manager, and I was like, “I’m not feeling well,” and he’s just like, “Okay. Look Ben, just tell Ralph to bus your tables.” And Ralph was like, “But we’re so busy!” And I was like, “I just gotta go man.” And he could tell that I was not okay. And so I went out in the parking lot, sat on the curb, and just started crying. Like, I don’t know. I tried calling my mom. I tried calling my dad. I called my sister. No one picked up. [sic]

The following week Ben was diagnosed with manic depression, a condition he now shares with his father. Ben described how his father’s manic depression is “well-managed” and “well-controlled” since his father is so productive, “gets his work done,” and was able to get advanced, professional degrees to further his career goals. Ben explained how his father manages his manic depression and “doesn’t like to be asked” about it because “his is controlled.” While his father knows he has manic depression, he chooses to not talk to anyone about it. Ben told me how his father justifies this choice because he “gets his shit done, he’s a super productive guy, you know? Doin’ surgeries and things? And…and like, he doesn’t want people to find out. You know… You don’t have to disclose that…you know?” [sic]. Ben described how he chose to follow his father’s lead by “not disclosing it” except to his immediate family and one friend.

Like Ben, Laura refrains from telling many people about her learning difficulties and history of alcohol and drug abuse. In her narrative Laura describes how she confides in a only a few people but she chooses to participate in projects such as mine because she thinks they are important. She explained in her narrative how when she first came back to college she was “terrified” by her learning disability that resulted from her memory
issues, her history of drug and alcohol abuse, and her age. Ultimately, though, she saw herself as “very blessed [since] things worked out for [her].” Laura recognizes that she is one of the ones who “made it,” and how there are many people with disabilities who are not as “blessed” as she. As her narrative revealed, Laura finds it important to share her experiences with her disabilities because she hopes they her narrative will help students like her who have no opportunity to voice their views.

Unlike Laura whose disability onset was gradual and occurred over decades, Ben explained how his most significant impairments resulted from a major accident that he experienced when he was nineteen. He decided to go on a cross-country bicycle tour with a friend that year, and on that trip, a truck ran over him while he was camping out in a national forest. When Ben and his friend were sleeping a truck came through the area, ran over Ben’s sleeping bag with him inside of it, dragged Ben for 410 feet, and left the scene. Ben woke up a month later in a hospital after having been in a deep coma since the accident; the comatose state that he experienced qualified his traumatic brain injury (TBI) as “severe” (TBIs are also known as intracranial injuries and result from an external force that damages the brain, skull, and/or scalp). In addition to putting him in a deep coma for a month, the accident Ben experienced resulted in great damage to his facial skin, traumatic injury to his right temporal lobe (necessitating an additional 4 months of hospitalization), vertebral fractures (including his L1, 2, 3, 4, 5, and coccyx (requiring him to have several back surgeries and metal rod implants to relieve pressure to prevent him from becoming paralyzed). Ben was required to go through speech, cognitive, and occupational therapy and use a wheelchair for 6 months. Though he is not paralyzed as
the doctors predicted, Ben does not have plantar reflection in one foot and has extensive nerve damage in his back that resulted in permanent numbness in parts of his feet.

As soon as he recovered from that accident, Ben experienced a second bicycle accident when a car ran a red light and hit him in a crosswalk. Doctors told him that he had a subdural hematoma (a walking concussion) prior to the accident that resulted in his experiencing a major psychotic episode in the accident’s aftermath. While he had no major physical damage to his body, the impact of the crash on his mind lasted quite a while. During the episode Ben dropped out of school, thought the FBI and CIA were after him, and stayed in a series of mental hospitals before he returned to school. Ben told me that the episode felt almost “schizophrenic.”

While Ben refused to take his ADHD medication because he disliked how it altered the ways in which he interacted socially, Ben exhibited more internal conflict about his issues connected to his STBI and psychological conditions including his manic depression. When it came to his manic depression and STBI, Ben described being anxious about “outing” himself and how he preferred to “pass” as non-disabled. Theorist Sandra Lee Bartky (1997) explains internalization of something as what happens when “it gets incorporated into the structure of the self [...] those modes of perceptions that of self-perception which allow a self to distinguish itself both from other selves and from things which are not selves” (145). Ben structures his consciousness of his disability through seeing himself from the perspective of people who do not have disabilities. Similarly, Laura lived in fear for as long as she could remember as a result of the messages everyone around her was sending about her inability to measure up. Over time, these painful messages became incorporated into Laura’s “structure of herself” until
Laura found herself unable to stand being in academic atmospheres; she dropped out of school several times, self-medicated through substance abuse, and later found herself facing consequences of this former and lasting internalization when memory issues and age became educational barriers.

Like Ben’s anxiety about “coming out” about his disabilities, Laura found herself frozen in fear when she was in school, especially in high school. Laura spent only three years in high school since she graduated early, but while she was miserable during those years. She attributes her misery to having “thought so poorly of [her]self.” She even admitted, “I would shoot myself before I would go through high school again. I really would [and it was that bad because] I just, I was afraid of everybody. I had these terrible boobs that were so big, I thought I was grossly fat when I wasn’t, and I, I just was afraid of everybody.” While she did not have memory issues when she was in high school, Laura felt alienated and fear, discomfort, and a constant sense of despair resulted. Laura admitted that her mother told her years and years later when Laura was in her thirties, “I had no idea how unhappy you were in high school.” Laura paused for a minute to reflect at that point. She then told me, “the only reason I wasn’t suicidal then was because I found alcohol, and because…there was this little part of me that wanted to know what would happen next… Oh, but it was a terrible time. So, I… I rate high school as the worst experience of my life.” Laura was miserable as a result of her internalized anxiety and a paralyzing sense of never being enough. At least in part, both of these seemed to relate to her body, particularly her female body. “I was so miserable, Zoe. I don’t believe I can tell you in truth. I can only tell you from my own perception. Because… I was only, only slightly overweight at that time but I thought I looked like I actually do now…” She went
on by explaining how her fear led her to self-medicate: “I was so afraid of everybody… and alcoholism makes you feel, made me feel better… one of the things you feel is the ‘I’m outside the window lookin’ in’ syndrome and everybody else was… better…” [sic].

Laura’s fear stemmed from her hyperawareness about others’ perceptions of her. Like Ben, Laura internally struggled with others’ expectations about who and what she should be. In response, her expectations came to align with others’.

When Laura sees young women in their late teens and early twenties in her university classes, Laura explains how she is relieved and “so glad [she doesn’t] have to be that age or go through that again [since] it was so hard.” In high school and college Laura was afraid of everything, and, as she put it, “fear is just about the answer to everything that can, that [did] hurt my life.” Even in work environments Laura found herself internalizing her feelings of never being good enough: “everybody was better than I was…in…any sense. I couldn’t measure up. I couldn’t. I couldn’t be enough … I also just wish them all luck because it’s… even if you’re a normal, happy, healthy person, it’s hard. Growing up is hard.” While she does not explicitly say that girls and women have different challenges to face because of society’s particular expectations for them, she reflected on how she felt every day in high school as a result of surveillance of her “feminine” body:

My boobs were big by the time I was 11. I had a shrink I was seeing tell me they did a survey that said that women with big breasts suffered more trauma than rape victims […] I don’t know if that’s true or not but they made my life hell… I was afraid to walk past a group of guys and I’d walk around the whole high school than walk one door down and pass a bunch
of guys. And, uh… I was just so miserable in high school that I… I really don’t know… [sic]

Similar to how Laura internalized her anxiety and dis-ease with how she and other girls her age were monitored and disciplined for their bodies even in school, Ben’s resistance to sharing with others his experiences with manic depression and/or having had an STBI stems from fear. Bartky’s conception of internalization applies quite aptly to both cases. Ben’s awareness about commonly held stereotypes about manic depression and brain injuries (implying potentially unproductive, unstable, and unpredictable) led him to internalize his anxiety and, subsequently, rarely talk to people about his disabilities. Likewise, the fear that Laura lived with her entire life was the result of internalizing feelings about failure, about never being able to meet society’s unattainable expectations about what a girl or woman should be.

Extending Bartky’s definition of internalization, she explains how it is “the sense of oneself as a distinct and valuable individual [being] tied not only to the sense of how one is perceived but also to what one knows, especially to what one knows how to do” (145). Whatever its effect ultimately is, “discipline can provide the individual upon whom it is imposed with a sense of mastery as well as a sense of identity” (Bartky 145). Ben’s experienced internalization exemplifies how the complexities of being forced to socially navigate through and with disability when disability is not explicitly written on the body/mind, i.e., when it is not visible. As seen in the following examples, Ben discusses his disabilities with specific people and, in particular circumstances, because in certain social scenarios “coming out” might result in judgment, accusation, and discipline for being “Other.” He chooses to act cautiously as a result of how he makes sense of his
disabilities through acknowledging the policing, disciplining, and monitoring of others in response to their (non) disabled status.

Ben rarely discusses his manic depression with people outside his family, and he chooses to only tell a few friends about his STBI because he liked to keep his disabilities “separate” for particular reasons. He explains why:

Yeah… Just cuz like…there’s a lot of layers to me …you know…there’s like quite a few problems. But…I mean…it just…you have to pick a… a special kind of person that can understand, you know? And not… not judge and not just be like, “Okay… ‘Manic’? …[means] ‘crazy.’ ‘Depression’? … [means] ‘sad.’ You know, like, ‘Brain injury’? Like…what the fuck [does that mean?]’ You know, I can’t… I can’t deal with that. You know? [sic]

Ben feels as though many people “jump to conclusions” about what it means to have multiple disabilities, and namely disabilities that affect one’s mind and emotions. He attributes this “jumping to conclusions” to stereotyping and being “biased against people that have…mental disabilities.” Ben describes how he only feels comfortable telling certain individuals about all of his disabilities because of his anxieties surrounding how people assume things about him because of his specific disabilities. Feminist and disability scholar Ellen Samuels (2003) illustrates the constantly shifting and opposing meanings of disability that exemplify Ben’s hesitancy to “come-out” in particular circumstances. Samuels explains how this complexity is often most evident in “the uneasy, often self-destroying tension between appearance and identity; the social scrutiny that refuses to accept statements of identity without ‘proof’” (233). Ben hesitates to
disclose and explain his disabilities to others out of fear. This apprehension illustrates the shortcomings and violence that can be done by sensemaking through our limited (and quite limiting) Western tendency to exclusively rely on what we can see, what is visibly marked, and what is visually intelligible as “disabled.” As in other theories and practices of identity formation in Western culture, “the logic of visibility” (Samuels 236) reigns absolutely in discourses surrounding disability; Ben’s reluctance to “out” himself exhibits how much is at stake if disability discourse continues to exist within the confines of what can be visibly read as “disabled” on physical bodies.

