LABELING HISTORIES:
MENTAL DISABILITY IN AMERICAN SCHOOLING

by

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ABSTRACT

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The purpose of the study is to examine the effect that dominant cultural schemas (norms) had on the educational outcomes and identity formation of students with mental disabilities. Through an examination of histories of psychology and public schooling in the United States, as well as oral history interviews with 7 participants, the research investigates how these cultural schemas have shifted over time and what role students with mental disabilities have played in reproducing or resisting schemas which marked them as deficient. Sewell’s (1992) theory of structure and agency, Disability Studies theory, and theories of labeling and intersectionality are utilized to analyze the identity formation of students with mental disabilities in light of those cultural schemas. By using a collage of narrative vignettes, leading to theoretical analysis, the practical implications of the above-mentioned theories upon the lives of people with mental disabilities are examined and discussed.
Table of Contents

Abstract iv

Chapter 1: Introduction 1
    Researcher Reflection and Positionality 1
    Terminology 4
    The Social Construction of (Mental) Disability 6
    Statement of the Problem 9
    Purpose of the Research 12
    Research Questions 14
    Potential Significance 15
    Outline of the Dissertation 16

Chapter 2: Literature Review & Theoretical Framework 17
    Introduction 17
    Structure, Power, & Agency 18
    Medical Model of Disability 20
    The Disability System 25
    The Power of Labels 30
    Intersectionality 33
    Example of Emotional Disturbance 35
    Conclusion 38
Chapter 3: Methodology

Introduction
Description of Conceptual Framework
Revisiting the Research Questions
Labeling Histories
Research Relationship
Setting & Participant Selection
Data Collection
Data Analysis
Validity or Trustworthiness
Strengths & Limitations
Conclusion

Chapter 4: Historical Background

Introduction
Origins of Psychology and Psychiatry
Origins of Public Education in the United States
Origins of Special Education
The Influence of Psychology on Public Education
The Nature versus Nurture Debate in Psychiatry
Returning to the World of Education
Psychiatric Survivors & Mad Pride
Conclusion
Chapter 5: Performing “Good”

Successfully Performing the Role of Good Student

Unsuccessfully Performing the Role of Good Student

Performing the Role of Good Patient

Chapter 6: Adopting New Cultural Schemas

Difficulty Accepting Labels

The Process of Self-Reflection

Mental Disability as a Difference and/or Strength

Teachers Informing New Schemas

Conclusion

Chapter 7: Implications and Conclusions

Revisiting Labeling Theory

Revisiting the Social Model of Disability

Revisiting Intersectionality Theory

Implications of the Study for Teacher Education & Classrooms

Schemas of Mental Disability in Teacher Education

& Pedagogy of Discomfort

Pedagogy of Caring & Universal Design for Learning

Revisiting Limitations

Conclusion

References
List of Figures

Figure 1: Comparing Medical and Social Models of Disability  56
Figure 2: Labeling Theory and Intersectionality  57
Figure 3: Organizational Coding  60
Figure 4: Theoretical Coding  61
CHAPTER 1: INTRODUCTION

Researcher Reflection and Positionality

Nelson was one of the more memorable students I taught as a middle school special educator. A few weeks into one school year, Nelson was moved from a self-contained special education class of twelve students into my integrated special/general education class of 35 students. He was, without question, one of the brightest people I have ever met. He could answer any question I posed and was quick with a joke. His jokes often came at inappropriate times, however, and he regularly argued with teachers and classmates. Not long after his transition into my class, his mother was asked by another teacher to come to school and discuss Nelson’s progress in the new setting. It was the opinion of that teacher that Nelson did not “belong” in the integrated class and that his presence was a distraction to other students.

As I walked to the meeting with Nelson’s mother (a meeting that would consist of four or five teachers, a school administrator, her, and Nelson), I ran into one of Nelson’s former teachers in the hallway. When he learned where I was headed, he informed me that Nelson’s mother was “bipolar” and that Nelson was probably bipolar too. With that word he dismissed Nelson’s mother as a meaningful contributor in the conversation about her son’s well being and dismissed Nelson as a serious student. He also conveyed the vague sense that the two of them posed a threat.

That brief conversation in the hallway stayed with me because of my own history with mental disability. Almost ten years ago, I was given the diagnosis of Bipolar Disorder I, or what the facilitator of a support group I once attended referred to as “the scary kind” of bipolar. In that setting, such a description earned me looks of sympathy, although I no longer felt supported. In other contexts, I have had my intelligence, rationality, and abilities doubted because of my
diagnosis. A few people have broken off burgeoning friendships with me because of that label. Others have admitted feelings of fear and pity.

My own understanding of what that label means has shifted in dramatic ways since it was given to me, in working as a teacher of children labeled with various disabilities and by being introduced to the work of Disability Studies scholars through the PhD program at the CUNY Graduate Center. For many years, I believed that my diagnosis indicated a fundamental flaw in me. This is hardly surprising given the deficit view of disability that is common in American society. I took my understanding of people with mental disabilities from the media, where as a group we are more often than not portrayed as violent, unpredictable, and antisocial. It was a long time before I could reconcile those implications of the label with my view of myself. More tragically, I carried my original assumptions about the nature of mental disability into my job as a special educator. These negative beliefs went mostly unquestioned in my pre-service coursework and were further reinforced by the attitudes of many of the people I worked with. Harmful discourses about disability are pervasive in our culture and even as a person with a disability, it was difficult to escape their influence.

In his book, *Bending Over Backwards: Disability, Dismodernism, & Other Difficult Positions*, Davis speaks candidly about his personal history as a child of working class and deaf parents. He writes that it is a pleasure to not have to “flee from my working class self and my deaf self; that the very issues of my upbringing – the Bronx, deafness, class position – are capacious enough for me to make my work” (2002, p. 163). My work as a special education teacher and my personal experience of mental disability are where I hope to make my work. As a person with a disability, I seek to advocate for others (especially children) in a similar position and as an academic I have the great opportunity to tell their stories through my work, stories that
have historically been overlooked. That said, I approach this project from the place of a disabled person but also from the knowledge that I was (and am) a contributor to the system that disables.

I am white, with a middle class upbringing, and my mother was a special education teacher and later a school administrator. She knew how to work within the system and advocate on my behalf, which is likely why I was never labeled as a child. When I later worked as a teacher in a school where the students were predominately Black and Latino, in one of the poorest Congressional districts in the country (in the Bronx), I saw how children were placed in to special education often as a means of controlling their behavior and isolating them from the “good” students. Many of my special education students had suffered trauma, or were in foster homes, or were first generation immigrants (or a combination thereof), or had any number of other life experiences that could explain the behaviors that led to them being labeled with mental and emotional disabilities. I do not now remember the label that Nelson had been given, but it is almost irrelevant. He was a child who did not operate within the boundaries of what was considered “normal” student behavior and his teachers spent as much time trying to decide where he belonged as they did trying to figure out how to engage him.

Generally, the outcomes for special education students in New York City are not encouraging. By means of illustration, the official high school graduation rate for students in the city was 60.7 percent in 2008. However, only 22.5 percent of special education students graduated that year (New York City Department of Education, 2009). Although there have been special classes available to (at least some) students with disabilities in New York City since the late 1800s, it is clear that these children are still not being well served by the educational system. Indeed, as will be discussed, special education labels, especially labels that might signify mental disability (Learning Disabled, Emotional Disturbance, Intellectual Disability) have been utilized
throughout history not to help students with disabilities, but rather to separate students deemed abnormal on the basis of not only their ability, but also their class, race, and gender (Reid & Knight, 2006).

It is not comfortable to think that the some of the most vulnerable of our citizens, our children, have not been well treated by our public schools. Winfield discusses the need for introspection among historians, stating that “investigators who work with, and accept, their emotional reactions to the artifacts with which they work have a unique opportunity to reveal the shared cultural knowledge that originally went into their production” (2007, p. 43). I believe that my experiences as both a disabled person and a former special education teacher make me uniquely suited to examine the “shared cultural knowledge” that has led to the labeling of children with mental disabilities over the history of public schooling in New York City and the treatment that they received as a result of those labels. It is my hope that studying this history will inform education policy and practice in the present and help to create better outcomes for students with disabilities.

**Terminology**

In this study, I focus on mental disabilities and have chosen to use the term “mental disability” as opposed to “mental illness” or “cognitive disability” for several reasons, some of which are described by Price in her book *Mad at School: Rhetorics of Mental Disability and Academic Life* (2011). Price discusses the dynamism of terminology and the need for flexibility when using labels to describe particular groups of people, as well as the necessity of choosing the most inclusive or least limiting terminology to describe groups. As stated by Dajani, “labels play an important role in defining groups and individuals who belong to those groups” (2001, p. 199). For this reason, “mental disability” is preferable to “mental illness”, which as a concept
employs the medical model that seeks to regulate the mind, implying that people who are mad are perpetually sick and waiting to be cured, when this is not in fact the case. In addition, it is important to note that the term “mental disabilities” is inclusive. It can indicate a wide range of disabilities, not only psychiatric disorders, but also cognitive disabilities, emotional disturbance (ED) and autism, which also challenge commonly held ideas about the rational mind. It also can encompass many historical labels that indicate cognitive or psychological disability, such as the category of feeblemindedness.

In addition to the term “mental disability”, I occasionally use the terms “mad/madness” to describe those with mental disabilities, because as Price says, “this term achieves a flexibility that mental illness and cognitive disability do not: it unites notions of that ‘central concept’ through time and across cultures. As with queer, the broad scope of mad carries the drawback of generality but also the power of mass” (2011, p. 10). Both “mental disability” and “mad” are inclusive terms and also do not imply any lack of agency for the individual or group described. For these reasons I will use both “mental disability” and “mad/madness” throughout this study.

Other terms may be utilized throughout to describe particular people or instances (“feeblemindedness”, as mentioned, also “deviant”, “lunatic”, “backwards”, “naughty”, etc.) (Winzer, 1993). It should be noted that terms other than “mental disability” and “madness” (or forms of those) are historically rooted and are used in order to be true to the historical record.

Mental disability is not one illness or even a range of impairments. It is a shifting and porous concept that can morph over time. Labels can change and overlap and can be given in an official capacity or used in an unofficial manner. The participants of this study were given labels by medical professionals and/or teachers and/or self-prescribed their own labels. Labels of mental disability can be transient or life-long. For the purpose of this study, mental disability is
broadly defined as to be inclusive of all of the categories in which the participants place themselves.

**The Social Construction of (Mental) Disability**

Seeing disability from a medical standpoint – i.e. that it is a deficit or defect of the individual – ignores the social barriers in place that prevent disabled people from full participation in society. From a social standpoint, it is these social barriers (discrimination, stigma, segregation, etc.) that disable people with impairments, rather than the impairments themselves (Linton, 1998a; Hamre, Oyler & Bejoian, 2006). Disability is not an inherent trait of the individual, but rather stems from a social construction of what is “normal” and what is “abnormal”. Davis argues that “the disabled body is not a discrete object but rather a set of social relations” (1995, p. 11). I would assert that the same could be said of the disabled mind.

Biklen suggests that it is necessary to look beyond a “static understanding of disability” such as is found in literature and media, where impairment is the defining characteristic of the individual, fixed and permanent, and something to be feared and/or pitied (2000, p. 338). Looking beyond a “static understanding” involves two assumptions. First, that what constitutes disability is ever changing and second, that the effects of impairment on the individual are not fixed and are dependent on social context.

The history of the special education label of Learning Disabled (LD) illustrates these ideas. A Learning Disability could be considered a mental disability in that it is not an obvious physical impairment but rather attempts to explain “abnormal” mental phenomena. Sleeter (1996) traces the history of the LD label to show the transition over time in how the label has been used. Originally conceived of as a way to give additional supports to children who were otherwise “normal” (based on IQ testing), in the 1950s and 60s, the label was predominately
used as a way of differentiating children who were failing based on seemingly biological causes (which resulted in mainly white, middle class children being given the label) and those who were failing because of environmental factors (mostly poor and minority students, who were given other labels to explain their failure – slow learners, mentally retarded, emotionally disturbed, culturally deprived) (Sleeter, 1996). It is important to mention that, at the time, white children scored, on average, 15 points higher on IQ tests than children of color. Over time and due to pressure from minority groups, the IQ scores used to classify children as learning disabled versus mentally retarded were changed and more minority students were placed in classes for LD students (Sleeter, 1996).

This example illustrates both the fact that disability is not fixed (there was not even a label of LD before the 1950s) and that both the process of labeling and the effects of labeling are based on social context. The definition of a “normal” child is based on policy decisions, potentially biased assessment, social power structures, and interpersonal relationships, to name a few (Sleeter, 1996). Once labeled, a child is then defined as disabled and faces a society in which people with disabilities are not valued.

Impairment, whether mental or physical, is used as an excuse to disable. As Davis says, “the ‘normal’ people have constructed the world physically and cognitively to reward those with like abilities and handicap those with unlike abilities” (1995, p. 10). The reality of lived experience may be much the same for people with physical and mental disabilities, but it is worth making a distinction between the two categories, ironically because of the improved ability of the medical community to name physical impairments that has occurred since mental disabilities were medicalized. Today, it is more common for mental disabilities to be mislabeled than physical ones because the indicators of mental disability are not, in fact, objectively
measurable. A diagnosis of mental disability depends heavily on clinical judgment, which allows for the possibility that factors such as racism or poverty will influence the labeling of people with these disabilities (Biklen, 1988). This is not to say that a similar process does not happen to people with physical disabilities, but it does not happen as often - particularly in schools. Children of color are disproportionately likely to be placed in special education compared to their white peers and the disability categories they are labeled with usually fall under the umbrella of mental disability instead of physical disability – Emotional Disturbance, Learning Disability, Mental Retardation/Intellectual Disability (Harry & Klingner, 2006).

Because there is significant room for error in the labeling of these types of disabilities does not mean that there is more stigma or discrimination attached to them than to physical disabilities. It only means that, by the nature of their malleable definitions, the weight of mental disability, and therefore the stigma attached to all disability, can be unleashed not only on those with obvious impairments but also other disenfranchised people.