If we examine Ben and Laura’s cases through a Foucauldian lens, and with disciplinary power in mind, the social and emotional impacts of having disabilities and navigating the world with them epitomize how punishment, in general, is uniquely “situated in a certain ‘political economy’ of the body” (Foucault 172). Even when the punishment is not violent or bloody, and is, instead, social in origin and nature, disability almost always implies a body or mind that is “at issue” (Foucault 172). Drawing from Foucault, this “problematic” body/mind combination is grounded in “the body and its forces, their utility and their docility, their distribution and their submission” (Foucault 172). The body and the mind are connected, once again. Identity is entwined with experiences through, and as a result of one’s body. Both Ben’s body (that resulted from his nerve injuries from his accidents) and mind (that resulted from his ADHD, his manic depression, and his STBI) and Laura’s body (that resulted from her advanced age, knee problems, severe restless leg syndrome) and mind (her memory issues stemming from former drug and alcohol abuse and concentration difficulties) epitomize Foucault’s “body that is at issue.”
Laura and Ben’s bodies/minds illustrate the complex relationships between mind, body, and disability identity in that they might exemplify “docile” bodies/minds. This is so not because they might seem “damaged” by their disabilities but because Laura and Ben are under multiple layers of surveillance since they have both a “disabled” bodies and “disabled” minds. As applied in this context, the docile body that I refer to here is a version of Foucault’s (1977), a body that needs no intervention because it so exhaustively polices itself. As Foucault describes in *Discipline and Punish*, disciplinary control has expanded to such a degree that it has ultimately created an entire society of docile bodies: “We have seen that, in penal justice, the prison transformed the punitive procedure into a penitentiary technique; the carceral archipelago transported this technique from penal institutions to the entire social body“ (Foucault, 1975: 298). In my analysis, Laura and Ben are rendered “docile” because they are individuals who seem to be deeply influenced by the disciplinary power exerted on them. They internalize how others perceive them and their views of themselves, at different points in their lives, merged with others’ views of them. Though Ben and Laura are not physically punished for having a “problematic” body/mind, they experience discipline and surveillance to such degrees that they, in turn, participate in self-discipline and self-surveillance. They thus become “docile bodies” in that they figuratively become their own jailers. In both cases, this disciplinary power that has a lasting influences on them and their identity formations. Laura and Ben socially and emotionally experience their bodies and minds like the fictitious prisoners experience their incarceration in Jeremy Bentham’s design for the Panopticon, the model prison that perfectly encapsulates for Foucault what disciplinary societies entail. Like Ben’s experienced sense of alienation from his friends after he is discharged from the mental
hospital, each prisoner in Bentham’s Panopticon is “alone, shut off from effective communication with his fellows, but constantly visible from the tower” (Bartky 131). The inmate thus experiences overwhelming isolation and a distinct sense of being constantly visible, judged, and monitored. This ensures that each prisoner takes on the role of serving as his own jailer. The automatic functioning of power, in these ways, concurrently ensure that the body and mind of every prisoner are under constant disciplinary control.

When Ben spent several months in a mental hospital he felt isolated from most of his friends because none of them visited him. When they came to his house after he left the hospital, many of them “distanced themselves” from him because they did not understand what he was going through, why he was acting in the ways that he was acting, and what made him say and do the things that he did: “I would just be talking about the CIA or the FBI or whatever, and …um…and they’d just kinda be like… ‘That’s weird…’ And they’d talk to my mom, and my mom was like, ‘Well, Ben is not doing too well right now…”’ [sic]. While some of his friends were aware that he had experienced an STBI, Ben chose to not tell them that he had manic depression. He chose to not tell them about it because he thinks people quickly jump to conclusion about what it means to have an STBI. He describes how people have clear “stereotypes, for sure,” as well as “biases against people [with disabilities].” Such fears led Ben to not share part of his disabled identity with his friends. This choice led to their lack of understanding about what was going on with Ben after his STBI and mental hospital experience. Since Ben decided to keep his manic depression to himself at that time in his life, even though he is fully aware and explains how his particular “mental disability affects [his] learning and everyday
life,” his friends disciplined him through distancing themselves from him. As a result, he was left to recover in isolation with only his family as support.

Laura experienced similar disciplining and responded to it by being constantly afraid. As she describes: “I was scared every living minute. I was scared that my friends only tolerated me, I was scared about what people were saying about my body, I was scared that I was a freak, I was scared that nobody really liked me, I was scared that I had nothing of value, I was scared that I couldn’t be enough. …And I lived under that fear 24/7. Um, so…that’s not a happy time [sic]” Ben and Laura’s disabled bodies/minds led them to engage in constant renegotiations of their identities. Their being forced to make meaning of, with, and through their disabled bodies/minds at issue qualify them as Foucauldian “docile bodies of modernity,’’ problematic bodies and minds that are constantly shaped and reshaped by disciplinary practices and serve as sites where power relations reign. In addition to being socially isolated by his friends, Ben experiences other forms of control as his perceptions about his disabilities (i.e., his internalized definition of what it means to be “disabled”) render him hyperaware of his disabled identity in particular social settings. He is forced to renegotiate his identity as disabled just like Laura was forced to do the same once she reentered college. Laura’s struggles with her identity in high school led to her self-medicating with substances and, ultimately, the health conditions that resulted led to her LD/Ds in college.

As the former examples reveal, internalization and self-discipline result from power that originates from outside of the self. Ben, for instance, explains in his narrative how the discipline to which he is subjected gradually stopped coming from the outside. As he storied his experiences, Ben identified occasion after occasion in which he changed
his own behavior as a result of disciplining, limiting, and monitoring himself to most effectively minimize the chance of others knowing about his disabilities. Similarly, Laura’s self-discipline ultimately resulted in decades of self-medicating with alcohol and drugs that, in turn, negatively affected her learning experiences in educational circumstances on a regular basis; daily, Laura experiences the educational consequences that resulted from having had to self-medicate and self-soothe with substances for decades.

4.3 Bringing Body Politics & Feminist Theory to Disability

Each of us receives information from the world through our body, a body that is distinctively connected with our mind (Grosz, 1994). How we interpret our identities, what we are capable of, and how we might manifest our potential result from the ways in which we are treated. Thus, our social experiences have grave consequences. In efforts to resist the Cartesian view of the disparate body and mind I focus my analysis on the interconnected, fused interiority and exteriority of being that is located at the mind/body junction. This figuration intentionally and fundamentally challenges dualistic and oppositional ways of thinking about minds and bodies by calling for a simultaneously cerebral and embodied relationship that “implies a strengthened connection between thought and life, a renewed proximity of the thinking process to existential reality” (Braidotti 1997, 60), and fluid approach to meaning making that takes the mind, body, and how both are treated into account. Like a body that is disabled when buildings built to shelter and laws created to protect do not take it into account, a student is disabled when that individual’s needs are not taken into account by educational practices and
practitioners. The following analysis brings to light how students’ experiences of
disability in education exemplify the social model of disability, and, more importantly,
how necessary it is for students’ LD/Ds to be considered alongside as students’ other
identities.

Power relations saturate not only discourse but also our thinking and embodied
experiences that are intrinsically and inevitably connected. The body and mind that are
concurrently disabled can be interpreted as a site where such power relations play out.
The welded disabled mind/body is a place from which meaning making occurs in various
ways. In Ben and Laura’s cases, in particular, their minds/bodies emerge as what provide
them with their unique, myriad perspectives on and narrated experiences of their disabled
bodies/minds. Experiences through, with, and because of this unified disabled body/mind
reveal how meaning making happens when one is forced to come to terms with multiple
disabilities that affect the mind and body concomitantly. These individuals’ perceptions,
interpretations, and meanings of their own disabled bodies/minds illustrate the
interconnectedness and interdependence of consciousness and embodiment, how
becoming disabled sometimes necessitates renegotiations and reconceptualizations of
one’s relationships to one’s body/mind and to how one thinks of themselves and their
identities in relation to disability.

Our minds are forever embodied, and our bodies are constantly experienced
through our minds since our identities result from, first, how others and we in turn
interpret and discipline bodies/minds and, second, our interpretations of how we navigate
the world in and through our individual bodies/minds. This postmodernist feminist
perspective of bodies leads to interpretations of bodies as not mere vessels of our minds.
In contrast, bodies are what permit us access to our environments. Susan Bordo (1997) describes bodies as what serve as surfaces on which “the central rules, hierarchies, and even metaphysical commitments of a culture are inscribed and thus reinforced through the concrete language of the body” (Bordo 90). Exemplifying this through my analysis, I regularly return to the disabled body/mind as a contested site saturated and defined by socio-political power relations and associated disciplinary tensions.

Feminist poststructuralist and postmodernist criticism discusses the body as a cultural construction. The body, and body parts are taken to be “symbolic forms in a culture” (Wendell 324) and the body serves as both “a powerful symbolic form” as well as “a medium of culture” (Bordo 90). If we consider the body as a literal “medium,” the body is seen as a substance used to convey an idea, an effect, or a force to others. Thus, it exists in relation. It is constantly interpreted, read, deciphered, and redeciphered. Almost like paint used on a canvas where a story is told, the body tells a story, and “your body must be heard” (Cixous, 1971). The idea of the body as a medium of culture informs this exploration as it facilitates showing how coming to terms with one’s multiple disabilities concomitantly influence an individual’s mind and body as well as constant renegotiations of one’s identity. Disability influences individuals in social-emotional as well as existential ways, and this analysis exhibits how these influences co-exist and fluidly overlap, constantly in relationship with one another.

The chapter that follows shifts the focus from socio-emotional to existential and from the existential to the educational to illustrate through examples from the narratives how they fluidly interrelate. In order to reveal how students’ identities in regard to their disabilities relate to their educational experiences, the following chapter shifts from
socio-emotional influences of LD/Ds to existential and educational influences. In order to effectively meet students’ educational needs it is necessary to sufficiently understand both the complexities of how students with disabilities make meaning of their disabilities in social settings as well as how their identity formations and reformations might influence their educational experiences.
Chapter 5. From Existential to Educational

This chapter extends my analysis of how disabilities influence an individual from social and emotional to existential. I illustrate through Ben and Laura’s narratives how experiences with education depend on students’ emotional and existential meaning making when it comes to their LD/Ds identities in social interactions. I draw primarily from Julie’s narrative in the latter half of this chapter to reveal how oral histories about experiences of disability and education might be used to advance education, particularly education that more effectively meets the needs of students with disabilities. I conclude this chapter with an introduction to regime theory as a tool that might be used to alter the educational status quo for students with LD/Ds.

The first example from which I cite to explore the relationships between identity and disability in education comes from Ben’s narrative. He recognizes his participation in self-disciplining when he acts in ways to protect himself from standing out too much, being stigmatized or ridiculed, and being accused of lying about his disability (since it is often not visually apparent that he has a disability). Immediately following Ben’s return to college after his STBI, he was “afraid to give his input” when he was assigned group work: “for a long time I was scared that… I was stupid. That I was… you know, just like when I felt like manic depression defined me, and I thought [my traumatic brain injury] was gonna define me. After a brain injury you think that” [sic]. Ben constantly found himself wondering, “Am I gonna be inside of this person who’s disabled for the rest of my life? Just like, I’m cuz I have to park in handicapped spaces, you know? Does that
mean I’m a handicap for the rest of my life?” He was concerned about having to identify himself as permanently “disabled” because he used a “disabled” parking pass. As Ben’s excerpt show, recognizing (through diagnosis or personal realization) one’s own disabling conditions can negatively influence an individual on emotional, social, and existential levels. Ben, however, came to terms with his disabling conditions quite quickly when he decided: “No [it doesn’t mean I’m a handicap for the rest of my life], it just means that […] I have this special condition that I need…accommodations.” He reflected on his group work experiences: “So, when I first started with groups, I really thought that… I was still battling with that […] traumatic brain injury. Of course, not everybody knew, but [I still thought], ‘Is my input valid?’ ‘Does anyone even wanna hear from me?’ Like, they don’t know that I had a brain injury…” Even though his classmates were not aware of his conditions, Ben was anxious about participating in academic settings because he was afraid of people rejecting, judging, and making assumptions about him because of his multiple disabilities.

In line with Ben’s experience doing group work in his classes, Laura experienced anxiety about school as a result of her disabling conditions; her emotions led her to make new meanings of her disabled identity which, in turn, influenced how she perceived her place and student identity in academic spaces. While Ben’s apprehension manifested in the form of refraining from active participation, Laura’s difficulties making meaning of learning with disabilities took the form of anxiety when she first returned to the university setting. She describes, “the [most] basic thing [about her learning disability], is between my age and my drug and alcohol use, I can’t remember anything and that terrified me when I first came back […] there are times when it’s been very difficult
because I’ve had to remember things, and I… and… I don’t. …Sometimes I’ll remember something and I’m amazed, it scares me. But, on the whole, I don’t.” Laura describes how she was extremely anxious about her memory difficulties when she first returned to college, but how as a result she sought out help and now uses academic accommodations to do well in her college classes.

Feminist scholar Diane Price Herndl (2006) raises the question of identity after major illness in her work “Our Breasts, Our Selves: Identity, Community, and Ethics in Cancer Autobiographies.” Ben and Laura’s narratives bring to light existential questions concerning identity in relation to disability. In their own ways each narrative poses questions about disability that aligns with Price Herndl’s reflective queries concerning breast cancer and identity: who am I now that I am a person who has a disability? More precisely, the student narratives that I refer to in this analysis reveal how disability, like illness, requires individuals to reimagine what kind of person they are, and in this case what kind of student they are, and who they can be in the future now that they have a disability. Price Herndl’s work encourages novel explorations of the ways in which “the body, its inadequacies, and its fragmentation become part of a new narrative identity” (222). The existential and educational focus of this analysis exemplifies how these students make meaning of their identities through their experiences with disability and education.

One part of Laura’s narrative, in particular, draws important connections between identity, disability, and education. She explains why she decided to meet with me regardless of the fact that none of her learning disabilities have ever been diagnosed as such: “I wanted to do this because… … well, here we go… because I’m different. I
didn’t think anybody was gonna come for my viewpoint which is that of a recovering alcoholic and a… a terrified person… and someone whose schooling has been so colored by my disease… and by fear.” She articulates how her unique perspective, her experiences with drugs, alcohol, and fear, and her age make her accounts of disability and education unique. Laura also explained to me how she never expected that anyone would ask for her story, her experiences, and her perspectives. Her narrative made it clear that she chose to participate in this research because she wants people to understand, to hear how education has been for her so that the world can become an easier place to live in, especially for people like her who are forced to navigate their worlds with conditions that disable them. To illustrate her point, Laura references a quote from the book *Dune* that she was assigned to read for one of her college English courses: “Fear is the mind killer.” She responded with: “And it is. Fear kills everything. Fear leaves you unable to function from your heart, from your head, from love. Fear leaves you cowering in a corner, even when you’re walking around. And, I went through my whole life that way, and I survived it, and I’ve been reborn, kind of, through school.” Laura describes how school saved her from herself. School became Laura’s passion, and it makes her “just blossom.” Laura explains how one day her therapist told her, ‘You should see your face when you talk about school.’ And I can feel it! It lights up! Because I love it so much. And… I didn’t think my path was quite usual, and I don’t think that my thinking is quite usual.” Laura’s reflections illustrate how she chose to talk about her educational and personal experiences with disability because she wants to dispel any fears people have about disability and education.
In his narrative, Ben experiences fear and insecurity akin to Laura’s. Ben’s reflections demonstrate his internalization of social anxieties about brain injuries and what might be called “emotional” or “psychological” disabilities like manic depression. Ben reflects on how it was for him to return to the university setting after his accidents and diagnoses. He explains that he had very little confidence in classroom settings: “so many insecurities [were] always on my conscience,” he said, and he was constantly afraid of “how [others] would misinterpret [what he might say].” Ben was so anxious about not “being on the same page” as his peers that he decided to not speak in class even when he felt had something to contribute. His all-consuming fear of saying something that was “totally off base [and doing so] because [he] had a traumatic brain injury” prevented him from participating fully in his classes and meeting his educational potential. Ben’s self-discipline left him “down in the dumps” when he first returned to college post-accident. This instance shows how Ben participated in meaning making and identity formation through such behaviors. In so doing, he all together changed the reality of the student that he was inside (one who has multiple disabilities) into a student that he imagined other people preferred him to be (one who does not have disabilities, or one who is not “out” about them). Post-diagnoses, Ben participated in self-surveillance and self-discipline by forcing himself to renegotiate his relationship to his mind/body as well as renegotiate his relationships with his peers and in classroom settings. Gradually, Ben realized his potential and that he was “on the same page” as his peers. By beginning to speak in class and actively participate in group work, Ben reassigned meaning to his body/mind in the aftermath of his disability diagnoses.
Considered with power relations in mind, the self-discipline in which Laura and Ben engaged immediately following their reentry into academic atmospheres brings to light the workings of a process similar to Judith Butler’s “exclusionary matrix” (1999) by which subjects are formed (237). Since this matrix requires “the simultaneous production of a domain of abject beings, those who are not yet ‘subjects,’ but who form the constitutive outside to the domain of the subject” (237), the subject is constituted through forces of abjection and exclusion. Laura and Ben feel different, excluded, on the periphery in these academic spaces. Symbolically, they enter the domain of abject beings while those around them occupy the subject positions, i.e., positions of power via qualifying as in-group. Since first returning to college, Ben’s level of comfort speaking out in group academic settings has “slowly but surely [been] progressing” as his internal sense of strife about being misinterpreted (because of how his disabilities might impact his processing) is gradually diminishing. This exemplification of Butler’s exclusionary matrix demonstrates not only that “bodies and minds that matter” are assumed to be non-disabled, but also how emotionally and academically scarring even the threat of being victim to assumptions and stereotypes about disability can be.

Following his STBI and manic depression diagnoses, Ben felt he had to internally redefine his relationship to, and interpretation of his own body/mind because he came to understand it as “disabled” by and in society. To extend my application of Butler’s exclusionary matrix process, though neither his mind nor body was marked by his disabilities, Ben came to an awareness of himself as “damaged.” Robert Murphy explains

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5 Throughout this thesis I use “subject” and “individual” to refer to people contained, restricted, and limited by the cultures and societies of which they are a part. Delving further into the debates surrounding these terms is beyond the scope of this project.
the ways in which illness negates a “lack of awareness of the body in guiding our thoughts and actions [since] the body no longer can be taken for granted, implicit and axiomatic, for it has become a problem” (quoted in Wendell 1999, 326). Ben’s problem – his inability to walk long distances – led him to a new awareness of his body and mind through numbness. Ben arrived at this awareness when he realized that he was being forced to contend with and find accommodations for his newly disabled body. Disability scholar Susan Wendell’s work illustrates how such new senses of awareness result from new confrontations with “pain, discomfort, [and] physical difficulty” (326). Such a new awareness is apparent in Ben’s justification for why he uses a “handicapped tag.”