Our conclusion is that disability is socially constructed rather than a defining biological characteristic of the individual. It is, thus, most useful for us to consider disability as a category of identity (but not the sole defining marker of the person). To that end, I will be using person-first language throughout this paper– i.e. “a person with a disability” versus “disabled person” – in order to maintain the individuality of the people mentioned and not define them by their disability. I will use “disabled person” or similar language only when speaking of the “object created by abelist society”, not an individual human being, but rather the entity constructed by the economic, medical, political, and social policies of disablement (Davis, 1995, p. xiii).
Statement of the Problem

“The patient-citizen, governed by the norm of representation and by the hegemony of normalcy, passes in one lifetime through a series of institutions – day care, primary, secondary, and higher education facilities, corporate employment, managed care, hospitals, marriage and family, and finally nursing homes – all of which are based around legal, juridical, medical, and cultural normalizing concepts” (Davis, 2002, p. 116).

Mental disability is a shifting, porous concept, dependent on definitions of able-mindedness which are rooted in classist, racist, and sexist assumptions (Scheff, 2009). And yet, mental disability is used as reason enough to exclude children from regular schools or general education settings, even to keep them from schooling altogether (Fleishner & Zames, 2011). Let us examine a particular disability category as an example of this phenomenon. The disability label of Emotional Disturbance (ED) certainly fits under the umbrella of mental disability. The definition of ED, as stated in the Individuals with Disabilities Education Act, paints a picture of an irrational child, one who is not able to confine him/herself to behaviors that are appropriate for school and thus failing to thrive in an intellectual climate. The definition of ED is as follows:

   Emotional disturbance means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:

   a. An inability to learn that cannot be explained by intellectual, sensory, or health factors.

   b. An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
c. Inappropriate types of behavior or feelings under normal circumstances.

d. A general pervasive mood of unhappiness or depression.

e. A tendency to develop physical symptoms or fears associated with personal or school problems. (IDEA, 2004)

This definition is problematic in a number of ways. For example, who decides what are “inappropriate types of behavior”? It becomes even clearer that the labeling of children with disability is influenced by social factors when we consider the following statistics. In schools, it is much more common for boys, especially boys of color, to be labeled with ED than it is for girls or whites (Reddy, 2001). Girls are, in fact, underrepresented in the population of children with ED. About one-third of children labeled with ED come from families living below the poverty line and these children are also disproportionately more likely to live with only one parent (Reddy, 2001). Black and Latino boys are, as indicated above, disproportionately given this label and other disability labels falling under the context of mental disability (Harry & Klingner, 2006). And so we again see that social, cultural, political, and economic factors come into play in the labeling process. Indeed, they also factor into the classroom. In practice, children labeled with ED in the urban districts studied by Losen and Orfield (2002) were more often placed in restricted settings (examples include Philadelphia – 98.7 percent, and Baltimore – 96.63 percent) than the national average (82.0 percent). Children labeled with ED were at least 32 percentage points more likely to be excluded from school by suspension or expulsion than their peers, even their peers labeled with other types of disabilities. In fact 73 percent of students labeled with ED had been suspended at some point during their school career according to one study (SRI International, 2006; U.S. Department of Education, 2005).
It becomes apparent from the example of ED that much more than mental impairment is involved in the labeling of a child with a mental disability and the subsequent treatment that they receive. Issues of race, class, and gender come into play. The issue at hand is that labeling is not benign, especially when there is so much room for interpretation in the giving of that label. A label brings with it the weight of the dominant discourse around mental disability, legitimizing stigma and diminished personal agency. Labels of mental disability can be used, and indeed have been used historically, to keep certain children from full participation in public schooling (Reid & Knight, 2006).

Several researchers have written about the history of special education labels, for example Danforth’s book on learning disabilities, The Incomplete Child: An Intellectual History of Learning Disabilities (2009) and Franklin’s From “Backwards” to “At-Risk”: Childhood Learning Difficulties and the Contradictions of School Reform (1994). In addition there has been research done on the history of special education (Osgood, 2008; Winzer, 2002) and histories of the role that psychology has played in the development of teaching and learning in public schools (Giordino, 2005; Lagemann, 2000). Also, researchers have written about the intersections of race, class, gender and special education in the present (Harry & Klingner, 2006; Losen & Orfield, 2002) and Winfield discusses intersections of race, class, and gender in education generally in her book Eugenics & Education in America: Institutionalized Racism and the Implications of History, Ideology, and Memory (2007). All of this research is important, serving as critical accounts of the impact of disability and/or race, class, and gender on the education of children. These studies were all written from an institutional standpoint, however, examining the process of labeling from the point of view of schools, psychologists, teachers, and policy makers. Very little historical research has been done including the voices of people with
mental disabilities. The goal of my own research is to investigate the process of labeling people with mental disabilities from both an institutional and individual standpoint. In this study, I examine the intersection of the histories of the field of psychology and public schooling and I include the voices of people labeled with mental disabilities in order to recognize their point of view and their experience of the process.

**Purpose of Research**

The ultimate goal of this research is to further develop and refine social theories of disability, labeling, and intersectionality, especially as these theories help us to understand the identity formation of and actions taken by people with mental disabilities. I undertook an analysis of disability in history and in the lives of people with disabilities that does more than seek to describe the lives of people who are not often given voice. Although that is a worthy goal, I also wanted this study to contribute “to the emancipation and liberation of the disabled individual” (Verstraete, 2007, p. 57). In other words, the type of analysis is a form of activist scholarship with a goal of influencing policy and practice in schools. The social meaning of disability, its power to validate oppression, has implications for all people and all social institutions, but perhaps most poignantly it should be recognized that “interpretations made about some people’s differences holds direct and profound implications for how they are educated in our public schools” (Baglieri, Valle, Connor, & Gallagher, 2010, p. 271). It is the process of interpretation of difference that I aimed to document and critique.

It may be argued that public schools in this country have come a long way since their inception toward equitable education of all students. However, as Bredburg (1999) argues, the institutional history of disability is not one of unabated progress. Public schools, as social institutions, are no exception to this fact. The labels and language of disability (and mental
disability in particular) have been used in public schools to oppress and exclude certain children throughout their lives and, as mentioned earlier, continue to do so (for example, by segregating students into separate classes or suspending students with disabilities at a higher rate than their peers). The institutional histories of public schooling and of special education have been written by many historians, including several who examined ways in which disability labels have been used to separate and marginalize children. As one example, Ferri and Connor (2005a) make the argument that special education classrooms have been effectively used as a way to continue the segregation of minority students, despite such separation having been declared unlawful in the U.S. Supreme Court’s Brown v Board of Education decision of 1964. The authors show that students who did not assimilate during the process of desegregation were re-segregated into special education classrooms. These institutional histories are invaluable in adding to our understanding of how students with disabilities have been educated throughout history. I aimed to supplement these institutional histories by examining lived experiences of children affected.

The oppression of children by the institutions of public schooling will continue if the dominant discourse of disability marks children thus labeled as less than full citizens. It is, therefore, imperative that we recognize the ways in which we are disabling children in our schools. As Barton remarks, “any attempts fundamentally to change the existing conditions [of special education] will necessitate an engagement with issues of equality, politics, power and control, in which forms of discrimination will need to be identified, challenged, and changed” (1997, p. 232). My research focuses on identifying the ways that oppressive discourses of mental disability are reproduced and resisted by schools and by people with mental disabilities and how these discourses have affected the lives of those people.
The process by which decisions are made about student labeling and placement is often based on ableist assumptions about the worth and capacity of particular children and without the input of the children themselves. There must be more equitable ways to make decisions about special education services, ways that allow students more agency in the process. We need a diversity model of mental disability that sees mental impairment as a natural part of human life. In her article, *Disability History: Why We Need Another ‘Other’*, Disability Studies scholar Kudlick asks the questions, “what does it mean to be human? How can we respond ethically to difference? What is the value of a human life? Who decides these questions, and what do the answers reveal?” (2003, p. 764). These are the questions that disability history seeks to answer. They are questions not only about impairment but also about the nature of how we, as a society, treat all of our members.

**Research Questions**

My intention in this research was to examine in depth histories of psychology and public schooling in order to draw out dominant cultural schemas used to inform the education of children with mental disabilities, as well as to explore the narratives of people with disabilities and their schooling experiences. My research questions were as follows:

1. How has mental disability been defined from the inception of public schooling in the United States and how have dominant cultural schemas of mental disability been used in schools and education policy making?

2. What do personal narratives told by people categorized as mentally disabled reveal about their experiences of public schooling?

   a. In what ways do these narratives reproduce and/or resist dominant cultural schemas about mental disability?
b. What personalized understandings are revealed through the narratives and how do they reframe how we think about mental disability?

Potential Significance

History informs our understanding of and actions in the present. The goal of this research was not merely to create a historical record and highlight the voices of students with mental disabilities, but also to inform research and policy in education. According to Fairclough, the power of people who control policy depends on discourse (2010). Discourse is used to help maintain the status quo and a critical examination of discourse can reveal many of the assumptions and ideologies that policy is built on. This process of unveiling underlying ideologies can then have the effect of transformation (Fairclough, 2010). My goal in conducting this research was to examine not only past stories of education and mental disability, but also to reveal the underlying assumptions and ideologies of American culture that allowed (and allow) for students labeled with these disabilities to be discriminated against and excluded, what Sewell (1992) calls cultural schemas (which will be discussed in the next chapter).

According to Smith in her book *Political Spectacle and the Fate of American Schools*, “education policies reflect the politics of the times and illustrate, at any particular time and place, which groups have more power to influence the state in its allocation of values” (2004, p. 8). In this study, historical analysis illustrates the ways in which American conception of mental disability has influenced policy decisions in public schools. At the same time, the examination of narratives from students sheds light on the effectiveness of those policies and reveals their shortcomings in order to inform policy makers and researchers in the future. Smith argues that much of recent educational policy making has been political spectacle, and has more symbolic than tangible effect on the lives of students (2004). Critical historical investigation uncovers
whether this has indeed been the case over time and also divulges some potentially effective policy making for students with mental disabilities, based on their words and their experiences.

In addition to providing information for policy makers, this study was aimed at informing future research. The goal of the inquiry was to refine theories of Disability Studies, labeling, and intersectionality in the hopes that an examination of these theories in practice would shed light on their validity for people with mental disabilities.

**Outline of the Dissertation**

In Chapter 2, I present a theoretical framework based on Sewell’s (1992) theory of structure and agency. I examine the medical model of disability as an example of what Sewell calls “cultural schema” (1992, p. 13). I then review literature in Disability Studies, labeling theory, and intersectionality theory to build a framework for viewing how cultural schemas have affected the agency of students with disabilities and how those students have expressed their agency. In Chapter 3, I provide an overview of the methodological framework for the study, which used analysis of secondary sources and interviews to investigate institutional and individual experiences of the cultural schemas that have affected people with mental disabilities in schools. Chapter 4 is historical background, which draws out the dominant schemas that have been used in American culture and in schools to describe and explain mental disability. In Chapter 5, I examine how the seven study participants reproduced dominant cultural schemas of mental disability through their varying success in acting as the “good student” and/or “good patient”. Chapter 6 is a discussion of the ways in which participants resisted dominant cultural schemas of mental disability and were able to adopt new, more positive schemas to describe their experience. Finally, Chapter 7 includes findings and implications of the study for theory and practice.
CHAPTER 2: LITERATURE REVIEW & THEORETICAL FRAMEWORK

Introduction

Chapter 2 begins with a description of Sewell’s theory of structure and agency and an explanation of how power is enacted within that system, with emphasis on the function of cultural schemas. I then offer a brief historical account of the development of the medical model of disability in American culture (focused on mental disabilities) as an example of a cultural schema in practice. Next, I review literature that frames disability as a means for the reproduction of societal structures, further demonstrating the ability/disability system as a cultural schema. Finally, I discuss the agency of people with disabilities. This includes Sewell’s critique of Bourdieu’s habitus as an explanation for why agents act outside their own interests and the introduction of labeling theory (as an example of Gramsci’s theory of hegemony) as a potential alternative. Finally, I will examine the complexities of the reproduction of structures and resistance to them through a review of literature in intersectionality.

It will be useful, in our further discussion of disability as a system of oppression rather than a deficit of the individual, to think about definitions of structure and agency so that we might examine how structures of inequality are produced and reproduced and what the role is of individuals (and especially individuals with disabilities) in this process. I shall approach this discussion using the work of social historian William H. Sewell, Jr. as a guide. Sewell grounds his argument in the idea that structure and agency are dualistic concepts, in that while structures are “mutually sustaining cultural schemas and sets of resources that empower and constrain social action and tend to be reproduced by that action”, agents can mobilize resources and enact schemas, and “even the more or less perfect reproduction of structures is a profoundly temporal process that requires resourceful and innovative human conduct” (1992, p. 27). In other words,
structures influence the actions of individuals, leading to their reproduction, but individuals also have the power to change structures because of their knowledge of the schemas and resources that comprise those structures. Disability Studies theorists have worked in the last two decades to unmask the particular ways in which structure serves to separate and oppress people labeled with disabilities, critiquing what is commonly held to be true about the natural deficiency of people with disabilities (known as the medical model) in order to theorize an “ability/disability system” or “social model” of disability that illuminates the processes by which cultural schemas and resources marginalize disabled people (Garland-Thomson, 2002, p. 2; Linton, 1998a). In this chapter, I will discuss both the construction of cultural schemas around disability and also individual action in response to those schemas. The ultimate goal of this research project was to investigate both how cultural schemas work within schools to disable particular people and how individual agents reproduce or resist these schemas.

Structure, Power, and Agency

In Disability Studies theory, disability is viewed as a social construct, a means by which certain people are marginalized on the basis of physical or mental impairment (Linton, 1998a). As mentioned before, these theorists critique our deficit-laden cultural ideas about disability, which make it seem natural that people with disabilities are more likely to be unemployed and live in poverty than those without disabilities (despite the fact that most are of working age and desire employment) or that they are less likely to graduate high school (American Psychological Association, 2014). These factors seem to be a natural consequence of impairment to many, rather than an indication of cultural models or ideas in place that negatively affect the lives of people with disabilities.
The concept of structure has been theorized many times (particularly in the field of anthropology, in its relationship to culture) in order to explain how inequitable systems of resource distribution are reproduced over time through not only the exercise of power by elites, but also the actions of individuals affected by those structures. The flaw in many theories about structure has been their deterministic nature, where individual agents act in a way that is all but scripted by the structures in which they play a part. And yet, social change does happen. Sewell theorizes a relationship between structure and agency that both accounts for the reproduction of oppressive structures and also allows for the possibility of change based on individual agency. It is with this theory that we are now concerned.

For Sewell, the relationship between structure and agency is one in which the two “presuppose” each other (Sewell, 1992, p. 4). Structures influence the action of individuals but that action also has the possibility to uphold or tear down existing structures. This is not to suggest that all agents have equal power. According to Sewell, “structures, in short, empower agents differentially, which also implies that they embody the desires, intentions, and knowledge of agents differently as well. Structures, and the human agencies they endow, are laden with differences in power” (Sewell, 1992, p. 21). Structures are thus maintained through the exercise of power, and some agents have more than others, but Sewell also believes that all people within those structures have some ability to change them because of their knowledge about the way those structures work.

Sewell defines structure as consisting of two parts – cultural schemas and resources, which “mutually imply and sustain each other over time” (1992, p. 13). Resources are physical entities – factories, weapons, currency – or what Sewell calls “actual” (1992, p. 13). Schemas are the cultural reasonings that give those resources their power, but are also reproduced and
made powerful in their own right through the accumulation and use of those resources. Schemas are “virtual” (Sewell, 1992, p. 13). Thus, structures can only continue to exist if the relationship between cultural schemas and resources is maintained and reinforced.

Public schools would be considered resources in this theory, and I would argue that ideas about success and failure, proper placement, and appropriate school behavior are cultural schemas that exist within schools which lead to the exclusion of children with mental disabilities and the maintenance of structures in which people with mental disabilities have little power. McDermott and Varenne (1995) have documented that “school has become a primary site for the reproduction of inequality in access to resources” (p. 339), a conclusion shared by other social-justice oriented scholars such as Anyon (1981) and Apple (2013). I wish to argue that schools also reproduce cultural schemas that normalize the idea that some people have more right to those resources than others. One example of this might be the medical model of disability, which is a deficit model that has been used to justify the labeling and exclusion from school of children with physical and mental impairments, but also children from minority backgrounds and those who are poor (Reid & Knight, 2006). To give an example of this cultural schema in practice, I will begin with a brief historical account of how the medical model of disability was introduced to American culture and schools.

**Medical Model of Disability**

Before the late eighteenth century, mental disability was not medicalized in the way that it is today. Instead, people with mental disabilities were considered lazy, criminal, or possessed by demons. In the book *A Mad People’s History of Madness*, there is the example of George Trosse, a Presbyterian minister who himself believed, in 1714, that his madness was in part possession by the devil and in part the fault of his sinful lifestyle (Peterson, 1982). Foucault, in
his historical work on madness, stated that, “it is not immaterial that madmen were included in
the proscription of idleness. From its origin, they would have their place beside the poor,
deserving or not, and the idle, voluntary or not” (Foucault, 1988, p. 58). Whether lazy or
possessed by the devil, madness was considered the fault of the person experiencing it. It was not
until Enlightenment philosophies began to influence medicine and science that mental
disabilities were transformed from idleness to disease (Winzer, 1993).

During the period from the late 18th century until the middle of the 19th century, there was
an enormous shift in the importance of medicine and science in Western culture, including its
influence on the life of the mind. Empirical, scientific research was considered to be the gold
standard of knowledge creation (Alexander & Selesnick, 1966). This required a change in
thinking among medical professionals. What had been considered the soul (and thus subject to
the laws of the church) was now conceived of as the mind or personality and subject to the same
laws of medicine as the rest of the body. Psychotherapy began in a crude form in the beginning
of the 19th century with a publication by Johann Christian Reil, who recognized a mind/body
connection and believed that a study of the mind could be a tool by which doctors could
diagnose not only mental, but also bodily diseases (Alexander & Selesnick, 1966). Reil also
posited that distinguishing an atypical personality required the definition of normal personality, a
theory that would become essential to abnormal psychology and still profoundly influences the
way we think about mental disability and mental wellness today. Reil stressed at the time,
however, that the field of psychology should not merely consist of making decisions about what
is normal behavior but rather be treated as a tool to treat both mental and physical diseases. In
1803, Reil published a piece called Rhapsodien uher die Anwendung der psychischen
Curmethode auf Geisteszerruttungen – Rhapsodies about the Application of Psychotherapy to
Mental Disturbances – which was indicative of a cultural shift away from conceptualizing mental disabilities as criminality and towards the medicalization of those disabilities (Alexander & Selesnick, 1966).

The idea that Reil put forth about the importance of defining a normal personality became an important goal of the new field of psychology. As Winzer says in her history of special education, that in “the middle of the nineteenth century there appeared in all branches of science, and especially in medicine, a growing demand for greater precision and accuracy, which ultimately translated into more cogent definitions and classifications for exceptional conditions” (1993, p. 146). This process was true for all of medicine and affected people with all types of impairments. For mental disabilities, it meant trying to define the limits of rationality and irrationality, sanity and insanity. It meant identifying the traits of the normal human mind. In schools, this translated into measuring intelligence and identifying normal behavior.

Charles Darwin published The Origin of the Species in November 1859 and ten years later his half-cousin, Francis Galton, applied Darwin’s ideas to human behavior in his book, Hereditary Genius. Where Enlightenment philosophies of the 18th century had prompted the use of the scientific method for studying human behavior and society, Galton’s work took a step toward applying ideas of evolution and heredity to human intelligence. It would not be long before assessments were developed to measure human intelligence and aptitude and thus, in theory, objectively classify people as normal and abnormal. This led to the question of what to do with people who deviated from the norm. Measurement itself perhaps could have been a useful tool, but with it came hierarchical placement in schools and the shadow of biological determinism. Alfred Binet himself, father of the IQ test, argued against innatist interpretations of his assessment schema, preferring that it was used to identify children who needed extra help,
not to deem some unteachable. But ultimately that is what happened and students who fell below the average on these measurements were segregated from regular schooling (Gould, 1996). Psychological measurement became a tool by which certain children were kept out of school and sometimes placed in institutional settings. But even in those establishments, not all “abnormal” children were welcomed. Samuel Gridley Howe said about his experimental school for the feebleminded in Massachusetts, founded in 1848 as the first of its kind, that “the institution is not intended for epileptic or insane children”, among others (quoted by Winzer, 1993, p. 147). Even under the umbrella of mental disability, there were hierarchies.

Advances in psychology during 19th century not only affected the medical and scientific realms; their effects were also seen in philosophy, art, and literature. Authors like Hendrick Ibsen, and Fyodor Dostoyevsky1 wrote about characters with psychological and cognitive issues, and even mental disabilities (Alexander & Selesnick, 1966). Art and science thus came together to shape the ways in which disabilities, and mental disabilities in particular, were conceived of by the public. The picture was harmful for those labeled with these types of disabilities but it had far-reaching affects.

Medicalized thinking took root in schools. In order for there to be an “abnormal” child – a child labeled with some sort of mental disability, what is “normal” need be defined. Educational psychology has, in the last hundred years, been focused on this. As Dudley-Marling and Gurn suggest in their book *The Myth of the Normal Curve*, “a large part of the problem is that the field of education has a long history of commitment to a vision of teaching and learning

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1 Dostoyevsky wrote *Crime and Punishment* and *The Idiot*, both of which deal with the intellectual capabilities and psychology of their main characters. Ibsen’s plays (*Hedda Gabler*, *The Master Builder*, and *A Doll’s House*) contain characters who experience psychological conflict due to rigid social structures.

2 Mental disability as a threat has multiple meanings. Those labeled or potentially labeled with
based on the assumption that intelligence and many of other human characteristics are distributed along the ‘normal curve’” (2010, p. 107). They refer to the fact that scientific (and especially psychological) research and testing in education is founded on the idea that ‘normal’ human behavior should fall along the Bell curve or normal distribution curve. This means that while the majority of students will perform within average ranges, some will necessarily fall along the edges of the curve. It is with these students that we are concerned.

The idea that some students fall within the range of average and some do not seem like common sense to educators today, but we can see that this idea is socially constructed if we examine the normal curve in more depth. Originally called an “error curve” by Adolphe Quetelet (a mathematician), outliers at both ends of the spectrum, that is whatever deviated from the average, were considered to be errors. It was Francis Galton who succeeded in “reconceptualizing the error curve as a continuous normal distribution (and probable errors into standard deviations) so that desirable – that is, above average – people were not viewed as errors” (Dudley-Marling & Gurn, 2010, p. 31). People who fell below the average, however, were pathologized. This statistical tool became an instrument for eugenicists, who wished to eliminate those outliers, and also became an integral part of educational testing and ideologies of schooling and remains so to this day. The issue is not that some students perform well on these assessments while others do not, but rather that human behavior is not random.

Ideas about normal and abnormal and mental disability versus the average personality might be seen to constitute a cultural schema in Sewell’s theory. Certainly, medicalized concepts of what is a normal, and therefore desirable, human being have had extensive influence as we see from the example of educational testing. In order for Sewell’s theory to apply, the cultural schema of the medical model would then have to be used to maintain existing structural
inequalities through unbalanced distribution of resources. This is what this study was meant to demonstrate, but if we again look at history, we can see the beginnings of proof of this hypothesis. The disproportionate number of children from racial and ethnic minority backgrounds that we see being placed in special education echoes the period after Brown v Board of Education when schools placed minority children in special education to maintain a type of segregation (Ferri & Connor, 2005a; Ferri & Connor, 2005b). Indeed, in the present, children with mental disability labels (like ED) are more likely to be placed in separate settings and schools. We know that they are also more likely to be of minority background and poor (Reddy, 2001). It seems, thus, that the cultural schema of the medical model affects resource distribution in schools but it also seems that the medical model is used to uphold inequalities other than those based on ability and disability. Indeed, Sewell discusses the need to see society and structures as “multiple, contingent, and fractured” in order to understand the effect that various schema and resources have on agency, but also to understand why and how change is possible (1992, p. 16).

Theorists of disability have tackled this complexity of society and the idea that individuals are disabled in many ways, not only because of impairment. Disability is thus seen not as a problem with the individual but as a systemic means by which unequal structures are reproduced, as I have argued. Let us now examine Disability Studies literature and how it has conceptualized medical and social models of disability in order to better understand their power as schema in American society.

**The Disability System**

We have seen that inequalities that exist between disabled and non-disabled people are socially constructed and reproduced through structures rather than being biologically determined.
Garland-Thomson refers to this phenomenon as the “ability/disability system” (2002, p. 2). McDermott and Varenne claim “culture as disability” (1995, p. 324). Other theorists distinguish the medical model from a social model of disability that considers disability as a “social, political and cultural phenomenon” rather than a deficit of the individual (Linton, 1998b, p. 527).

Physical and psychological impairment may be real but it is important to draw a distinction between “disability as a social oppression and impairment as functional limitation” (Connor, Gabel, Gallagher, & Morton, 2008, p. 443). The social construction of disability, not impairment in and of itself, is harmful to individuals in that it portrays them as abnormal and deficient. Social construction of disability does not discount biology, but recognizes that stigma and discrimination disable people in ways that biology by itself does not. Impairment is a natural part of human diversity while employment discrimination, lack of physical access to public spaces, and media-fueled stigma are examples of how people with physical and mental impairments are disabled by society.

Disablement of people with impairments, particularly psychological or cognitive impairments, is based on historical context. According to Erevelles:

In the specific historical context of laissez-faire capitalism, “rational” behavior represents those behavior traits that maximize benefits, minimize costs and contribute to the efficient realization of profit. Those people who exhibit behaviors that prove to be counterproductive to the efficient logic of capitalism are marked as abnormal, and are either punished and/or segregated from the “normal” populations (2002, p. 13).

The structures of capitalism, in this case, work to disable people who do not fit the mold of the good worker, using the cultural schema of the medical model, which sees difference as deficiency. We will recall that Sewell says that schemas and resources only
become structures when they work together to sustain themselves (1992). The medical
model of disability has been used to reinforce the reproduction of structures by ensuring
the marginalization from resources (for example, housing and employment) of anyone
deemed “abnormal”.

One way that this marginalization has been accomplished is through the
institution of schooling (which we are considering a resource, using Sewell’s theory).
McDermott and Varenne say, “If the social structuring process in America must be fed by
repeated identifications of failure in school and school-like institutions, then American
education will continue acquiring people for its positions of failure. America will have
its disabilities” (1995, p. 344). Their conclusion is that school is a site for the
reproduction of structures (and thus the reproduction of structural inequality). Disability
is one way by which the institution of schooling succeeds in giving advantage to some
while hindering others. A diagnosis of mental disability depends heavily on clinical
judgment, which allows for the possibility that factors such as racism or poverty will
influence the labeling of people with these disabilities (Biklen, 1988). As seen above,
Black and Latino children are disproportionately likely to be placed in special education
compared to their white peers and the disability categories they are labeled with usually
fall under the umbrella of mental disability instead of physical disability – Emotional
Disturbance, Learning Disability, Mental Retardation/Intellectual Disability (Harry &
Klingner, 2006). Because there is significant room for error (or biased clinical judgment)
in the labeling of these types of disabilities, the stigma attached to mental disability can
harm not only on those with obvious impairments but also other disenfranchised people.
In practice, all children could be considered at risk to be labeled with mental disability, but children who are already marginalized in some way are more at risk.

Garland-Thomson says it this way, “female, disabled, and dark bodies are supposed to be dependent, incomplete, vulnerable, and incompetent bodies” (2002, p. 7). Educational resources are used to thus disable those inferior bodies in order to maintain the status quo of power held by the white, male, able body. Davis says, “deformed, deafened, amputated, obese, female, perverse, crippled, maimed, blinded bodies do not make up the body politic” (1995, p. 72). Children labeled with disabilities are inhibited from becoming full members of society.