Though Ben identifies as an athlete and loves sports, he explained that standing on his feet for a long time is a problem for him because of the way that his muscles paralyzed during the accident. Because he is unable to use parts of his feet, they do not work like others’ feet since: “everything is sitting on [his] ankles, all the weight is on these two ankles.” Walking long distances hurts his feet but running or bike riding redistributes his weight so as to not cause an issue for him. Ben’s use of “justify” makes it clear that he felt he needed to explain his use of a “handicapped tag.” This demonstrated his anxiety about being perceived as using accommodations that he might not actually need. Hidden disabilities, like learning disabilities, bring to light issues of anxiety about being perceived as someone who is granted accommodation when they might not really need it. Ben concluded this portion of the interview by explaining how he prefers when people are unaware of his disabilities because, in those circumstances, he need not worry about justifying, explaining himself, or risking rejection or judgment. Ben’s finding comfort in “passing” as non-disabled in certain contexts exemplifies the
ever changing, fluid, and simultaneously public and private negotiations in which
disabilities might be forced to participate (depending on how their
disabled bodies/minds are publically read). This example demonstrates Ben’s constant
hyper-awareness of other people’s potential interpretations of his body/mind, i.e., their
surveillance of him because of his disability. As a result of his increased awareness of
non-disabled people’s surveillance and assumptions that are made about individuals with
disabilities, Ben monitors himself, and symbolically, he exemplifies a self-disciplining,
self-surveilling prisoner in Bentham’s Panopticon.

5.1 Identity & Identification to Practice & Policy

Julie’s narrative aligns with Ben’s and Laura’s in that all three the students
offered recommendations for the future that stemmed from their personal experiences
with disability and education. Like those of all students, these three student narrators’
experiences and recommendations for educational reform and practical interventions
were greatly diverse. That they differed so significantly from one another merely shows
how important it is to have equally as nuanced and multiple interventions, solutions,
and accommodations for students with disabilities. On a broader level, the diversity of
these three students’ experiences and recommendations might even be seen as diversity
akin to that of all students with LD/Ds in the U.S. educational system.

Ben explained how one of his major recommendations would be to create
opportunities for students who had learning disabilities to get together on campus to be
able to “talk about their experiences” with one another. In his words, Ben reflected on
what it was like for him to be in the hospital with other TBI patients. He told me,
“...thank god I was in that hospital because, if I wasn’t – if I was just like in another hospital… I probably wouldn’t have gone back to school.” Ben reflected on that during our interview and explained how it really came down to sharing and building community with one another. Ben recommended that students create for themselves this kind of situation in which they could regularly meet and participate in a kind of organization or club centered on LD/Ds or even brain injuries specifically. Following his STBI experience, Ben described how extremely important it was for him to have had the chance to speak with other individuals who had also experienced TBIs. He explained how his entire hospital floor was dedicated to TBI patients (when he was hospitalized after his STBI diagnosis) and that ended up being life-changing for him, “...every day ... you connect with these people. You know? Like, Roc. Like he flew off a cliff in his truck. You know, like slipped on black ice [when he was] on leave from Iraq. He didn’t get shot in the head or anything, he flew off a cliff.” Ben went on, “You know? And, he got a traumatic brain injury. He was in a hospital. …But he was really bad off in a really bad way. But now he boulders [rock climbs] and stuff, and he’s doing awesome.” Ben reflected, “…some of my really, really close friends had these really bad things happen to them.” He explained how they all become extremely close and, eventually, many of them returned to school following their hospitalizations. Ben told me that without that sense of community he would not have felt motivated. Thus connecting with people who had similar experiences, i.e. severe traumatic brain injuries like he had made him feel like he was no longer alone, like he was not the only person in the world who had ever experienced an STBI. As Ben described it, that experience led him to think of himself as being “able to relate to anybody,” it helped
him open up and be more confident in himself and his capabilities, especially when it came to academics.

While Ben reflected on how he wished support groups existed for students with TBIs, or even for students with LD/Ds, Laura’s recommendations focused on self-advocacy and taking it upon oneself to seek out help when you need it. Toward the end of her interview, Laura explained, how it is important to know that “things grow out” and people want to give and they want to be felt. I don’t care what they say. We’re born. We’re made to touch each other and to interact and to interchange so…it’s okay. It’s okay to be who and how you are.” Referring to students who have LD/Ds, Laura goes on to reiterate, “I can’t say it any more differently than, ‘It’s okay.’ And to put those words into action, I would say…again, communicate, for God’s sake. Communicate. Please don’t go around all locked inside yourself cuz you’re scared. Talk to someone. That’s really the rest of the story.” Laura offered these recommendations for students who have LD/Ds in response to her educational experiences. As she explained it, “what I think my favorite classes were are those with an emphasis on class discussion or whatnot…[because] I think it’s so important to have everybody’s input whether it’s in a class and you’re getting a student’s input, or whether it’s me talking with [a student’s with disabilities services director] and she gets my input…whatever it is, everybody should be heard. Everybody should be listened to.” Laura emphasizes how being heard and getting the help one might need depends on someone advocating for her or himself. In Laura’s words, “…the ultimately responsibility for any recovery from any thing … lies with you.” Unlike Ben’s more collective approach to sharing experiences with one another to boost confidence and feel less alienated, Laura
recommends that students self-advocate and communicate in order to get accommodations that they might need.

Like Julie, Ben and Laura spoke with me out of a desire to change the status quo for all students who experience disability in educational settings. As is evident, their recommendations differed greatly from one another. The narratives that Laura, Ben, and Julie offer uniquely illustrate the interconnections between the socio-emotional, existential, and educational and exemplify diversity in that they represent how different each and every student with LD/Ds is from other students with LD/Ds. Concurrently, they represent how students with similar (or even the same) LD/Ds might experience their LD/Ds in quite opposite ways. More broadly, these oral histories bring to light the great diversity of reforms that could lead to improvements in education for students with LD/Ds. Even if they might have similar LD/Ds, students are individuals who have their own preferences, opinions, strengths, and weaknesses. A one-size-fits-all model could never work; in its place innovative, holistic approaches to addressing and understanding disability in education are needed.

Future educational policies, practices, and resources for students like the three I feature in this thesis might be forever improved if the approaches to LD/Ds are considered. Julie’s interview, in particular, stood out as distinctively illustrative of how and why students with LD/Ds continue to remain unidentified and, thus, fail to receive intervention. Shifting the focus from Ben and Laura’s narratives to Julie’s I reorient this analysis in a way that suggests how a holistic view of the influences that disability has on a student might lead to necessary educational reform. I propose that such reform has the potential to create education system that can more effectively meet the needs of
students who have LD/Ds. I introduce urban regime theory as a theoretical approach to reforming education in such an innovative way.

Since the 1990s the political paradigm of regime theory has been applied to urban educational reform. Strategic implementation of this theoretical framework has the potential to significantly invigorate the politics of education. Overall, regime theory has proven quite useful in examinations and formulations of U.S. urban politics since, when applied to the politics of schooling, regime theory “approaches governing arrangements as the outcomes of conflict and cooperation, not as the aggregation of fragile, individual choices” (Shipps 89). Rejecting the idea that governing arrangements result exclusively from separate, particular, and micro-interpersonal choices that are made, regime theory recognizes how conflict and cooperation are necessary for change to occur on a macro-institutional level. Regime theory’s distinct and unambiguous ethical approach renders it exceptionally suitable to this project. As Dorothy Shipps (2008) describes it, regime theory posits that the enduring governing relationships and institutions can “give voice to marginalized groups and improve their collective circumstances” (89). Furthermore, regime theory does not assume that “all other governing arrangements are hegemonic systems of legitimacy” (Shipps 89). This approach emerges as a useful tool of social action since it typifies what some feminist scholars might describe as a method of dismantling the master’s house using the master’s tools (to reference Audre Lorde’s legendary words in her 1984 masterpiece *Sister Outsider*). Considering how the current educational system might be reformed to better meet the needs of students with LD/Ds regime theory proves quite suitable and its applications exceptionally feasible. As I reveal through examples taken from Julie’s
narrative, while the entire metaphorical house (i.e., the U.S. educational system) need not be completely dismantled, how students with learning disabilities are identified, and their needs accommodated, can be significantly enhanced. Julie’s case is a prime example of how regime theory plays out since it brings to light how earlier identification and intervention has the potential to positively transform the educational experiences of students with disabilities, like Julie. More generally, Julie’s case illustrates how relationships among and between educational actors might be reconceptualized as sites of future transformation in educational policy.

I extend my analysis from this point to exemplify how socio-emotional and existential influences of disability might be useful to improve future educational policy reform. Through Julie’s narrative it becomes evident that new tools are needed to change the status quo for students, especially those who might have undiagnosed LD/Ds. I reveal how regime theory, in particular, might be employed to reform how and when students with LD/Ds in our U.S. education system are identified and receive the interventions and accommodations that they might need. The following excerpt from Julie’s narrative epitomizes the experiences of millions of students with LD/Ds in the U.S. It also brings to light how the educational system and its actors, as examined through a distinctly regime theory lens, hold the power needed to improve the educational status quo for students like Julie, Ben, and Laura.

Julie’s narrative reveals the extremely difficult time she had when she was in high school because she remained undiagnosed with ADD until she was a sophomore in college. Before that point in her academic career, Julie “didn’t even know that [she] was fighting uphill… [even] all through [her] first two years of college until [she] was
done with [her] sophomore year.” She describes how she was never able to pay attention to anything in her classes, how she would sit down to do her homework and she would think about the fact that she had dishes in the sink, that she could clean her room, and that she had five loads of laundry that she knew that she could be doing “instead of actually reading the material that [was] right in front of [her].” In her words, she “was basically fighting uphill for something that [she] didn’t even know was a problem. Nobody even told [her] about it…” Considering the fact that her dad had a severe learning disability, it is evident that teachers and educational staff members should have been wary of the possibility that Julie could have had a learning disability or learning difference that was leading to her difficulties in school. Regardless, Julie remained unidentified as a student with a learning disability until extremely late in her academic career. Despite the many warning signs along the way, Julie was not identified, nor accommodated, until halfway through her college career.