Schools, and public schools in particular, are meant to nurture the next generation of citizens. The rise of universal schooling in the United States was not an isolated phenomenon, but rather corresponded with the rise of the working class and intense periods of immigration (Katznelson & Weir, 1985). According to Katznelson and Weir (1985), early battles over the creation of common schools helped to generate a more unified American working class by creating a political realm outside of work in which ethnic and religious conflicts could be resolved. Cremin (1980) agrees with the image of education as a battle ground and states that during the nineteenth century, “education not only became an ever more significant American undertaking in its own right, it was increasingly perceived as such and assigned and appropriate public value”, becoming an ever more political arena (p. 12). Schools were meant to not merely teach reading, writing, and arithmetic, but also to prepare children for work and for democratic citizenship in a diverse nation (Katznelson & Weir, 1985). Some children were not welcome in that vision of democratic citizenship. Children who did not fit the definition of rationality or of having a normal personality were excluded because of “strict adherence to certain normative concepts that are narrowly defined, and that, if challenged, would topple the entire edifice on
which liberal individualism and capitalism is erected” (Erevelles, 2002, p. 9). The exclusion of some children from public schooling on the basis of mental disability was a political act meant to uphold unequal structures (under the guise of care for the mentally handicapped and protection of the general population). The medical model and the reasoning of deficiency was the schema that was used to justify this action.

This is not to say that teachers and school administrators consciously harm the students they aim to help. Sewell differentiates between the depth of structures (which has to do with schema) and the power of structures (which has to do with resources). He defines deep schemas as:

Pervasive, in the sense that they are present in a relatively wide range of institutional spheres, practices, and discourses. They also tend to be relatively unconscious, in the sense that they are taken-for-granted mental assumptions or modes of procedure that actors normally apply without being aware that they are applying them (1992, p. 22).

According to this definition and the evidence that has been presented, the medical model of disability is a good example of a deep schema. In other words, it is an ideology that is seen as given. It is acted upon unconsciously and thus is rarely questioned.

**Habitus and Hegemony**

Actions of people maintain structures, but how and why do people reproduce structures of inequality? Sewell discusses Bourdieu’s *habitus*, which he believes does not allow enough room for social change that does happen. *Habitus* can be defined as the embodiment of social structures. That is, taking on the preferences and actions expected by members of a particular class, race, gender, etc., thus reproducing structures by acting as those structures (Bourdieu, 1977). Sewell believes that this is a useful concept and true to a certain extent, but that it does
not allow for people to make creative and agentic decisions based on a range of cultural schemas. Another useful concept might be Gramsci’s theory of hegemony, in which the elite class propagates its own ideology (or schema) as truth so that it is adopted by all. For Gramsci, consent was necessary in order for the elite to maintain power (1999). In both cases, people act according to the rules and reasonings of cultural schemas in order to reproduce existing structures and both will be useful in our ongoing discussion, while still being guided by Sewell’s theory of individual agency, which will be discussed more later. As an example of the process by which individuals are convinced to act against their own interests in maintaining unequal structures, a discussion of labeling theory will be helpful, as it seeks to explain the process of identifying with one’s own label of deviance (such as a label of mental disability).

The Power of Labels

Labeling theory is a sociological theory of deviance. In this case, we will use a definition of deviance taken from Becker, which is “the interaction between the person who commits the act and those who respond to it” (1963, p. 14). Becker contrasts this definition to more common ideas about deviance, including the idea that deviant behavior is indicative of some sort of mental illness. He also does not agree with the more common definition of deviance as simply the “failure to obey group rules” (Becker, 1963, p. 8). Becker theorizes that deviance is not solely dependent on the action of the individual, but rather that it is a consequence of rule formation and the enforcement of rules and thus deviant behavior exists in the interaction between those who create and impose rules as well as the individual labeled deviant. Thus a person may be labeled as deviant for having been merely perceived to break a social rule (he calls these people “falsely accused”) and, on the other hand, a person who has broken a social rule might not necessarily be given a label (he refers to these people as “secret deviants”)
(Becker, 1963, p. 20). Becker sees this as a dilemma of sociological research because, generally speaking, only those who have been given a label of deviance are studied, but this does not account for all types of deviant behavior or take into account the relationships that cause deviance.

A common misconception about labeling theory is that it is the label itself that leads to deviant behavior. Becker does not say this. What he does say is that being publicly labeled as deviant is a step on the path to a deviant career, rather than a single offense. He believes that “treating a person as though he were generally rather than specifically deviant produces a self-fulfilling prophecy” and makes it difficult for that person to regain a life within conventional circles of society (Becker, 1963, p. 34). Cultural rules and norms (what Sewell calls schemas) are powerful and this process of labeling is one way in which they are upheld. Not only does it reinforce the power held by those who create rules, but also begins a process in those labeled of self-identification as deviant. On the one hand, people who are labeled do have agency in this theory to continue with a deviant career or not. On the other hand, the power structures of society can make it very difficult for the labeled person not to begin to identify with their label.

In his book *Being Mentally Ill: A Sociological Theory*, Scheff (2009) discusses this phenomenon specifically in regards to mental disability. He states that “the process of social control involves both control by others and self-control” and believes that social control (both formal, such as laws, and informal, such as social norms) constructs reality for the individuals within that society (p. 39). Labeling is one way in which this is accomplished. Scheff borrows from Becker to construct a definition of deviance that says that “deviants are not a group of people who have committed the same act, but are a group of people who have been stigmatized as deviants” (2009, p. 54). This is important to Scheff as people labeled with mental disabilities
have not all deviated from the same rules or norms yet are all stigmatized in much the same way. Indeed, if we look at the causes of mental disability, they are numerous. Although medical science has attempted to pinpoint biological causes, there has been little success and we know that people may exhibit signs of mental disability for reasons as far ranging as lack of sleep, trauma, depression and drug use. However, we also know that societal reactions to mental disability are less similar to reactions to other non-contagious diseases (were we to think of mental disability as disease) and more similar to reactions to other types of deviant behavior, as Szasz (1970) outlines in his comparison of psychiatry and the treatment of mental patients with similar reactions to witchcraft during the Inquisition. According to Szasz, both the labeling of someone as mad and the labeling of a person as a witch came from similar motives, to eradicate abnormal and potentially dangerous behaviors and protect society from unwanted elements. As Scheff (2009) says, “one component of the stereotype of insanity is an unreasoned and unreasonable fear of mental patients that makes the public reluctant to take risks in this area of the same size as risks frequently encountered and accepted in the ordinary round of living” (p. 80). He believes that this is due to the fact that stereotyped behavior is learned in early childhood and continually reinforced into adulthood by a biased media. Clearly, people with labels of mental disability are not treated as sick so much as dangerous and others react to that sense of danger in ways that can be dangerous for the person labeled.

So what does this mean for people labeled with these types of disabilities? Scheff (2009) sees the acceptance of a label of mental disability as a type of role-playing, which is not entirely voluntary. He states that people are rewarded for playing a stereotyped role in the form of treatment and that a mental patient undergoing treatment is the only socially acceptable role that one can fill, once labeled. In the crisis moment of being labeled, the individual is subject to the
pressures of society and then is rewarded for fulfilling the role of deviant (or, stated differently, for conforming to the role of mental patient) and is punished and stigmatized against for trying to re-conform into the greater society (or leave treatment). And, as we learned from Becker, that label is the first step on the road to a career of deviance and the individual’s self-identification with that deviant role. This is similar to Bourdieu’s concept of habitus, in which individuals learn and perform the roles that are expected of them.

This phenomenon paints a bleak picture. We know from our discussion of Sewell’s work that all people have agency within this system to conform or resist, however, power differentials exist and there are strong social rewards and consequences for fulfilling specific roles. Labeling theory can help us to see how individuals labeled with mental disability might work within cultural schema and against their own interests. That said, the situation is not quite so straightforward. Sewell says, “the multiplicity of structures means that the knowledgeable social actors whose practices constitute a society are far more versatile than Bourdieu’s account of a universally homologous habitus would imply: social actors are capable of applying a wide range of different and even incompatible schemas and have access to heterogeneous arrays of resources” (Sewell, 1992, p. 17). I will now examine theories of intersectionality to investigate how knowledges of different schemas and access to different resources complicates this theory of labeling and how this works both for and against individuals with mental disabilities.

**Intersectionality**

Agency is determined by historical circumstances and culture, as well as by the creativity of particular agents in their use of schemas and resources, and by their collective endeavors. According to Sewell:
…agency arises from the actor’s knowledge of schemas, which means the ability to apply them to new contexts. Or, to put the same thing the other way around, agency arises from the actor’s control of resources, which means the capacity to reinterpret or mobilize an array of resources in terms of schemas other than those that constituted the array.

Agency is implied by the existence of structures (1992, p. 20).

However, particular actions taken by people are not always predictable based on the forms that structures take.

Intersectionality is a theory of identity politics that seeks to explain the particular experiences of marginalization faced by people when different aspects of their identity intersect (Crenshaw, 1991). Originally an explanation for the experiences of black women when feminism was aligned to the needs of white women and anti-racist politics to the needs of black men, intersectionality approaches have been used to examine many different aspects of identity, including disability. The goal behind such research is in the assumption that “the social power in delineating difference need not be the power of domination; it can instead be the source of social empowerment and reconstruction” (Crenshaw, 1991, p. 1242).

The identity categories of race and gender and disability, according to this framework, are social constructed and examining the “way that power has clustered around certain categories and is exercised against others” is the fundamental purpose of intersectional analysis (Crenshaw, 1991, p. 1296-7). Some researchers in intersectionality use what McCall calls “anticategorical analysis”, which looks at each category as a separate social construction (2005). This framework has been critiqued by many feminists of color, like Crenshaw, who argues that “the descriptive content of those categories and the narratives on which they are based have privileged some experiences and excluded others” (Crenshaw, 1991, p. 1241). Feminists of color have therefore
been more likely to use an “intracategorical” framework for intersectional analysis that explores how the intersection of race and gender affects lived experience. Yuval-Davis suggests that in addition to illuminating the experiences of women of color (or others living in intersections of oppression), a “constitutive” analysis can go a step further and describe structural conditions and the historical processes by which these identity categories were constructed (2006). As an example, Erevelles and Minear explore the educational history of Cassie, a young Black girl, living in poverty, who was labeled with a disability. The researchers describe the violence, turmoil and isolation that marked much of Cassie’s educational career. She attended a different school every year and her perceived emotional disability was treated with essential incarceration, isolation from others, and frequent expulsion. The authors contextualize her story with historical analysis of the special education system and its history of using disability labels as effective segregation of Black children in the aftermath of Jim Crow (2010). The authors conclude that “individuals located perilously at the interstices of race, class, gender, and disability are constituted as non-citizens and (no)bodies by the very social institutions (legal, educational, and rehabilitational) that are designed to protect, nurture, and empower them” (Erevelles & Minear, 2010, p. 127). This type of constitutive analysis uses historical context as well as individual experience to examine the effect of political, economic, and educational structures. I believe this type of analysis is most useful when examining intersectional identities from the approach of structures and agency.

**Example of Emotional Disturbance**

Let us return to the example of Emotional Disturbance (ED) to illustrate some of the concepts discussed. As we have seen, the definition of ED is ill defined and thus labeling a child with ED is heavily reliant on clinical judgment (Biklen, 1988). It is important, then, to
understand how ED is conceptualized. According to Danforth, ED is generally conceived of in one of two ways – either as a mental illness or as deviant behavior (2007). These ideas about the cause of ED are deficit-based and ignore the greater social contexts that might play a role in a child’s behavior and the interpretation of that behavior. In either case, the problem of ED rests solely within the individual, which is consistent with the schema of the medical model.

**Cultural Schemas & Resources**

In order for a cultural schema to play a part in upholding oppressive structures, it must reinforce and be reinforced by resources (Sewell, 1992). Let us use schools as an example of resources and examine whether this is the case. For Sewell’s theory to be true, the cultural schema of the medical model (in regards to ED) must uphold the operations of schooling and the operations of schooling must fortify the significance of the medical model. According to Harry and Klingner in their study of the overrepresentation of minority students in special education, the label of Emotional Disturbance (which they call EH – Emotional Handicap) allows schools to segregate students based on their defiance of perceived norms of school behavior. According to Harry and Klingner:

The existence of the EH category encourages school personnel to assume child deficits without examining context and to place children who are troubling to teachers or peers in separate settings that defy the law’s call for the least restrictive environment (2006, p. 158).

Indeed, this theory seems to be reinforced by the statistics of overrepresentation. Reid and Knight argue that children are judged as abnormal based on “the historical White European ideal” and that thus “it seems natural to many Americans that students of color, the poor, and immigrants lie outside the predominant norm” (2006, p. 19). This explains, at least in part, why
so many children of color are given ED labels. So we see that schools use the medical model to separate students who threaten normal operations. But does the process of labeling reinforce the significance of the medical model? I would argue that the poor outcomes of students labeled with ED (lower graduation rates, poor employment outcomes, difficulty with social relationships, high rates of incarceration) serve to strengthen the deficit view of children labeled with ED (Bradley, Doolittle, & Bartolotta, 2008). It would thus seem that the medical model functions as a cultural schema, upholding unequal structures, in the example of ED labeling.

Labeling

When school personnel, as representatives of the dominant social group, label a child with ED, it is generally believed that the child is (as Danforth says) either mentally ill or deviant (Danforth 2007). They are then treated as such. Students labeled with ED are more likely to be placed in segregated classes and to be suspended or expelled from school, as well as having poor post-school outcomes (Bradley, Doolittle, & Bartolotta, 2008; Harry & Klingner, 2006; SRI International, 2006; U.S. Department of Education, 2005). The very fact that most available research on students with ED is related to their poor educational and life outcomes shows that the label itself creates an expectation.

If we return to Scheff’s idea of role-playing, we will recall that people labeled as deviants often conform to that role because there is incentive to do so. Obiakor (1999) talks about the low expectations of minority students that lead to them being labeled and follow them into special education and the subsequent negative effects on their self-concepts. Clark (1997) documented the attitudes of teachers to the failure of students with disabilities and the effect on the mindsets of those students. If through teacher expectations and attitudes it is communicated to students
with ED that they are unlikely to succeed in school (or post-school) then it can be unsurprising when this is what transpires.

**Intersectionality**

What is missing in much of literature and discussion of ED is an examination of context. We know that children labeled with ED are more likely to be poor, to come from single parent households, to be of color, and to be male (Harry & Klingner, 2006; Reddy, 2001). All of this would suggest that the experience of being labeled with ED is one of intersecting oppressions, and cannot be explained by merely examining the label itself. Danforth suggests that ideas of mental illness and deviance are less useful to a discussion of ED than attending to “the social activities that produce student identities at the bottoms of various social hierarchies” (2007, p. 23). In this analysis of the agency of people given labels like that of ED, it was crucial to examine these intersecting oppressions.

**Conclusion**

In this study I use a historically centered, intersectional approach as a way of looking at the possibilities and constraints of human agency in various historical contexts. Sewell says, “agency differs enormously in both kind and extent” (1992, p. 20). Some people have more opportunities to act creatively within schemas because they are empowered to do so by those schemas. On the other hand, individuals find inventive ways to resist reproducing oppressive structures using the power that they have as agents. Examining the ways in which categories of race, class and gender have intersected with mental disability in the lives of students to both reproduce existing structures and to change them over time, while seeing disability as a the “organizing grounding principle” in the construction of these categories, leads us to a better
understanding of how schools and students work to both maintain and disrupt structures of inequality (Erevelles, 1996, p. 526).
CHAPTER 3: METHODOLOGY

Introduction

At the heart of this study are the processes by which dominant cultural schemas of mental disability, particularly the medical model, have been used in public schooling in this country to determine the educational path of certain people labeled with emotional, behavioral and other mental disorders. Ultimately, I aimed to gain a better understanding of how the medical model of disability has been reproduced and resisted through the actions of individual students. I used a combination of theories in my conceptual framework culled from: 1) Disability Studies, 2) labeling theory, and 3) theories of intersectionality to examine the relevance of those areas by forging a composite lens to better explain the experiences of children with mental disabilities in public schools. I was especially interested in examining the actual voices of students in order to gain a better understanding of what effect different cultural schemas and policies had on their lived experiences.

Description of Conceptual Framework

For the purpose of this study, I undertook historical research using what Zinn calls a “problem-centered approach” (Zinn, 1990, p. 29). I began with a current problematic issue of inequality, namely the poor educational outcomes of students labeled with mental disabilities (Losen & Orfield, 2002; SRI International, 2006; U.S. Department of Education, 2005). I examined history to see how culturally-determined models of categorization and related practices have informed our educational system and affected the schooling of children with mental disabilities.

Cultural schemas, oftentimes conceived of as norms, are reproduced at all levels of society and this creates inequitable systems. The concept of hegemony means that even
oppressed people play a role in the reproduction of structural forces and structural oppression (Gramsci, 1999). Of course, resistance by the oppressed to structures of oppression is also ongoing. The reciprocal relationship between structures of inequality and individual agency plays out at all levels of society. In Disability Studies theory and labeling theory, a label of disability is itself considered a means by which power is inscribed upon the body of another. As discussed in Chapter 2, labeling is an act of control by the majority (separating the disabled from the able-bodied) that usually impacts the actions and identity of those labeled (Becker, 1963; Scheff, 2009). Disability itself is a status that can be examined both as a form of cultural disempowerment that negatively impacts an individual’s identity and as something to be “claimed” and celebrated, as a positive marker of identity (Linton, 1998).

Sewell (1992) argues that all people possess the capacity for full agency. For some people, however, that capacity is inhibited because of the cultural schema of deficit that accompanies impairment. It is important to recognize that the mechanisms by which people with recognizable impairments become disabled may be applied to all of us. In Disability Studies research, the non-disabled are sometimes referred to as “temporarily able-bodied” to acknowledge the fact that ability is contextual, and also possibly fleeting, as it is related to both age and physical health (Society for Disability Studies, 2012). Perhaps those people who do not have a diagnosed mental disability might be described as “temporarily able-minded”. The Center for Disease Control has found that about half of Americans will experience some type of crisis of mental health in their lifetimes – ranging from conditions like depression and anxiety to temporary mental distress and Alzheimer’s disease (Center for Disease Control, 2011). Mental ability or disability, then, is a fairly transient state and the experience of mental disability is not
all that uncommon. According to McDermott and Varenne (1995), in schools this contextual nature of disability means that:

Over the past forty years, there has been developing in the United States a system of categorization which limits us to only two ways for a person to be. One way is to have been classified, occasionally remediated, and often mistreated as disabled. The other way is to be temporarily a half-step ahead of being classified, remediated, and mistreated as disabled (p. 332).

If we take a historical look at the issue, it becomes clear that mental disability is a category of analysis that has expanded and contracted over time. There are countless examples of this process throughout history, for instance homosexuality, which until 1973 was considered a mental deficiency (Silverstein, 2009). In another example, Drapetomania (defined by a physician in 1851) was the “the disease causing Negroes to run away” from their enslavement (Cartwright, 1851, p. 1). It is clear that the mechanisms of disablement, by labeling with mental disability, can be turned on anyone and then used to justify ill treatment and exclusion based on the idea that people with mental disabilities are dangerous or sick or that their incarceration or exclusion is for their own good (Corrigan, Edwards, Green, Diwan & Penn, 2001).

Many disability historians have thus argued that disability is not merely a description of impairment, but rather a malleable category of social and historical analysis, much like gender or race (Davis, 1995; Kudlick, 2003). Some, including Baynton (2001), argue that disability is even a more useful category than those other constructions and identities because, as has been discussed, it not only describes people with obvious physical impairments, but the discourse of disability is used to disempower all people considered to be outside of “normal”, which can and has included women, African Americans, immigrants, and other marginalized groups. I would
argue that the categories of disability - and mental disabilities in particular - are the means by which power is enacted over those who fall outside of dominant cultural schemas (or norms).

All of us can be considered disabled in some way or, at the very least, at risk for being classified as disabled due to injury, disease, or emotional trauma; or perhaps it is our race or sexuality or gender that will be defined as pathological, depending upon the context. As Davis says, “what is universal in life, if there are universals, is the experience of the limitations of the body” (Davis, 2013, p. 276). The practices of defining and operationalizing disability, then, are better conceived of as a tool for both enacting power and limiting agency, rather than as a medical condition inherent within the individual. As Catherine Kudlick has noted, studying disability therefore:

…offers the conceptual tools for exploring the underlying assumptions beneath Western societies’ creation of the very environments where historians work – environments built on the assumption that everyone is young, strong, tireless, healthy, of similar size and shape, independent, and with all physical and mental components in working order (2003, p. 769).

Those bodily and social characteristics are, in fact, idealizations making them faulty assumptions. As Gould (1996) says in his seminal work, The Mismeasure of Man, “inferior groups are interchangeable in the general theory of biological determinism” (p. 135). Mental disability has been integral to the means by which that theory of biological determinism has been upheld. This phenomenon manifests itself in a self-fulfilling prophecy wherein people in power chose who to determine as disabled, claiming the knowledge on which they based their decision is a universal truth that subsequently creates substandard bodies and minds. Using disability as a category of analysis to illuminate these processes of disablement in American public schools and
to examine the effects of those processes on individual students labeled with mental disabilities is a step towards allowing researchers to resist categorizing people by how “normal” they are or appear to be and instead to work toward a different conceptual model of human difference that values diversity.

Revisiting the Research Questions

This study consists of examining historical background in order to shed light on dominant cultural schemas surrounding disability and how and if these have shifted over time. The study includes oral history interviews of students with mental disabilities who attended public schools during this time to investigate their experiences with disablement and their resistance to it.

To revisit, my research questions were as follows:

1. How has mental disability been defined from the inception of public schooling in the United States and how have dominant cultural schemas of mental disability been used in schools and education policy making?

2. What do personal narratives told by people categorized as mentally disabled reveal about their experiences of public schooling?
   a. In what ways do these narratives reproduce and/or resist dominant cultural schemas about mental disability?
   b. What personalized understandings are revealed through the narratives and how do they reframe how we think about mental disability?

To answer the first research questions, I used secondary sources to build a comprehensive historical background of mental disability in American public schools. My sources included written histories of disability and special education, as well as articles from the New York Times - detailed in a later section of this chapter. The goal of this part of my research was to examine
how and if the dominant cultural schemas of mental disability have changed over time in order to provide context for interviews that examined the lived experience of people with mental disabilities.

The second part of this study consisted of interviews with people who identify as having mental disabilities and who attended public schools. The study examined to what degree changing cultural schemas had an effect on the lived experiences of children in schools, not only in the services they did or did not receive, but also in the way they understand their own disability and in whether or not they accepted or resisted common notions of disability, as demonstrated through their thoughts and actions.

**Labeling Histories**

Labels of mental disability carry with them the weight of structures and yet greatly affect individual lives. In order to examine both the structural and the individual, an approach that Weis and Fine (2012) call “critical bifocality”, I developed an interviewing approach that I call labeling histories (p. 174). In this section I define labeling histories and their relationship to oral history interviewing.

A type of oral history interviewing was useful in answering the above stated research questions in two important ways: 1) oral histories focus on the effect of individual people, often people overlooked by traditional histories, and their effect on the world around them; and 2) oral histories are meant to investigate how these individuals make meaning in their own lives from the events that transpire around them. Oral history is a forum in which the speaker – regardless of assigned or perceived status in society – is the center of a narrative, thereby contributing a knowledge that has traditionally been downplayed or deliberately stifled. The term “oral history” was coined in the 1940s, and originally used to refer to narrative accounts of historical events.
spoken by presidents and other prominent figures. However, in the latter part of the 20\textsuperscript{th} century, oral history has transformed into what Jordanova (2000) calls “a democratizing approach to history”, meaning that it brings to the forefront the voices of people who are not often cited in traditional, written histories (p. 55). Oral history as a discipline recognizes that individuals have personal experience of major historical events but also that all people play a part in constructing society and the incidents that shape that society (Portelli, 2004). This is complementary to Sewell’s ideas about the relationships between agents and structures that I utilize in this research and is thus the method that I used to explore the processes of reproduction of and resistance to cultural schemas and through them, structures of inequality.

Oral history relies on participant memories and has at its heart the meaning that participants make from historical events. It is the only historical discipline that involves conversation between researcher and participant. As Abrams (2010) states “oral history is a dialogic process: it is a conversation in real time between the interviewer and the narrator, and then between the narrator and what we might call external discourses or culture” (p. 19). The value of oral history is in understanding how participants make meaning of their experiences within a historical context, how they express their relationship to cultural schemas, and how their sense of self is influenced by these processes (Portelli, 1990).

Oral history interviews have been used as a method to examine subjects as far reaching as generational stories passed on by Dakota women (Wilson, 1996), the role of gender in experiences of World War II Britain (Summerfield, 2004), personal understandings of major historical events such as the Armenian Genocide (Miller & Miller, 1993) and September 11\textsuperscript{th} (Clark, 2002), and how Italian factory workers made meaning of events surrounding the death of one of their own (Portelli, 1990).
Of note is that few scholars have written histories, much less oral histories, that include the voices of people with mental disabilities, one exception being Dale Peterson’s *A Mad People’s History of Madness* (1982), which is not an oral history but does include the voices of people with mental disabilities. Furthermore, few historians have interviewed people with mental disabilities to understand how they “express their sense of themselves in history” (Portelli, 1990, p. ix). An exception to this phenomenon is *What We Have Done: An Oral History of the Disability Rights Movement*, which examines the role of people with mental disabilities in the Disability Rights Movement (Pelka, 2012). Oral histories helped me to explore the cultural schemas that people with mental disabilities have utilized to express their sense of self as students and as disabled people, and thus the effect of structures on their lives and labeling.

In this case, the historical event that was examined is the labeling of each of the participants. Labeling carries with it the weight of historical cultural schemas and can give us insight into the structures that influence the lives of particular people. That said, labeling is also a deeply personal experience that had effects on the schooling experiences of the individual participants as well as on their process of identity making. Seidman (1998) says, “at the root of in-depth interviewing is a interest in understanding the lived experience of other people and the meaning they make of that experience” (p.9). *Labeling history interviews* are as attempt at a lens of critical bifocality to examine the lives and labeling of people with mental disabilities from both a structural and individual standpoint by investigating both history of labeling and the effects that those labels have on individuals.
Research Relationship

Forging positive relationships in the interview process is an important task for the researcher. The researcher should establish some measure of rapport with the participants while still maintaining professional reserve in order to avoid exploitation of the participants by creating a false sense of friendship (Seidman, 2013). While the temptation might thus be for the interviewer to maintain distance in order to lessen their effect on the participants, in reality the very nature of the interview process is such that the interviewer exerts a measure of control and influence. The participants, after all, have offered to tell their stories but have not sought to do so. It is the interviewer who has created the circumstances. Thus it becomes imperative that the interviewer work to create a safe and equitable space for the conversation.

According to Portelli, the oral history interview in particular “does not begin with one abstract person observing another, reified one, but with two persons meeting on the ground of equality to bring together their different types of knowledge and achieve a new synthesis from which both with be changed” (Portelli, 1990, p. xii). He goes on to say that:

An inter/view is an exchange between two subjects: literally a mutual sighting. One party cannot really see the other unless the other can see him or her in turn. The two interacting subjects cannot act together unless some kind of mutuality is established. The field researcher, therefore, has an objective stake in equality, as a condition for a less distorted communication and a less biased collection of data (Portelli, 1990, p. 31).

With the idea of encouraging mutual synthesis of knowledge and creating a space of equality during the interviews, I disclosed my own disability status to the participants. Portelli believes that “one cannot expect informants to tell the truth about themselves if we start out by deceiving them about ourselves” and I agree with that statement (Portelli, 2004, p. 31). I believe
that my personal disclosure in this case was an important step towards creating a more open space for sharing. This type of disclosure promotes trust, especially in a situation where stigma might otherwise be perceived on the part of the researcher. This is demonstrated by Hill and Thomas’ interviews of women in interracial partnerships, where the interviewer revealed her own experience in such a relationship to reassure participants (2000). Greater trust leads to richer data because the interviewees feel freer to speak on what could be a sensitive topic.

While I did not share my theoretical framework with participants in the initial interviews, as not to influence the way they told their own stories, I did share with them some of the theories that I worked with in the second interview and communicated my initial analysis of their words in the third and final interview so that they had the opportunity to respond to my analysis and offer some of their own. The process of interviewing is detailed further in this chapter.

**Setting and Participant Selection**

The participants of this study were seven men and women who were, at some point during their lives, given a label of mental disability. Mental disability was defined broadly as any condition identified as such by the participants. I was interested in speaking with people who self-identified as disabled, rather than associating them with a structurally inscribed disability such as “being” Emotionally Disturbed.