When Julie was in elementary school she was “always the class clown” and she did everything that she could to avoid doing work that was difficult for her or that she did not understand. One instance of this tendency was her fourth grade experience. She identified that year as when all of her problems began. As she puts it, “I…didn’t do any math in the fourth grade … don’t ask me how it worked, but… I didn’t.” I followed up by asking if she was required to take a math class that year, and she said she was, but that her teacher never checked her marble composition notebook in which all students were expected to do their homework. “Yeah. And, um, she like assigned us homework every night in it…but didn’t check it then next day…? So…I went the whole fourth grade year [without doing any homework at all]. I don’t know my times tables, and I
can’t do long division very well. Even to this day because I found out a way to cheat the system, so that I wouldn’t have to do it because it was too challenging for me then.” Julie explained that she never had to face the consequences when she made that choice, but she “deals with the repercussions of it every day.” She asked me, “What twenty-one year old doesn’t know how to multiply? And what twenty-one year old can’t do long division in her head? I don’t know my times tables, I don’t know how to divide. I can’t…do any of that! So that hindered me throughout all of the rest of my math learning. It all started in fourth grade.” I prompted Julie to explain how her parents reacted when her teacher called to tell them about Julie’s choice to not complete any math homework that entire year. Julie told me that her mother asked the teacher why she had not been checking her homework the entire year. Julie explained to me that she blames her fourth grade experience with math on her teacher, but she also blames herself for not “learning the material.” Immediately following that statement, Julie reflected, “But, then again, what fourth grader consciously thinks, ‘this is gonna hurt me for the rest of my life!’” Julie made an important point, and that she was the one and only student who had not completed her math homework for the entire year should have signaled to her teacher that there was something wrong. Intervention should have occurred at that point to prevent Julie from moving on in school without the necessary mathematics skills.

Like many students’ parents, Julie’s parents were as involved as they could have been and did what they were able to do to help Julie with her schoolwork. When Julie was in elementary school her mother worked full-time and was also student and her father worked long hours since her parents owned their own business. Both,
however, were involved in her personal and academic life. Despite their involvement, neither parent identified their daughter as a student with a learning disability. In conjunction with Julie’s teachers not identifying her as needing help, school staff members, administrators, and her parents all being unaware led to Julie ending up in college being completely unaware of her LD.

Julie described how when she was in high school she “never paid attention to anything.” She explained, “I was always chattin it up with the kid next to me about like, ‘Hey! What are you doin’ this weekend?’ Like, I [my mind] was never in the room when we were supposed to be in the room. In high school I was like class clown, best dressed, perfect smile… I didn’t pay attention. I didn’t learn… I didn’t…perform” [sic]. Similar to her math experience in elementary school, Julie’s high school behavior during classes should have served as a cue to teachers, staff, and/or administrators but it did not. Julie was distracted, not focused, and not engaged in what was happening in her classrooms because she felt alienated from other students much like Laura did when she was in high school. Unlike Laura, however, Julie felt isolated because she could not focus on topics at hand and she found herself to be different from other students since she did not learn the ways other students learned.

Julie explains that many subjects were difficult for her and still are because she is unable to comprehend and retain material like other students. Even though Julie had a long family history of learning, cognitive, and developmental disabilities and disorders on both sides of her family, she was the one who recognized that “something was off.” Julie was the one who advocated for herself by seeking medical help to identify and receive the intervention and medical treatment (ADD medication) that she
needed. Julie explains that her inability to succeed in college “didn’t even make sense” to her until she decided to visit her doctor to explain that she was unable to pay attention and “wasn’t keeping up” with everyone else; he informed her that she had “adult attention deficit disorder” (ADD). In her narrative Julie explained how she really wished she had known that when she was in high school, and even prior to that, because she “probably could have… learned to fix it, correct it [much earlier].” The doctor that she visited prescribed Adderall. Since then, the medication has proven to be greatly helpful to Julie. Once she was regularly taking Adderall, the “corrective medicine completely transformed [her] learning experience. Everything [changed]. Totally. [She] started getting ‘A’s and ‘B’s on tests … which … even just now, [she] got an ‘A’ on a test.” As Julie put it, “ADD is a disability [for her] in that without that corrective medicine … [she] would be disabled … by the system.” As her narrative demonstrates, Julie would have greatly benefited from earlier diagnosis of ADD and earlier prescription of “corrective” treatment, both of which would have necessitated earlier identification.

Like Julie, students with LD/Ds are not always easy to identify. There are, however, warning signs, cues, and indications of which teachers, parents, administrators, and/or school staff members should be aware. Training to be able to determine when a student might have LD/Ds is necessary since students might not always be able to self-advocate like Julie did when she was in college. The system must train teachers, administrators, and staff members to be able to catch students earlier to provide them with the tools, the interventions, and the accommodations that those students might need to help them succeed academically and beyond. Through critical
reflection on Julie’s experiences, in particular, it is clear that now might be the perfect time to develop new approaches to identification and intervention. One approach that I recommend is stems from applying urban regime theory in novel ways.

5.2 A New Tool for Change: Regime Theory in Disability & Education

On a macro scale, regime theory can be used for educational reform to better meet the needs of marginalized individuals in the U.S. educational system. Julie’s narrative about her experiences not having known about her disabilities early enough in her academic career exemplifies how much is at stake when we fail to provide educators, staff, and administrators with the tools and skills that they need to improve learning conditions for students, especially for students whose needs often remain unmet. Ben and Laura’s interviews also shed light on how important it is to provide students with what each of them, individually, needs to succeed regardless of their LD/Ds. Varying recommendations were discussed in all three interviews because the solution to education for students with LD/Ds is not a simple one; how we address the needs of these students is complex, though doing so is necessary as it means humanizing these students, seeing and treating each of them as an individual with distinct needs, strengths, and skills that can only be fostered and enhanced with the appropriate support and accommodations. While the three student voices featured in this thesis told different stories, collectively they revealed how extremely diverse this student population is and how necessary it is to take on the challenge of recognizing, responding to, and providing needed resources for each student with LD/Ds.
Since regime theory “assumes institutions shape and are shaped by political, economic, and cultural contexts” as well as “attends closely to the role of human agency in constructing institutional options and sustaining them over time” (Shipps 89), it emerges as a potentially useful tool to improve education of students with LD/Ds. The “context” in this case is the currently problematic way that society, education especially, treats disability. A broader, more universal model that took into account the diversity of students with LD/Ds would be more proficient at training professionals to more quickly and effectively recognize patterns and trends (such as the growing number of LD/Ds diagnoses over the past decade) and disability in education might be reframed and reimagined as a social issue, i.e. a repairable condition that must be given attention and resources if change is the goal. “Both descriptive and predictive in its orientation” (Shipps 90), regime theory can be used as a new lens through which we might view disability in education.

The U.S. educational system can better meet the needs of students with LD/Ds by changing how complicated the process is to identify and offer accommodations for such students. In order to be eligible for accommodations, a student can be identified and evaluated in one of two ways (according to the National Dissemination Center for Children with Disabilities September 2010 report on Evaluating Children for Disability). A student’s parents must request an evaluation or the student’s school must request one. Since a request can come from any teacher’s recommendation or observation, but there are many complicated steps involved by which many teachers are deterred. While the evaluation is at no cost to the parent(s) and cannot commence until the parents’ consent to the evaluation, teachers and school personnel are required to
follow a quite daunting process in order to get the child the evaluation and interventions that they might need.

The educational system puts educators in the position of being the most likely actors to identify and obtain help for students who might need assistance. Together, observation, screening, and identification of a student who might have a learning disability or learning difference, assessment and evaluation to determine required accommodations and particular educational needs, and intervention on behalf of the student create a laborious process for teachers to initiate and endure. While human agency, and in this case educators’ agency, plays a major role in forming and reforming institutional options and upholding them over time, the current educational system and structure – even though meant to meet the needs of students with disabilities – systematically, and unremittingly fails students. While all teachers have the power to initiate and follow through with the process of identifying and intervening for a student in need (and many have the necessary understanding of and experiences with what ought to be happening with kids at particular ages in order to determine what ought not be happening) more support is necessary to facilitate earlier identification and intervention for students like Julie.

Regime theory comes into play at this point as it “seeks new explanations for school governing arrangements and addresses schooling where policy change typically takes place” (Shipps 89). I propose that school-governing arrangements that are in place to ensure that the needs of students with LD/Ds are met must be changed so that students no longer fall through the cracks. Students’ educational needs should never remain unidentified until students are in a university setting, as was Julie. According to
Stephen Samuel Smith (2004), the most basic concern of regime theory is coming to an understanding of “how the different resources that various local actors (business leaders, educators, community organizations, and so forth) bring to the task of governance can be organized to create an enduring set of arrangements (a regime) whose operation will facilitate local goals” (Smith 7). This basic tenet of regime theory can almost seamlessly apply to facilitating the “local goals” of identifying, evaluating, and intervening on behalf of students with LD/Ds. The different resources that should be available are wherein the problems lie.

Teachers must not remain the sole, primary bearers of the responsibility of managing the identification and intervention of students with learning disabilities. Regime theory informs us that reorganizing resources in tactical ways can create enduring regimes whose operations have the potential to facilitate change, most importantly change that can result in improved circumstances for historically marginalized populations such as students with disabilities. I return here to the holistic approach that I introduced when considering how disability influences students. The narratives from which I draw in this analysis bring to light complex socio-emotional and existential ways in which individuals might be influenced by disability; these influences must be recognized, taken into account, and on educators’, staff members’, parents’, and administrators’ radars as well as students’ to ensure that students receive accommodations that they might need.

One specific way to reorganize resources to effectively and immediately meet the needs of students would be to expand the notion of the team staffing approach that is currently used to write and implement Individualized Educational Programs (IEPs).
Expanding this notion on a grander scale would facilitate earlier intervention. While the team approach exists for the individual child who has already been assessed and has an IEP written, students who have yet to be assessed would greatly benefit from such a change. If the educational system at large worked more like an individual IEP team, policy makers who write the laws and steps that must be followed, educators in classrooms who implement them, principals and vice principals who oversee and monitor the processes, and parents who are involved at various stages in the process would all play more major roles. Additionally, all would need to be significantly more educated about the process, in observing, identifying, assessing, and intervening in students’ educational experiences in order to meet the needs of students with disabilities. Such an approach to providing students with the support that they need throughout their educational lives would remove the primary burden from the teacher to identify and manage the process every step of the way. Ideally, if actors occupying various positions in the educational process more effectively and frequently communicated with one another, had more substantial training and knowledge about the roles of the other actors, and fostered greater parent participation in these processes, students like Julie would be identified much earlier as students who might need corrective medicine and/or particular accommodations.