I used two methods to recruit participants for this study. First, I used a snowball method by reaching out to people I knew personally to engage participants via word of mouth (Bogdan & Biklen, 1982). I also contact the New York City branch of the organization The National Alliance on Mental Illness (NAMI), which sponsors local support groups for people with mental disabilities in the city, and asked them to distribute my recruitment flyer at their meetings (although no participants joined the study via this method).
I strove to ensure that participants were as diverse as possible in terms of race/ethnicity, background, and sexuality, social class, as well as age and gender. That said, they were a small group and it was not possible to fully represent the diversity of the human experience within a group of seven people. Most notably, there were no Black males among their number, which is significant when considering the overrepresentation of Black males in official categories of mental disability (such as ED) in schools. I will discuss this further in the limitation section in the final chapter.

I took additional measures to ensure the safety and well being of the participants of this study. I wished to consider their particular needs when entering into the project as not to inadvertently cause them harm. First, I provided a confidential space in which to conduct the interviews so that our conversations were private. I also restricted access to the data from the interviews by using aliases in transcripts and keeping both transcripts and identifying information locked away (in separate places). This helped to ensure that the participants were not be subject to potential stigma due to their disabilities. Second, I provided contact information for emergency mental health services to all participants in the event that any of our discussions caused them distress. I also made it clear to participants that they could stop the interviews at any time if they felt that it was necessary.

**Data collection**

**Historical Context**

Oral histories center on the effect of historical events on individuals. The researcher thus must be a historian as well as a facilitator of interviews. The historian Portelli (1990) suggests examining recorded and archival history first, before delving into oral histories, in order to help put the interviews in context. In order to build context for the labeling history interviews in this
study, I studied written histories of special education, psychology (particularly in its relationship to educating children), mental disability labels, and the disability rights movement. Researching these areas, intimately interconnected with my study, helped me construct a broad picture of the cultural schemas that have influenced the way we think about mental disability in public schooling. Once I established this picture and had a sound foundation of historical knowledge about mental disability in public schooling in the United States, I began the labeling history interviews, better able to investigate in what ways the cultural context made a difference in the lives of children in schools.

The following is a selection of books that I used to construct this historical background. This list is far from exhaustive but rather provides examples of the types of resources I used to provide historical context and investigate cultural schemas that have been used over time. My goal, ultimately, was to bring together a wide range of different viewpoints in this research. Examples of books include:

  The origins and purpose of school psychology are examined in this book. It includes an overview of how school psychology began and also investigates the evolving objectives of the profession. It offered historical insight as well as information about the practical aspects of school psychology.

  The connection between science (particularly psychology), philosophy and educational practice is the core of this book. Lagemann examines these relationships and the
outcome of psychology, and thus a more quantified approach, overtaking educational research and practice. This book supplied perspective on how the medical model of disability was applied to education through the field of psychology, which espouses a deficit view of mental disability.


While a relatively brief history, the focus of this book is on the lived experiences of children with disabilities in schools from the beginning of public schooling in the United States until the present. It is written with a Disability Studies framework and was valuable not only for the historical information it provided but also because of its focus on the cultural context of schooling and the effect of that context on children with disabilities.


Winzer has written a thorough and detailed history of education for children with disabilities, spanning hundreds of years. This book offers a wealth of historical information as well as cultural context to explain choices made about how children with disabilities were educated at different times.

In addition to reading approximately 15 written histories, I accessed the archives of the New York Times to examine what and how they were reporting about the schooling of children with disabilities at different times. This was helpful as a case study of cultural schemas as seen through the media.
The overall goal of this historical background research was to discover the dominant cultural schemas around disability (and mental disabilities in particular) that existed throughout the history of public schooling for children with mental disabilities. Thus, I did not create a factual history so much as investigate changing cultural notions of disability so that the interviews could be carried out within the context of that framework.

**Labeling Histories**

I conducted labeling history interviews with a group of people who self-identified as having mental disabilities, individuals who are not often thought of as history makers. I aimed to bring to light the ways in which historical cultural schemas had an effect on how they made sense of their disability and their schooling experiences. In particular, I investigated ways in which the participants both reproduced and resisted the medical models of disability throughout their years of schooling.

The labeling history interviews took place over three sessions, each lasting approximately 60 to 90 minutes, as suggested by Seidman (2013). I modified his three-interview sequence slightly to make room for discussing theory and a review of my initial analysis with participants during the second and third interviews.

**Interview 1.** The initial interview was aimed at getting to know the participants and beginning to discuss their schooling history and their relationship with their disability label. The guiding interview questions for the initial interview were as follows:

1. Can you tell me a little bit about yourself? What words would you use to describe your personality? If I said the word “identity” what words do you associate with? What parts of your identity are important to you? Which aspects of your identity would you say define you the most?
2. Can you please describe your earliest memories of when you were identified as having (or being labeled with) a form of mental disability? Can you remember a specific incident that you associate with becoming labeled disabled?

3. When you were younger, how did teachers and other students respond to your disability when you were in school? Can you describe some specific memories that have stayed with you?

4. When you were younger, how did family members and friends respond to your disability outside of school? Can you describe some specific memories that stayed with you?

5. What years did your educational experiences span? Please describe the schools you attended from kindergarten until graduation or leaving school.

6. Describe the neighborhood(s) you lived in while you were in school.

7. Did you receive special education services (e.g. separate class, counseling) or accommodations (e.g. different instructions) while you were in school? If so, can you describe them?

8. In general, tell me about your interactions with teachers and administration while you were in school. Can you share a couple of examples of memorable occasions (at least one positive and one negative)?

9. In general, what were your interactions with peers when you were in school? Can you share a couple of examples of memorable occasions (at least one positive and one negative)?

10. Did you know other people labeled with a mental disability (or behavior disorder) while you were in school? If so, how did you interact with them?
11. To what degree do you feel you “fit in” in school? Can you describe why you felt this way? What were you successful at in school and what were you unsuccessful at? Can you share some examples?

12. How would you compare your experience of mental disability (a) during school, (b) outside of school, and (c) throughout your adulthood to date?

13. Given our topic, is there anything I haven’t touched on that you would like to share?

**Interview 2.** The second interview occurred after I began to analyze the data from the first interview and was aimed at delving deeper into the participants’ role in reproducing and resisting the medical model of disability. I discussed the medical and social models of disability with participants during this interview to glean their opinion on whether or not these models had any relevance to their life and in their schooling history, utilizing the chart detailed in Figure 1 to help explain the medical and social models of disability to participants. Much of this interview consisted of an in depth discussion, in which I encouraged participants to share their reactions to and thoughts about the models, as well as ask any questions that came to mind. I also posed the following questions to explore their experiences further:

1. What are some circumstances or situations in which you have explained your disability to others?

2. How do you explain your disability to others?

3. How has your disability been explained to you by doctors, teachers, and other professionals? How has your disability been explained to you by your parents?

4. What is your opinion of the medical and social models of disability?

5. Which of the models do you think best describes the way you think about your disability and why?
6. What did you learn about people with disabilities while you were in school through the (a) official curriculum, i.e. what teachers taught, and (b) the unofficial curriculum, i.e. what else you learned e.g. through friends, social situations, school structures and practices?

Figure 1: Comparing Medical and Social Models of Disability

<table>
<thead>
<tr>
<th>Medical model of disability</th>
<th>Social model of disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Traits</strong></td>
<td><strong>Language</strong></td>
</tr>
<tr>
<td>- Problem is within the individual</td>
<td>- Sick/ill</td>
</tr>
<tr>
<td>- Treatment consists of trying to change the individual so that they better fit in society</td>
<td>- Normal/abnormal</td>
</tr>
<tr>
<td>- Doctors and other service providers as experts</td>
<td>- Patient</td>
</tr>
<tr>
<td>- Diagnosis</td>
<td>- Treatment</td>
</tr>
<tr>
<td></td>
<td>- Normal/abnormal</td>
</tr>
</tbody>
</table>
**Interview 3.** The third interview took after I had analyzed data from the first two interviews, becoming cognizant of patterns of information and emerging themes. I shared a summary of my tentative analysis with the participants in order to verify my initial findings and explore additional possible explanations. In addition, I explored in more depth questions of intersectionality and labeling theory by sharing pertinent literature (in the form of very brief quotes and/or explanations – detailed in Figure 2) with the participants. Again, this interview consisted chiefly of conversation about my initial analysis and concepts related to intersectionality and labeling theory. I also asked the following questions of participants:

1. Can you tell me about a time when you may have thought your gender or race was linked being labeled disabled? Can you tell me about a time if/when your label of disability was connected to your gender or racial identity?

2. Did you ever feel at times that the disability label was accurate for you? What made you think this way? Can you describe an instance or two when this happened?

3. Did you ever feel at times that the disability label was inaccurate for you? What made you think this way? Can you describe an instance or two when this happened?

**Figure 2: Labeling Theory and Intersectionality**

<table>
<thead>
<tr>
<th>Labeling theory</th>
<th>Intersectionality</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUOTE 1:</td>
<td>QUOTE 1:</td>
</tr>
<tr>
<td>“…social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders” (Becker, 1963, p. 9).</td>
<td>“…ignoring difference within groups contributes to tension among groups” (Crenshaw, 1991, p. 1242).</td>
</tr>
</tbody>
</table>
Society creates rules and punishes people who break those rules by labeling them as abnormal.

QUOTE 2:
“...patients who manage to find evidence of “their illness” in their past and present behavior, confirming the medical and societal diagnosis, receive benefits” (Scheff, 1999, p. 86-7).

People who play the role of a psychiatric patient (or other label) after they are diagnosed are treated better than those who do not.

We all have many different aspects to our identity (ability, race, gender, class, age, etc.) and these affect each other. Some people have more power than others. If, for example, disabled women and able-bodied women were both working to better the situation of women in general, the concerns of the able-bodied women might be given preference because able-bodied women have more privilege in our society. Different aspects of identity work to privilege or disempower us in different situations.

To review, the first interview consisted of a more formal conversation aimed at exploring the participants’ educational histories and their relationships with their disabilities labels. The second and third interviews were less formal. Both involved conversation about theory - Disability Studies in the second interview and labeling theory and intersectionality in the third interview – in order to give space for the participants to reflect on these theories and their
reactions to them. The third interview also involved soliciting feedback from the participants about my initial analysis.

**Data Analysis**

My analysis of the interviews in this case examined participants’ words for common themes, for explicit or implicit connections to the theoretical framework, and links to the historical cultural schemas drawn out of my historical analysis in order to fully connect all the elements being studied. I used several different techniques for analysis of the interview transcripts. Maxwell (2013) suggests that there are three analytic options for qualitative data: (1) categorizing strategies; (2) memos; and (3) connecting strategies, all of which are explained in the following section. I utilized all three of these options in strategic ways in order to both tell the participants’ stories in an authentic way, situated in the context of historical schemas, and connect their words to theories of structure and agency, labeling, and intersectionality that have been discussed.

**Categorizing Strategies**

In order to situate the participants’ narratives within various contexts, I first used a categorizing strategy - coding the interview transcripts for organizational topics. Maxwell (2013) discusses this type of coding as a process of sorting data for future analysis in which the coding categories are pre-determined and used to rearrange data for future comparison. Figure 3 details the organizational categories that I used for this first round of coding and the types of data that belong to each category.
**Figure 3: Organizational Coding**

<table>
<thead>
<tr>
<th>Sub-questions</th>
<th>Focus</th>
<th>Examples of data collected</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. What is the historical context in which the participant attended school?</strong></td>
<td>Historical context</td>
<td>1. Spans of years, historical events mentioned, etc.</td>
</tr>
<tr>
<td><strong>2. How does the participant relate to that context?</strong></td>
<td></td>
<td>2. Portelli – political, community, and personal levels</td>
</tr>
<tr>
<td><strong>1. What is the local social context in which the participant lived at the time they were attending school?</strong></td>
<td>Socio-economic context</td>
<td>1. Description of neighborhood, family history, mention of local support systems, etc.</td>
</tr>
<tr>
<td><strong>2. What is the local economic context in which the participant lived at the time they were attending school?</strong></td>
<td></td>
<td>2. Parent employment, description of living space, mention of employment while in school, etc.</td>
</tr>
<tr>
<td><strong>1. How does the participant describe the schools they attended?</strong></td>
<td>School context</td>
<td>1. School resources, extracurricular activities, tracked</td>
</tr>
</tbody>
</table>
I also used theoretical categories for coding the interview transcripts. Maxwell (2013) states that these categories represent the theoretical framework that the researcher is using. In this study, I used Sewell’s (1992) theory of structure and agency, as well as Disability Studies, intersectionality, and labeling theory. I thus used coding categories related to those theories, categories which are detailed in Figure 4 with the types of data that were included under each category.

**Figure 4: Theoretical Coding**

<table>
<thead>
<tr>
<th>Interview 1</th>
<th>Sub-questions</th>
<th>Focus</th>
<th>Examples of data collected</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What cultural schemas does the subject use to describe his/her/their own mental disability?</td>
<td>Cultural schemas and self</td>
<td>- medical terms, positioning of self in relation to others, deficit-based language, etc.</td>
</tr>
<tr>
<td><strong>Question</strong></td>
<td><strong>Cultural schemas and others</strong></td>
<td><strong>Interview 2</strong></td>
<td><strong>Resistance</strong></td>
</tr>
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<td>-----------------------------------------------------------------------------</td>
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<tr>
<td>What cultural schemas does the subject use to explain other people’s mental disabilities?</td>
<td>- medical terms, deficit-based language, expressions of emotion like pity</td>
<td>In what ways does the subject reproduce the medical model of disability through his/her/their actions and words?</td>
<td>- refusing treatment, refusing pity, seeking alternative methods of dealing with disability, disability activism</td>
</tr>
<tr>
<td>How does the subject resist the medical model of disability through his/her/their actions and words?</td>
<td><strong>Reproduction</strong></td>
<td>- how their disability is addressed by family and by the participant, treatment undertaken, referring to themselves as sick</td>
<td></td>
</tr>
<tr>
<td>Interview 3</td>
<td>What role(s) does the subject adopt after he/she/they are labeled?</td>
<td>Labeling</td>
<td>- “good” or “bad” patient, “good” or “bad” student</td>
</tr>
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<tr>
<td></td>
<td>What language does the subject use to describe intersections of identity?</td>
<td>Intersectionality</td>
<td>- comparing to other people, roles played by speaker (e.g. patient), references to race, class, gender</td>
</tr>
</tbody>
</table>

**Memos**

Once I had organized data from the interview transcripts, I began to write analytical memos in order to reflect on the data collected. I wrote memos after each round of interviews, with two levels of focus:

1. How do participants’ stories reflect the historical cultural schemas I have discovered through studying secondary sources?
2. How do the experiences of participants strengthen, contradict, or complement theories of Disability Studies, labeling, and intersectionality?