Most valuably, and arguably most importantly in such a reconceptualization of the educational status for students with LD/Ds would be expanding the role of the students themselves. As Laura recommended, self-advocacy is greatly important and every student should be included. Existing scholarship on disabilities and education exemplifies how students are often left out, and, as a result they frequently become
devoid of agency and awareness in evaluation and intervention processes. Increasing awareness about the socio-emotional and existential influences that disabilities can have on individuals (thus, better educating all actors on what to be on the lookout for as warning signs in students’ behavior) while encouraging greater student self-advocacy would facilitate earlier and more effective intervention. Like Julie, students would able to act on their own behalves while principals, policy makers, parents, and even politicians did what was necessary from their end to meet the needs of students of all ages, in all states, and with all kinds of learning differences and/or disabilities. In line with Susan Wendell, individual students with LD/Ds are the experts on how they learn most and least effectively, and thus students with LD/Ds should be considered “major contributors to our cultural understanding of [not only] the body” (Wendell 326) but also LD/Ds. The voices of such students are expert as they stem from personal experiences of LD/Ds.

Through such a pragmatic application of regime theory, I have aimed to introduce how a shared responsibility among all players involved in the educational system can lead to future change for students with disabilities. Such an approach illustrates how possible it can be to treat each student with LD/Ds as an individual and develop individualized plans to more effectively meet their educational needs. Considering what interventions and accommodations works for each individual student is essential as it recognizes each student as a human being, as a person different from the next student with LD/Ds. Oral history research on disability can uniquely raise awareness about how particular students are influenced by disability on socio-emotional, existential, and educational levels as well as lead to earlier identification and more effective
intervention and accommodations. On a larger scale, such research can ultimately lead to structures and policies that allow fewer and fewer students to fall through the bureaucratic, educational cracks.

While regime theory is commonly critiqued for how widely it has been applied, using it to strategically examine relationships at work in the educational system when it comes to students with LD/Ds brings to light how structures, procedures, and particular actors’ roles might be reorganized to enhance students’ educational experiences. Multidimensional approaches like this project have the potential to integrate personal narratives with theory, theory with application, and application with lasting policy reformation. In so doing, interdisciplinary research on disability and education has the potential to improve how students who are disabled in and by society experience education.

Like U.S. society, the U.S. educational system is comprised of networks of institutions in which all agents have their own, unique responsibilities and duties. Because of the existing diversity of knowledge, experience, and philosophy among all actors involved in the educational process, societal governance (or, in this case, the educational system) can be reimagined as a jumping off point for the future of education that is chock full of emancipatory potential. Multifaceted applications of feminist, body politics, and regime theory like this can open up the door to reform of our current system since such rearrangements have the ability to triangulate education and disability to enhance the learning experiences of all students.
Chapter 6. Conclusions & Future Directions

The need to sustain human growth should be a matter of concern for the entire society, even more fundamental than the problem of sustaining productivity. This, surely, is the deepest sense of homemaking, whether in a factory or a college or a household. For all of us, continuing development depends on nurture and guidance long after the years of formal education, just as it depends on seeing others ahead on the road with whom it is possible to identify. A special effort is needed when doubts have been deeply implanted during the years of growing up or when some fact of difference raises barriers or undermines those identifications, but all of us are at risk, not only through childhood but through all the unfolding experiences of life that present new problems and require new learning.

Education, whether for success or failure, is never finished. Building and sustaining the settings in which individuals can grow and unfold, not ‘kept in their place’ but empowered to become all they can be, is not only the task of parents and teachers, but the basis of management and political leadership – and simple friendship. (Mary Catherine Bateson, 55-56)

Education is growth, and accomplishing educational reform is possible because policies can be created and decisions arrived at through effective cooperation among distinct community actors. Even within a particular locale, regime theory reveals how the main players of a regime are ever changing, and the institutions involved maintain stability and ensure reliability while human agency plays its vital role. Though they
may differ depending on historical time or socio-political climate, regimes “represent relatively enduring orientations and coalitions” (Mossberger & Stoker 2001, 815). As I have revealed in this feminist oral history project, regimes have the potential to create and maintain not only lasting change but also future emancipatory prospects for historically marginalized populations such as students who have disabilities.

I offer this project with the hope that feminist disability oral history research on student experiences will pick up where I left off as I invite scholars to take on interdisciplinary, theoretically informed explorations of the intersections of disability, identity, narrative, and education. The circumstances for students with disabilities are complex, as I have revealed here, but the challenge lies in imagining new approaches. No singular model will work since no one approach can ever solve all of the problems that we might face. As Mary Catherine Bateson puts it, “the real challenge comes from the realization of multiple alternatives and the invention of new models” (62). Novelty, imagination, and risk taking are necessary to developrefreshingly original approaches aimed at improving the status quo for students who have disabilities. What we risk if this does not manifest is remaining a society that excludes, that continues to create divisions among its populations, and that isolates and alienates its masses. Multiple alternative and inventing new models has the potential to result in aspiration ceasing to be a one-way street. In Bateson’s words, “from child to adult, from female inferiority to male privilege, from exclusion to full membership [aspiration] instead becomes open in all directions, claiming the possibility of inclusion and setting an individual course among the many ways of being human” (62). Even that, however, is not an adequate phrasing in Bateson’s words since it “suggests the possibility of choosing an existing
model and following it toward a defined goal” (62). This is impossible, as I have revealed in this thesis. Existing models fall short in significant ways, for the answer is multiplicity, complexity, and intersectionality. We must work to shift the problem in our minds and see it in all of its lights, in its multiple, fluid, and intricate orientations.

This project exemplifies the impossibility of examining someone’s experience of disability and education without exploring how that individual was influenced socioemotionally and existentially by their disability or disabilities. In a similar vein, it is unfathomable to reform education in ways to better serve the needs of students who with LD/Ds without an awareness of how they think, what they feel, and how their identities morph, surge, ebb, and flow in relation to their experiences with their disabilities. Reforming education without such understandings would be like asking a person about their experiences of race and racism without discussing with them their experiences of their gender, sexual identity, or age. We are neither the sum of our body parts, nor the sum of our thoughts nor the mere catalogue of the events that unfold in our lives. Our experiences result from how we are interpreted in society, how we interpret ourselves, and how those interpretations connect with one another. The approach that I suggest here is necessarily panoptic for meaning making must take into account all elements and aspects of one’s identity and expect those elements and aspects to constantly evolve and devolve as individuals perpetually transform and grow.

Just as one is not born a woman, but becomes one⁶, one is not born disabled, but becomes disabled. Making meaning of one’s disability is a process. When it comes to education, we must be conscious of that process and respond accordingly. Bateson

⁶ Taken from Simone de Beauvoir’s 1953 renowned (translation) *The Second Sex.*
explains, “part of the secret of continuing development – especially for women, who may be pressed by social expectations into childlike positions of weakness – is the discovery through a variety of relationships that social expectations can be changed” (94). Furthermore, “difference can be a source of strength rather than of weakness. We grow in dialogue, not only in the rare intensity of passionate collaboration, but through a multiplicity of forms of friendship and collegiality” (Bateson 94). This feminist oral history project typifies such interpersonal relationship as it exemplifies the merging of individual students’ voices to form a sinuous, discursive space of mutual vulnerability.

The oral histories that I present here speak to one another and they create a hazy picture of the state of students with LD/Ds in the U.S. These three were a few of the already small number of “success stories” of students with LD/Ds making it to college. It is necessary to recognize that, in many ways, these students had privileges that other students with LD/Ds are not often granted. Laura’s age, for instance, gave her the insight and confidence to be able to self-advocate just as Ben’s socioeconomic status gave him the chance to connect with other individuals like him when he was hospitalized. Many students with LD/Ds are never identified, never receive accommodations that they might need, and thus fall through the cracks. One of the most important lessons learned through this analysis is that of diversity; these students’ experiences varied, differed, and contrasted with one another, necessarily so. No two students are the same and thus no two interventions should be. Since individuals require individual attention and accommodation, educators, parents, and students must be conscious of conditions under which students might need intervention. Most importantly, further research must be done on the socio-emotional, existential, and educational influences of disability on an
individual as it has the potential to raise consciousness about difficulties that students face because of disabilities. Such research can influence teachers’ and administrators’ abilities to meet the needs of students as well as stimulate educational reform that will do the same. Engaging in such scholarship must be considered a concurrently political and ethical act for a great deal is at stake. Disability need not be inevitable for anyone, neither specifically in education nor generally in society. As is assumed in both the social model (Shakespeare, 2006) and the feminist approach to disability (Garland-Thomson 2001), change can happen. Ultimately, raising awareness can lead to recognition, and identification can lead to reform that has the great potential to initiate positive transformation and socio-political advancement.
Works Cited


Avramidis, Elias, Phil Bayliss and Robert Burden. “A Survey into mainstream teachers’
attitudes towards the inclusion of children with special educational needs in the ordinary school in one local education authority.” Educational Psychology. 20.2 (2000b). 191-211.


Garland-Thomson, R. “Integrating Disability, Transforming Feminist Theory.” *NWSA*


Progress. Saskatoon, Saskatchewan.


Snyder, Rebecca Finley. “A Qualitative Study of Inservice General Education Teachers’ Attitudes and Concerns.” *Education* 120.1 (1999): 173.


Bibliography


Giroux, Henry A. *Border Crossings: Cultural Workers and the Politics of Education.*

Print.

hooks, bell. *Teaching to Transgress: Education as the Practice of Freedom.*

Hurston, Zora Neale, and Alice Walker. *I Love Myself When I Am Laughing ... and Then Again When I Am Looking Mean and Impressive: a Zora Neale Hurston Reader.*


Marks, Deborah. *Disability: Controversial Debates and Psychosocial Perspectives.*


Nielsen, Joyce McCarl. *Feminist Research Methods: Exemplary Readings in the Social*
Appendices
Appendix A. Recruitment Email, Flyer, and Interview Follow-up Email

Below is the email that Students with Disabilities Services distributed at my request.

Hi!
I am a graduate student at USF and I am looking for students to share their stories, feelings, and thoughts with me! I hope to interview students so that they can be a part of my research project entitled “Valanced Voices” (eIRB#4770). I am specifically interested in hearing about your experiences being high school and college as well as the way that education happens for students with disabilities. Please email me back if you are interested in chatting with me to help with my research. My email address is: zfine@mail.usf.edu

Thank you so much and I look forward to hearing from you 😊

~Zoe

Below is the recruitment flyer that Students with Disabilities Services distributed at my request.

Looking for Students to Interview!

My thesis is about how education happens for students with learning disabilities and learning differences.

If you are an student who would like to share any thoughts, opinions, and stories about your high school and college experiences, please take one of the tabs below and email me to schedule an in-person, conversational interview with me!

Those interested must be at least 18 years old AND must have already completed at least 1 semester of college.

Thank you!
~Zoe

*If you will need any accommodations for the interview, please let me know and I will arrange them.
Appendix A. (Continued)

Within 24 hours after the conclusion of the interview, I thanked my interviewees for meeting with me by reiterating everything that I explained at the conclusion of our interview and reminding them to contact me if they had any follow up questions or concerns. Each student participant received a version of the following email:

Hi (student’s name),
I just wanted to thank you again for helping me with my thesis by meeting with me for our conversational interview yesterday. It was an honor and pleasure to be able to sit and speak with you about your experiences. I really appreciate all that you shared with me. What you shared with me is already helping me so, so much in my work on education, learning differences, and disabilities. Thank you so much, Brian. I cannot stress enough how grateful I am.

Please stay in touch. Like I said feel free to contact me if you think of anything else that you'd like to talk about or expand on. My work and I are open books!

Thank you again,
Zoe
## Appendix B. Conversational Interview Protocol & Guiding Questions

<table>
<thead>
<tr>
<th><strong>Pre-Interview (not recorded)</strong></th>
<th><strong>General Information about Project</strong></th>
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<tbody>
<tr>
<td>Explain some things about the process that we will be going through together:</td>
<td>Who I am</td>
</tr>
<tr>
<td></td>
<td>My department, student status</td>
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<tr>
<td></td>
<td>What I am doing here, my thesis</td>
</tr>
<tr>
<td></td>
<td>Why I am having these conversations</td>
</tr>
<tr>
<td></td>
<td>What my research is all about</td>
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<tr>
<td></td>
<td>Plan to do with the conversations/narratives:</td>
</tr>
<tr>
<td></td>
<td>Transcribe</td>
</tr>
<tr>
<td></td>
<td>Look for connections, trends</td>
</tr>
<tr>
<td><em>Looking for students with learning differences or disabilities to describe what would work best for them in high school and college learning spaces/classrooms</em></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Equipment</strong></th>
<th><strong>Confidentiality + Anonymity</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Show what we are using</td>
<td>NOTHING you share will be connected to your name, I will change ALL names to pseudonyms (even those in stories you might tell me)</td>
</tr>
<tr>
<td>Why record: forget stuff, help me remember so I can write about it (more accurately)</td>
<td>I will secure recordings and transcriptions so that no one else can access it, store it in a locked cabinet, password protected on my computer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Transparency (Open to Following Up)</strong></th>
<th><strong>Please feel free to make any comments, ask questions, etc. (during or even after the interview)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I am very open to follow-up interviews, chats, communication, questions, etc.</td>
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</tbody>
</table>
Appendix B. (Continued)

At the end of the data collection process, the recordings and transcripts will be destroyed.

Once I finish my thesis, please let me know if you would like to see it, or any time in the writing process (everything that I gather and analyze is yours to see and read).

I do not want you to feel misrepresented, etc. (Please feel free to ask to see your transcriptions, add anything via another interview, etc.)

<table>
<thead>
<tr>
<th>Consent Forms</th>
<th>Do you have any questions before we start?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>➤ <strong>SIGN FORMS.</strong></td>
</tr>
<tr>
<td></td>
<td>Ready to start recording?</td>
</tr>
<tr>
<td></td>
<td>➤ <strong>START RECORDING.</strong></td>
</tr>
</tbody>
</table>
**Appendix B. (Continued)**

<table>
<thead>
<tr>
<th>General Personal and Educational Information (about high school)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How old are you?</td>
</tr>
<tr>
<td>How long have you been a student at USF?</td>
</tr>
<tr>
<td>What are you studying?</td>
</tr>
<tr>
<td>What do you do for fun?</td>
</tr>
<tr>
<td>Where are you from?</td>
</tr>
<tr>
<td>(please describe what it’s like there?)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>I would like to begin by learning more about you (some general info)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Year in school</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place of Origin</th>
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</table>

<table>
<thead>
<tr>
<th>Where did you go to high school?</th>
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</table>

<table>
<thead>
<tr>
<th>Thinking back to when you were in high school, what was HS like for you?</th>
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</table>

<table>
<thead>
<tr>
<th>What kinds of people did you go to school with?</th>
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</table>

<table>
<thead>
<tr>
<th>Probe: Did you go to more than one school?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probe: What kind of school was it?</td>
</tr>
<tr>
<td>Probe: Where was it located? (Big city, town, rural area, suburbs?)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Probe: What were the other students like?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probe: Were your peers pretty similar to or different from each other? How?</td>
</tr>
<tr>
<td>Probe: Were they similar to you or different from you? How?</td>
</tr>
<tr>
<td>Probe: In general, how did you feel about your peers?</td>
</tr>
</tbody>
</table>
**Appendix B. (Continued)**

*By emailing me back, you agreed to talk to me and help me with my thesis. Why? Why are you interested in this project and why are you here talking to me?*

You agreed to meet with me because you identify as having a learning difference or disability. How would you describe it?

How did your family and people close to you talk about, respond to, or “handle” your LD or difference?

How did these people’s interpretations of your L difference or disability influence your success or learning experiences in HS?

In college?

In general, what is it is like for you in learning spaces? What was it like for you at your HS?

Did your high school classes have other students who had any learning differences or disabilities?

| Probe: How do you feel about the language/labels of learning “difference” or learning “disabilities”? |
| Probe: What were your teachers’ responses to it? Parents? Siblings? Friends? |
| Probe: Did people try to come up with “solutions”? (Meds, for instance?) |
| Probe: Did people see your LD or difference more as a “disability” or as a “difference”? |
| Probe: Did anyone have a hard time “believing” you? |
| Probe: Can you tell me more about what it is like for you academically? |
| Probe: What was it like when you were in class? |
| Probe: How did it feel for you to be in class? |
| Probe: Are there better places than others? What makes these places “better” or “worse,” in your opinion? |
Appendix B. (Continued)

<table>
<thead>
<tr>
<th>Question</th>
<th>Probe:</th>
</tr>
</thead>
<tbody>
<tr>
<td>In your high school classes, were you ever the only student with a learning difference or disability?</td>
<td>Did only some classes?</td>
</tr>
<tr>
<td></td>
<td>Did all of your classes?</td>
</tr>
<tr>
<td></td>
<td>Were you the only student with a learning difference or disability?</td>
</tr>
<tr>
<td></td>
<td>What was it like to be the only one?</td>
</tr>
<tr>
<td></td>
<td>What was it like to have other people around you who had learning differences or disabilities?</td>
</tr>
<tr>
<td>Have you been in “inclusive” high school classrooms (where students with disabilities and those without disabilities learn)?</td>
<td>Was your school, or were any of your classes labeled in any particular way because of the kinds of students in it?</td>
</tr>
<tr>
<td></td>
<td>(“gifted,” “inclusive,” “sp. ed./needs,” “general,” “mainstream”)</td>
</tr>
<tr>
<td></td>
<td>What was HS like, socially?</td>
</tr>
<tr>
<td></td>
<td>What were the students like?</td>
</tr>
<tr>
<td></td>
<td>If so, what was that like?</td>
</tr>
<tr>
<td></td>
<td>If not, what was that like?</td>
</tr>
<tr>
<td></td>
<td>Did your experiences in these different kinds of classrooms differ?</td>
</tr>
<tr>
<td></td>
<td>What did the label or title mean, exactly?</td>
</tr>
<tr>
<td></td>
<td>If not, do you think you would have liked to be in school or in classes like that?</td>
</tr>
<tr>
<td>Appendix B. (Continued)</td>
<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>What were your <strong>high school teachers</strong> like?</td>
<td></td>
</tr>
<tr>
<td>Probe: If not, why not?</td>
<td></td>
</tr>
<tr>
<td>Probe: What did it feel like to have your classes be labeled like that?</td>
<td></td>
</tr>
<tr>
<td>Probe: Did you feel labeled?</td>
<td></td>
</tr>
<tr>
<td>Probe: How did THAT feel? What was that like for you?</td>
<td></td>
</tr>
<tr>
<td>Probe: How did they treat their students?</td>
<td></td>
</tr>
<tr>
<td>Probe: Who was your <strong>favorite</strong>? Why?</td>
<td></td>
</tr>
<tr>
<td>What do you mean by “favorite”? (Grades you got in the class? How much you learned? Classroom dynamics? Teaching style?)</td>
<td></td>
</tr>
<tr>
<td>Probe: What did that teacher do (or not do) that you liked so much?</td>
<td></td>
</tr>
<tr>
<td>Probe: What strategies, teaching styles, activities, etc. that your teachers used worked best for you? Why???</td>
<td></td>
</tr>
<tr>
<td>Who was your <strong>least favorite</strong>? Why?</td>
<td></td>
</tr>
<tr>
<td>Probe: What did that teacher do that made you not like them so much?</td>
<td></td>
</tr>
<tr>
<td>Probe: What strategies, teaching styles, activities, etc. that your teachers used DID NOT WORK best for you? Why???</td>
<td></td>
</tr>
<tr>
<td>What did you ever come across a high school teacher who did not treat all students the same?</td>
<td></td>
</tr>
<tr>
<td>Probe: Why do you think that was?</td>
<td></td>
</tr>
<tr>
<td>Probe: How did they treat students differently? (ask for behaviors, etc.)</td>
<td></td>
</tr>
<tr>
<td>Probe: What aspects of the students related to how the teacher(s) treated them?</td>
<td></td>
</tr>
<tr>
<td>Probe: Bodily difference? Disability? Gender? Race?</td>
<td></td>
</tr>
<tr>
<td>What was your <strong>favorite class in HS</strong> and why?</td>
<td></td>
</tr>
</tbody>
</table>