**Connecting Strategies**

In order to make connections between the participants’ narratives, I used Siedman’s (2013) technique of building profiles or vignettes of the participants’ interviews. This technique
allows the researcher to draw out themes that are similar in participants’ experiences, while presenting the participants’ narratives in their own words. I used shorter pieces of interviews (what Siedman called “vignettes”), in order to connect the participants’ experiences both to each other and to the theoretical framework of the study.

**Validity or Trustworthiness**

Validity in qualitative research is also often called trustworthiness. The value of qualitative research methods, and labeling history interviews in this case, is not reliant on the ability of these methods to discover absolute truths. Indeed, the results of qualitative research cannot be verified for how true they are, but rather whether or not they have reached what Polkinghorne (1988) calls a well-grounded conclusion. Assuring the validity of qualitative research then requires the researcher to identify plausible ways that his or her conclusions might be diminished (known as validity threats) and then plan for how to address those threats during the research process (Maxwell, 2010). Maxwell (2010) offers a checklist for testing the validity of qualitative research, several points on which I will address here as relates to this research.

1. “Rich” data

Maxwell suggests that an intensive interview process involving multiple sessions and a procedure of analysis that involves examining precise transcripts of the interviews reduces the possibility for researcher bias, as this process makes it more difficult for the researcher to draw false conclusions based on his or her own observation. I completed three interviews with each participant and closely considered the written transcripts.
2. Respondent validation

Also called “member checking”, respondent validation is a process of seeking feedback from participants on data gathered and conclusions drawn (Lincoln & Guba, 1985). I utilized member checking to validate my analysis through participant feedback.

3. Searching for discrepant evidence

In order to reduce the effect of my own biases and assumptions on my analysis and conclusions, I carefully considered discrepant evidence and solicited feedback from peers and advisors as I conducted my analysis and drew conclusions.

In the end, the validity of qualitative research in its persuasiveness (Riessman, 1993).

The aim of this type of research, as stated, is not truth in the absolute sense but trustworthiness. Claims are most trustworthy when theoretical claims are supported by evidence given by participants and discrepant cases are addressed. Qualitative research offers a means to examine theory and processes of making meaning. As Portelli (1990) says, “oral sources are credible but with a different credibility. The importance of oral testimony may not lie in its adherence to fact, but rather in its departure from it, as imagination, symbolism, and desire emerge” (p. 51). The labeling history interviews were not meant to primarily uncover factual evidence, but rather delve into human desires and actions and the analysis of those interviews involved an investigation of how memories are constructed from the subjectivity of the participants. A process of collecting rich data, checking conclusions with participants, and carefully considering discrepant evidence made for more trustworthy final findings.
**Strengths and Limitations**

The strengths of the labeling history interviews have to do with the ability of the researcher to examine in depth the ways in which people make meaning out of their lived experiences, how they situate themselves within the context of historical cultural schemas, and what processes they utilize to achieve both of these things. A study of 7 participants allowed me to dive deeply into the data and examine nuances. It also allowed me the opportunity to confirm the data that I collected with the participants, as well as my initial analysis.

The limitations of this study have to do with its size and scope. It is not a comprehensive historical analysis of the education of children with mental disabilities, but rather limited to a restricted number of oral testimonies. The ability of such research to inform future research or policy might thus be called into question. However, Eisenhart (2009) describes several ways that qualitative research such as this can be influential to researchers and policy makers. The most effective, she believes, is theoretical generalization, which involves the refinement and development of theory through research. My intention was to add to the existing body of research in the fields of Disability Studies, labeling theory, and intersectionality research with this study, by weaving together historical information and individual narratives to examine how social models of disability have unfolded over time for people with mental disabilities. I explored the degree to which given labels influence an individual’s actions and identity formation, and how these are perpetually (re)negotiated and (re)shaped by hegemonic yet changing discourses. The strength of labeling history interviews lie in the fact that they can lead to a better understanding of how people with mental disabilities navigate their schooling in light of dominant cultural schemas that paint these people as inferior and/or irrational due to being positioned outside of our cultural norms.
Conclusion

As stated, the overall goal of this research is to further develop and refine social theories of disability, labeling, and intersectionality, especially as these theories help us to understand the identity formation of and actions taken by people with mental disabilities. The end result is a collage of narrative vignettes, tied together by the context of historical cultural schemas and leading to theoretical analysis, which aims to illustrate the practical implications of the above-mentioned theories to the lives of people with mental disabilities. This research highlights the voices of people who are often neglected by history and, indeed, neglected by our public schools as can be seen in outcomes of students with mental disabilities. By illuminating the experiences of this population, this research helps to create space for people with mental disabilities to be valued as students and as agentic actors.
CHAPTER 4: HISTORICAL BACKGROUND

Introduction

This chapter explores the history of mental disability, and especially its intersections with the history of public schooling in the United States. Before the late eighteenth century, people with mental disabilities were variously considered as deviants, criminals, or possessed by demons. Until the development of the fields of psychology and psychiatry in the beginning of the nineteenth century, the treatment of people with mental disabilities was often indistinguishable from imprisonment and torture, including flogging and/or being restrained by chains (Shorter, 1997). Even when treatment was publicly seen to be restorative in nature, it isolated people with mental disabilities from the larger society. Asylums to house the insane were meant as protective measures, but they did not work that way for disabled people. Rather, the mentally disabled were not the only people housed in asylums, but also any person who was deemed a danger to society, which could, and did, include:

- Beggars and vagabonds; those without property, jobs or trades; political gadflies and heretics; prostitutes; libertines, syphilitics and alcoholics; idiots and eccentrics; rejected wives, deflowered daughters, and spendthrift sons (Winzer, 1993, p. 30).

In other words, anyone who deviated from the established social order could be imprisoned by reason of their being insane. Conditions such as autism, intellectual disability, and epilepsy were thereafter treated under the umbrella of insanity. The asylums were not sites for rehabilitation of the disabled, but rather were designed to keep the disabled isolated, preventing them from causing harm to the greater society. Any treatment that was offered was in the form of what we would now call torture, the belief being that such handling was the only effective means of responding to such deviant behavior (Winzer, 1993). Foucault (1988) argues that this kind of
treatment did little but further exacerbate these physical and psychological conditions. While enormous progress has been made in the fields of psychiatry and psychology in the last two centuries, leading to a greater scientific understanding of mental disability, public opinion has not always kept pace with scientific discovery. Baynton (2001) has written how mental disability as a concept has been used throughout history as justification to deny people basic human rights based on their race, gender or class.

This chapter will explore some ways in which scientific ideas about mental disability affected popular opinion (or cultural schemas) and vice versa. In addition, it will examine the nature/nurture debate about mental disability that evolved since the early nineteenth century. From the beginnings of the concept of mental disability as an illness put forth by Reil (1803) to Freud’s (1900) conception of mental disability as based in the childhood environment, to the American Psychiatric Association’s (2013) publication of the Diagnostic and Statistical Manual of Mental Disorders as a list of symptoms, there has been a lack of agreement about what constitutes a mental disability. I will argue that both sides of the nature (mental disability as biologically based)/nurture (mental disability as a result of environmental influences) coin represent deep cultural schemas that affect the way mental disability is conceptualized by individuals and by the larger society.

First, however, I will begin by considering the profound affect that psychology as a discipline had on the way we educate children with mental disabilities. The field of psychology came into its own at roughly the same time as public schooling emerged, at least in the United States, and the movements of psychology and common schooling in the United States were and are inexorably entwined.
These are complex histories and examining them demands the weaving together of many threads – cultural schemas of mental disability and scientific advances in the fields of psychology and psychiatry, with the history of public education in the United States. Given this wide scope, it is not possible in one chapter to examine these many threads in great depth. Therefore, this chapter provides a brief overview of the intertwined histories, with a specific focus on the cultural schemas or overarching ideas about mental disability that have played a role in public opinion and been used by mental health professionals, with a view to how these ideas might affect ways in which people with mental disabilities think about their own experiences.

**Origins of Psychology and Psychiatry**

We begin with the years between 1790 and 1840, when there was an immense cultural shift toward the application of reasoned scientific analysis not only of the physical world, but also to the life of the mind. This required a shift in thinking among medical professionals. What had been considered the psyche or soul was now conceived of as the mind or personality and subject to the same laws of medicine as the rest of the body. As Winzer (1993) states, by “about the middle of the nineteenth century there appeared in all branches of science, and especially in medicine, a growing demand for greater precision and accuracy, which ultimately translated into more cogent definitions and classifications for exceptional conditions” (p.146). For mental disabilities, this meant trying to define the limits of rationality and irrationality, sanity and insanity. While public schooling was emerging in this country in these years, the fields of psychology and psychiatry were also coming into their own. Charles Darwin published *The Origin of the Species* in November 1859 and ten years later his relative, Francis Galton, applied Darwin’s ideas to human behavior in his book *Hereditary Genius* (1869). Enlightenment philosophies of the eighteenth century prompted the use of the scientific method for studying
human behavior and society and Galton’s work took a step toward applying ideas of evolution and heredity to human intelligence. He is also known for being a pioneer in the field of eugenics, the pseudoscience of improving human beings by selective breeding. Alfred Binet and Theodore Simon’s publication of the article “New Methods for the Diagnosis of the Intellectual Levels of Subnormals” followed in 1903, and by then the separation of psychology from philosophy and psychiatry from medicine had begun (Lagemann, 2000).

Psycho-therapy began in a crude form in the beginning of the nineteenth century with a publication by Johann Christian Reil, who recognized the mind/body connection and believed that a study of the mind could be a tool by which doctors could diagnose not only mental, but bodily diseases (Alexander & Selesnick, 1966). Reil also recognized that distinguishing an abnormal personality required the definition of a normal personality. He stressed, however, that the field of psychology should not merely consist of making decisions about what is normal behavior but rather should be a tool to treat both mental and physical diseases. In 1803, Reil published a piece called *Rhapsodien uher die Anwendung der psychischen Curmethode auf Geisteszerrettungen* – Rhapsodies about the Application of Psychotherapy to Mental Disturbances – which was indicative of a cultural shift away from conceptualizing mental disabilities as criminality and toward the medicalization of these disabilities where the treatment took the form of psychotherapy (Alexander & Selesnick, 1966). Initially, this psychotherapy was little more than manipulation of behavior through rewards and punishment, the punishment being still related to the torturous techniques with which people with mental disabilities were treated in earlier periods. But Reil’s program was in fact the beginning of a research-based program of psychological rehabilitation. The kind of conditioning and behavior modification with which Reil began experimenting was made popular in psychology several years later by
Ivan Pavlov and John B. Watson and the idea that measurable behaviors can be affected by changes in the external environment continues to influence psychology and education today (for instance in the practice of functional behavioral assessment which focuses on changing behavior by addressing its antecedents).

During the late eighteenth century and into the nineteenth century, medicine and science became important to every aspect of culture, including the life of the mind. Empirical, scientific research was considered to be the benchmark of knowledge creation (Alexander & Selesnick, 1966). Advances in psychology and psychiatry during the late eighteenth and early nineteenth centuries not only affected the medical and scientific realms; their effects were also seen in philosophy, art, and literature. People like George Bernard Shaw, Henrick Ibsen, and Fyodor Dostoyevsky wrote about characters with psychological issues, even mental disabilities, and helped create a cultural space in which the field of psychology could grow and thrive and be taken seriously as a science (Alexander & Selesnick, 1966). Psychology and psychiatry captured the imagination of scientists and laypersons alike and began to shift cultural ideas about mental disability. People began to think that mental disability could perhaps be diagnosed and treated like any other illness. The medical model of madness was born while at the same time a foundation of scientific understanding of madness was developed. The relatively new realm of education was seen as a field in which psychologists on the cutting edge of empirical research could do practical work (Lagemann, 2000). It is for this reason that psychology has shaped education since almost the outset of public schooling.

**Origins of Public Education in the United States**

Horace Mann, an education reformer in the mid-1800s (often considered the father of public schooling in the United States), said that “the theory of our government is, - not that every
man, however unfit, shall be voters, - but that every man, by the power of reason and the sense of
duty, shall become fit to be a voter. Education must bring the practice as nearly as possible to
the theory” (Mann, 1840, p.58). Public education in this country initially had the goal of creating
an informed citizenry. There was a near universal wish for and commitment to common
schooling in the 19th century. In those early days of the American republic, citizens were aware
of the tenuous nature of their relatively new republic. History, after all, seemed to suggest that
such a government could not last long. This fear developed into a common belief that “the
survival of the republic depended upon the virtue of its citizens” (Kaestle, 1983, p.79). In other
words, children must be instructed in such a manner that they would grow up to be effective and
honorable American citizens. Many thought that education, particularly moral education, could
prevent criminal behavior and poverty and argued for common schooling, paid for through
taxation, based on this assumption. We need to understand that the framing of mental disability
as a disease only extended, at this point, to some types of madness or to some people. In public
opinion, there was still something abnormal about the minds of the poor and it was education
that was to be the answer to treating such personal abnormalities.

Increased pressures of industrialization, urbanization, and immigration meant that public
schooling had broad support in the United States in the first half of the nineteenth century, in the
hopes that moral education would prevent criminal behavior and that cultural education would
help immigrant children to assimilate (Kaestle, 1983). In 1830, the Working Man’s Advocate, a
newspaper published by workers in New York, put forth a popular argument for the development
of common school education in the United States

An opinion is entertained by many good and wise persons, and supported to a
considerable extent . . . that proper schools for supplying a judicious infant training,
would effectually prevent much of that vicious depravity of character which penal codes and punishments are vainly intended to counteract (Commons, Phillips, Gilmore, Sumner, & Andrews, 1958, p.98).