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**Appendix B. (Continued)**

| What was your **least** favorite class in HS and why? | Probe: What was it about that class that made it your favorite? Why? What worked so well for you?  
Probe: Why do you think it worked so well for you? |
|---------------------------------------------------|--------------------------------------------------------------------------------------------------|
| When you were in HS, what do you think would have been necessary for you to have the ideal learning atmosphere? | Probe: What was it about that class that made it your least favorite? Why? What did not work so well for you?  
Probe: Why do you think it did not work so well for you? |
| Thinking back to when you were in HS classrooms… | Probe: What would have worked the best for you, specifically? (environment, teaching/learning style, activities, studying spaces, etc.) |
| Do you feel as though any other aspects of your identity may have influenced how you were treated in high school classroom spaces? | Probe: Bodily difference? Disability? Gender? Race?  
Probe: How did you feel you were treated?  
Probe: How did your peers, teachers, principals, parent/siblings, friends treat you? |
<p>| If someone was just told that they have a learning difference or learning disability, and they were going into high school, and they asked you what it was like to have a learning difference or learning disability in high school…what to expect…would you say to them? | |</p>
<table>
<thead>
<tr>
<th><strong>Appendix B. (Continued)</strong></th>
<th><strong>General Educational Information (about college)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>College/University Learning Spaces - Experiences</strong></td>
<td><strong>Probe: All at USF thus far?</strong></td>
</tr>
<tr>
<td>Where have you spent your college years?</td>
<td><strong>Probe: Did you go to more than one college?</strong></td>
</tr>
<tr>
<td>Think about what college has been like for you.</td>
<td><strong>Probe: How would you describe the specific colleges?</strong></td>
</tr>
<tr>
<td>How would you describe it?</td>
<td><strong>Probe: Where was it (were they) located? (Big city, town, rural area, suburbs?)</strong></td>
</tr>
<tr>
<td>Thinking about your experiences at USF, what is it like to go to college here?</td>
<td><strong>Probe: Can you tell me more about what it has been like for you? (Socially? Academically?)</strong></td>
</tr>
<tr>
<td>What kinds of people do you have classes with?</td>
<td><strong>Probe: What are the other students like in your classes?</strong></td>
</tr>
<tr>
<td>Have you taken classes at USF with other students who have learning differences or disabilities?</td>
<td><strong>Probe: Are the people you go to class with pretty similar to or different from each other? How?</strong></td>
</tr>
<tr>
<td><strong>Probe: Are they similar to you or different from you? How?</strong></td>
<td><strong>Probe: How do you feel about your peers?</strong></td>
</tr>
<tr>
<td><strong>Probe: Have you been in only some classes with other students with disabilities?</strong></td>
<td><strong>Probe: Have all of your classes had students with disabilities?</strong></td>
</tr>
</tbody>
</table>
In your college classes, have you ever been the only student with a learning difference or disability?

Have you ever been in a program or been in a class while you’ve been in college that was labeled or designated in any particular way by the kinds of students who are in it? (“inclusive,” “special education/needs,” “general,” “mainstream”)

- “inclusive” college classrooms (where students with disabilities and those without disabilities learn)?
- college programs or classrooms that were specifically designed for LD or differences?
- in mainstream college classrooms?

Did your experiences in these different kinds of learning spaces/classrooms differ?

What have your college/university teachers been like?

Probe: Can you tell me more about what it has been like for you here at USF? (Socially with other students, out of class? Academically, in class?)

Probe: If so, what was that like? If not, what was that like? Probe: Did only some classes? Probe: Did all of your classes? Probe: Were you the only student with a learning difference or disability? (What was it like to be the only one? What was it like to have other people around you who had learning differences or disabilities?)

Probe: What did the label or title mean, exactly? Probe: If not, do you think you would like to be in a program or class like that? Probe: If not, why not?

Probe: How does it feel to have your classes be labeled like that? Probe: Do you ever feel labeled? Probe: Can you tell me more about what that is like for you? (For your friends?) (For other students in or out of the class?) (Probe: What was it like?)

Probe: How?

Probe: Who has been your favorite? Why? Probe: What did that teacher do (or not do)
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How have your college teachers treated their students?</td>
<td></td>
</tr>
<tr>
<td>Have you ever come across a college teacher who did not treat all students the same?</td>
<td></td>
</tr>
<tr>
<td>What has been your favorite class in college/university and why?</td>
<td></td>
</tr>
<tr>
<td>What was your least favorite class in college and why?</td>
<td></td>
</tr>
<tr>
<td>Considering your experiences thus far in college, what do you think has been (or is) necessary for you to have the ideal learning atmosphere?</td>
<td>Thinking back to your experiences in college thus far…</td>
</tr>
</tbody>
</table>

**Appendix B. (Continued)**
Do you feel as though any other aspects of your identity may have influenced how you have been treated in college classroom spaces?

In general, how would you say it has been for you to have a learning difference or disability?

Do you feel that you know how and where to access any college accommodations that you might need? What might help you more or make it easier, less stigmatizing, etc. to do this if you needed to?

If someone was just diagnosed with a learning disability or had a learning difference, and they were going to start college this coming year, and they asked you what it was like to have a learning difference or learning disability and be in college…or what to expect…what would you say to them?

Probe: What has worked the best for you, specifically? (Environment, teaching/learning style, activities, studying spaces, etc.)

Probe: Bodily difference? Disability? Gender? Race?

Probe: How is your current experience (or recent college experience) different from or similar to your high school experiences with a LD or difference?

Probe: How have you felt you’ve been treated while you’ve been in college?

Probe: How have your peers, teachers, and parents, siblings, and friends treated you since you’ve been in college?
### Appendix B. (Continued)

**Your Personal Views about Learning Disabilities/Differences and Education**

1. In your opinion, how have your experiences having a learning difference or learning disability in **college/university** been different from, or similar to, your experiences having one in **high school**?

2. Has having a learning difference or learning disability impacted your experiences in different ways now that you are in college?

3. What do you think makes your **college learning environments** different from, or similar to, your past **high school learning environments**?

4. Do you think that the kind of learning atmospheres in which you have learned have influenced your experiences having a learning difference or learning disability?

5. Thinking about your own experiences in high school, how do you feel about:

   - Inclusionary education at the HS level?
   - Mainstreaming at the HS level?
   - Special Education” or “Special Needs” classrooms at the HS level? (Define these)

6. Thinking about your own experiences in college/university, how do you feel about:

   - Inclusionary education at the HS level?
   - Mainstreaming at the HS level?
   - Special Education” or “Special Needs” classrooms at the HS level? (Define these)

   Probe: Have there BEEN any differences that you can explain?

   Probe: If so, how?

   Probe: If so, how?

   Inclusionary education at the HS level?
   Mainstreaming at the HS level?
   Special Education” or “Special Needs” classrooms at the HS level? (Define these)

   Inclusionary education at the HS level?
   Mainstreaming at the HS level?
   Special Education” or “Special Needs” classrooms at the HS level? (Define these)

   Inclusionary education?
   Mainstreaming?
   Special Education/Needs?
<table>
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<tr>
<th><strong>Appendix B. (Continued)</strong></th>
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</table>
| (7) How might what you shared with me about your experiences with your peers and teachers (in HS and college) relate to how you feel about:
| |
| (8) |
| a.) Thinking about all of your experiences in HS and college/university, what particular things (teaching styles, types of assignments, approaches to instruction, etc.) have been the least helpful to you as a student with a learning disability or difference?
| |
| b.) What specific things (teaching styles, types of assignments, approaches to instruction, etc.) have been the most helpful to you as a student with a learning disability or difference?
| |
| (9) Can you think of any particular times when you’ve had to seek out special accommodations for yourself to get what you needed?
| |
| Probe: Why do you think they have been the least helpful to you?
| What do you mean by “helpful”? Do you mean to help you get the best grades? To gain study skills? To connect with your classmates better? To connect and better understand the course material better?
| |
| Probe: Why do you think they have been the most helpful to you?
| Probe: What strategies have you used?
| Probe: What was it like for you?
| |
| **Appendix B. (Continued)** |
| **Close the Interview** |
| (Add final guiding questions depending) |
| Do you have anything else you would like to talk about regarding learning differences and disabilities and education?
| Probe: Are there any other things you wanted to talk about that we might not have gotten to?
| |
| Is there anything relating to what we have talked about that you think I should be sure to write about in my thesis?
| Probe: Is there anything that you think I should know, or that you would like to share, before we close?
<p>|</p>
<table>
<thead>
<tr>
<th>What needs to be addressed? Why? How?</th>
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<tbody>
<tr>
<td>Please feel free to contact me…</td>
</tr>
<tr>
<td>If there is anything else you think of that you want to share but forgot to during our talk we can set up another time to meet and do this kind of thing again!</td>
</tr>
<tr>
<td>The plan is that I will…</td>
</tr>
<tr>
<td>Transcribe the audio-recordings and analyze what I recorded. These interviews are for me to be able to write my thesis.</td>
</tr>
<tr>
<td>Please feel free to email me if you would like to follow-up with anything at all or if you would like meet again to tie up any loose ends, add more reflections and accounts, and see what I have used the interviews to produce (transcriptions, analyses, drafts of my thesis, etc.).</td>
</tr>
<tr>
<td>ANONYMITY and CONFIDENTIALITY.</td>
</tr>
<tr>
<td>None of what you told me will be connected to their names in anything I produce (I will use fake names), and your confidentiality will be kept throughout the process.</td>
</tr>
<tr>
<td>THANK YOU + FOLLOWING-UP</td>
</tr>
<tr>
<td>Thank you, again, so much for helping me. It was a pleasure to have the chance to listen to what you wanted to share with me. Because of the nature of my project, it is a bit difficult to get participants. Would you mind putting me in contact with one other person who might be interested in talking to me about their experiences?</td>
</tr>
<tr>
<td>How would you feel about me contacting you for future research? Follow up questions, etc.</td>
</tr>
<tr>
<td>PLEASE KNOW THAT YOU CAN CONTACT ME AFTER THIS VIA EMAIL, SET UP ANOTHER INTERVIEW, ASK TO SEE TRANSCRIPTS AND DRAFTS AND THE FINAL THESIS, ETC. If you would be okay with me contacting you for future research, please give me any contact info (phone numbers, email addresses, mailing address if you would like to see drafts, transcripts, etc.)</td>
</tr>
</tbody>
</table>