Thus in the beginning, public schools were intended to transform children into educated and proper American citizens. However, all children were not viewed equally. Poor children were, in theory, included in these institutions, but often attended overcrowded and poorly resourced schools despite the fact that the notion of the common school what that children of the poor, working class, and wealthy would attend school together. Children who were physically disabled and those who were thought to be “backwards”, “naughty”, or “dull” often did not attend school at all. The first public school in New York City was established in 1842, but it was not until 1897 that classes for those “deviant” children were founded by Elizabeth Farrell, who later went on to found the Council for Exceptional Children, a professional association for special educators (CEC, 2017). Children considered disabled during the early years of public schooling were excluded and thus likely kept from engaging in any type of employment requiring literacy skills and certainly from any involvement as full citizens of the democracy.

In the late nineteenth century, categories such as intellectual disability, autism, mental illness, and behavioral disorder had not yet been differentiated from one another. There was no clear distinction, indeed, between children with medical conditions and those who were merely difficult to manage and understand. As Winzer says, “children were labeled as neglected, vagrant, delinquent, or truant, or as part of that category of matchless elasticity – incorrigible” (Winzer, 1993, p.344). Despite the grand goals of public education, schools took very little responsibility for such children until the early twentieth century when social reformers began to take notice of the fact that these children were likely to face similar issues and problems into
adulthood. At that time it became a social imperative to rescue such children before they could turn into a greater burden on society. A *New York Times* opinion piece published in 1874 called for compulsory schooling as a way of managing such children. According to the anonymous reporter:

The great evil of street vagrancy among children has weighed upon this City since the memory of the earliest inhabitant. With the influx of a poor foreign population, the dregs of which were deposited here, there appeared the beginning of what has proved since a numerous class of homeless, vagrant, and street-wandering children (*New York Times*, 1874).

In sum, school was seen as the proper means by which such children could be civilized.

**Origins of Special Education**

Special education in the late nineteenth century, such as it was, was a separate entity from the education provided to the general population. Winzer (1993) states that “the standard constellation of educational influences in society – the family, the community, and the church – were not viewed as appropriate socializing agencies for disabled persons, for whom education was judged to be even more completely dependent on schooling than it was for normal children” (p.93). Disabled children were placed in institutional schools, more often than not, where they were sorted according to their disabilities (institutions for the deaf, for the blind, feebleminded children, and so on). Children who might be considered mentally disabled were more often than not grouped in with those who might today be considered intellectually disabled. At the same time, children who were neglected or truant were often dealt with within the justice system. These types of children, seen to be not so much disabled as merely evidence of a breakdown in the traditional family system, were not very welcome in public schools. As education reformer
Henry Barnard remarked in 1857, “such children cannot be safely gathered into the public schools…they soon become irregular, play truant, are punished and expelled, and from that time their course is almost uniformly downward, until on earth there is no lower point to reach” (1857, p. 2). From concerns about the well being of these children (and indeed, concerns about the well-being of urban America in general) came a response in the form of reformatories and industrial schools. Thus we see that by them mid-nineteenth century, mental disability was still framed as a threat to society and the response, more often than not, was to automatically exclude those children from the larger society. In brief, two distinct cultural schemas had come into play thus far – mental disability as a threat to society and mental disability as a disease that could be treated.

The Influence of Psychology on Public Education

In the late nineteenth century and early twentieth century, scholars of psychology began to influence philosophers of education and vice versa. Among the upper and middle classes there was generally a great deal of importance placed on social and moral reform at this time with the idea that social problems would not solve themselves and intervention from government and philanthropic entities was necessary (Alexander & Selesnick, 1966). While a push for compulsory public schooling was going on in the United States, so too was the movement to reform mental institutions and shift their focus from containment to rehabilitation, using some of the techniques being championed by early psychologists and psychiatrists. By 1880, the vast majority of the nearly 41,000 people who were institutionalized nationally for mental illness were housed in public institutions, showing the commitment by the nation to treatment of the mentally ill (Grob, 1983). By the turn of the twentieth century, an impressive network of public and private mental institutions existed throughout the country (Ibid.). At the same time, public
schools were growing rapidly. In 1890, there were about 12 million students attending public schools in the United States, a number that would more than double by 1930 (Fagan & Wise, 2000). Public schools were meant to prevent criminality and even mental disability while public institutions for the mentally disabled were used to protect the public from those who were deemed a threat.

Many prominent activists for public schooling were also activists for the reform of mental institutions (Grob, 1983). Horace Mann, perhaps the most famous promoter of public schooling, also was vocal in his support for the reform of mental institutions and better treatment for the mentally disabled (Grob, 1983). Adolf Meyer, a leading figure in American psychiatry from the 1890s to the 1940s, socialized with John Dewey and is rumored to have been heavily influenced by Dewey in his notion that a patient’s environment affects his or her outcomes (Grob, 1983). On the other side, psychiatric advocates were also advocates for public schooling. While public schooling developed in the United States, so too did reforming treatment of the mentally ill. While certainly there may have been humanitarian motives among individuals who championed these causes, the primary object of these reforms was to “protect” a society that was quickly changing because of a sharp rise in immigration and rapid industrialization.

As psychology emerged as a discipline separate from philosophy, the belief took hold that the mind and behavior could be studied and measured. The application of psychology to education was obvious, and with more and more children attending public schools, there was a huge laboratory open to the new field of psychology (Lagemann, 2000).

Until this period in history, what we now consider “childhood” did not exist, as children were previously viewed merely as small adults, without any consideration of developmental stages (Winzer, 1993). Even when education initially emerged as a field of study in psychology,
many psychologists paid no attention to the developmental stages of children, preferring to direct their inquiry to developing curricula that would prepare students for their place in society as adults (Lagemann, 2000). There were some, however, with G. Stanley Hall as the founding father of the movement, who believed that child study could greatly inform theories of pedagogy.

Child Study

While not the first to study the development of children, Hall’s work piqued the interest of those social reformers who were concerned about the ability of the educational system to create productive citizens. It is worth noting that public schools were becoming more diverse at this time (from the 1880s and on) as waves of immigrants from disparate parts of the globe shifted the demographics of the country. The number of children attending school was also growing and reformers saw the rote educational methods that were widely used at the time as unable to respond to these new challenges that schools were facing. Hall (1891) argued that psychology and the study of child development as applied to education could help to avoid “the mutilation which so powerful an engine as the modern school may inflict upon the tender souls and bodies of our children, and thus upon our entire national future” (p.121). In spite of these grand words, Hall and the child study movement were mostly concerned with the science of psychology. Their studies of children were on a mass scale, done through surveys and interviews, and concerned with what could be measured rather than on ways to improve teaching and learning (Lagemann, 2000).

The evolution of specialties within psychology placed greater emphasis on the practical applications of research rather than study for discovery or the improvement of greater society. Psychology increasingly broke away from its original parent discipline, philosophy. While both John Dewey and Edward L. Thorndike could be considered educational scholars, the two could
not have been more different in their views. Dewey was a philosopher concerned with social reform and the future of American democracy through public schooling while Thorndike and others of his school were focused on developing instruments to measure the innate capacity of individual children to learn (Lagemann, 2000). While Dewey’s work harkened back to the philosophical roots of educational psychology, Thorndike and others were firmly entrenched in the idea of psychology as a science. In fact, Thorndike encouraged his students to study statistics over conducting any experimentation in schools, in direct conflict with Dewey’s idea establishing and analyzing the impact of laboratory schools. Thorndike’s call for measurement had greater influence over the field of psychology at that time, as we can see from the development of standardized intelligence and achievement tests, which quickly found their way into schools.

**Psychological Testing in Schools and the Eugenics Movement**

In 1905, Albert Binet and Theodore Simon published the first intelligence test. It was also the year that the American Breeder’s Association Committee on Eugenics was founded and we will see that it is difficult, if not impossible, to untangle histories of educational testing from the eugenics movement (Winzer, 1993). Despite warnings from some psychologists, including Binet himself, that the tests were not meant to decide a child’s educational fate, we will see that in practice that is often what happened. The emergence of school psychology as a field introduced standardized testing as a tool for measuring academic achievement but also for categorizing students.

School psychology began in clinics, staffed by psychologists or special education teachers, which allowed teachers to refer students who posed behavioral issues (Winzer, 1993). The specialization of school psychology distinguished itself from other specializations by
merging “nomothetic” and “idiographic” means of research (Fagan & Wise, 2000). In other words, the field merged broad categorization of students along the lines of normative characteristics (nomothetic research) and individualized study through case studies (idiographic research). This double-pronged approach to child study continues to this day to be the purview of school psychologists.

By 1914, when J.E. Wallace Wallin, a psychologist who studied the mental health of school children, did a survey of 103 city school systems about the accessibility of psychological services, 84 responded that they were using psychological testing in their schools (Wallin, 1914). It was not always psychologists doing the testing; educators and administrators also performed this duty. According to Fagan and Wise, “the spread of psychological services was spurred by the development of psychological and educational tests and the interest of school systems in segmenting their student population” (2000, p.36). By 1918 compulsory attendance laws were in effect, resulting in schools being overwhelmed with increasing populations, driving their need to find ways to manage this problem. They turned to psychological testing.

Despite advancements in the field of psychology, there was still conflation of mental health, intellectual disability, and poverty, in the minds of the American public. Indeed, all three characteristics were often grouped together in the nebulous concept of “feeblemindedness”. Advances in the field of genetics strengthened cultural schemas about the inferiority of those living in poverty or those with mental disabilities. Psychiatrists believed that intelligence and general mental health were predetermined, hereditary conditions. As a result, psychiatrists “discovered” the concept of degeneration, which indicated that a mental disability was not only hereditary, but also a condition that became progressively worse with each new generation (Shorter, 1997). The logical extension of such beliefs about the inferiority of certain people and
the threat that they posed to society served as the catalyst for the birth and growth of the eugenics movement.

The eugenics movement called for the creation of a superior race of humans through extreme socio-biological measures. Winzer (1993) notes that eugenicists, “having adopted the idea that everything about a person’s condition – from socioeconomic status to life span – is inherited and immutable from the moment of conception, could argue that human society, like nature, must be harsh to its weaklings or it would foster within itself destructive social ills” (p. 284). This strain of thought was not limited to a discrete section of society but was encouraged by major corporations and even the United States government (Winfield, 2007). For example, by 1930 more than half the states had enacted compulsory sterilization laws targeted at the feeble-minded and mentally disabled (among others) (Winfield, 2007). Immigration laws in the early twentieth century were explicitly aimed at the exclusion of people with mental disabilities (Baynton, 2001). Eugenics ideology trickled into schools where, with the surge in psychological testing that was occurring at the same time, students were assessed for their mental capabilities and sorted accordingly (Winzer, 1993).

The period between 1900 and 1914, commonly known as the Progressive Era, was noteworthy for the sweeping social and political reforms, which included the theories of child-centered education. While catering to the individual needs of children seemed like a noble goal, psychological testing in schools did not benefit all students equally. Such testing meant that children could be both educated according to their scientifically-proven individual needs but also sorted in such a way that the feebleminded could not have undue influence on those children who were genetically superior.
Winfield (2007) argues that many of the social reforms popularized in the Progressive Era (like immigration reform) were backed by eugenic ideals.

[Reform] may seem antithetical to the Darwinian notion of natural selection and evolution which was used to justify the hierarchal access to wealth and power... It is, however, the same logic that drove the activist. Because of the perceived increase in the number of defectives in society (due to immigration and subsequent ‘prolific’ breeding), the process of evolution was thought to be simply too slow to adequately handle the needs of civilized society (p.59).

Schools were, as we have seen, given the task of creating that civilized society and so it was only logical that eugenic ideas would find their way into the structure of public education.

It was Henry Herbert Goddard, a student of G. Stanley Hall, who pushed psychological testing in schools from a eugenic standpoint (Winfield, 2007). He revised the Binet test and developed the idea of mental age, as well as coined the word “moron”. He initially took his revised intelligence test to Ellis Island to “prove” the mental inferiority of incoming immigrants. Soon the tests found their way into schools (Winfield, 2007). In 1911, the New York Times printed an account of a gathering of reform workers (which included Elizabeth Farrell, by then the Inspector of Ungraded Classes in New York Public Schools) at which Goddard estimated that one in eighty-seven people was feebleminded (New York Times, 1911). Goddard believed in separate education for the feebleminded and that, for them, moral education was more important than academic education if they were to become proper citizens (Goddard, 1921).

The compulsory schooling laws, in place by 1918, had brought a new set of challenges to public schools. Children who may not have participated in education at all prior to the passage of such laws were now part of the school landscape. This included many poor and immigrant
children and many who were in poor physical and mental health (Fagan & Wise, 2000). In an era when disability was rapidly being labeled and categorized because of advancements in medicine and psychology, schools remained a place where professionals (doctors and psychologists) could have access to a population in need of services. Mandatory examinations of physical and mental health were common in schools. Wallin suggested that children who were not progressing academically be inspected for physical defects as well as given “a psychological examination…for the detection of intellectual retardation and anomalies of sensation, movement, memory, imagination, association, attention, imitation, color perception, speech, number sense, fatigue…” (1914, p. 17).

It is worth noting that Wallin believed that children who presented with shortcomings in these areas should be segregated into special classes or even institutionalized (the common view at the time held that normal children would be negatively influenced by their disabled peers) (Fagan & Wise, 2000). The initial goal of school psychology was thus not to properly educate children with disabilities but rather to discover which children posed a threat to the education of the masses, and then remove that threat by segregating the disabled. Hall wrote an article for the *New York Times* in 1911, in which he stated “stammerers, stutterers, the mattoids and morons and those with other inherently morbid tendencies are sources of moral, not to say physical, infection” (p.14) and should be identified and segregated. Thus mental disability was seen as a disease, a contagious one that could spread to other children through contact with those infected.

There was no one method of providing psychological services to schoolchildren in the early days of school psychology. Oftentimes psychologists working with schools were employed by clinics in universities or health centers, serving several school districts simultaneously. Some school administrators or others without formal training might also provide psychological services
in the form of testing (Fagan & Wise, 2000). As more and more children were placed in special education and the profession evolved, school districts began employing school psychologists and the discipline became more respected, with the development of professional organizations and training programs in universities. Psychologists rarely offered any treatment of mental disability, however. Instead their purview was psychological testing. This testing again framed mental disability as a threat to the fabric of society, where the solution was segregation of disabled children from the general population.

The Nature versus Nurture Debate in Psychiatry

The tide of public opinion does not always keep pace with scientific discovery. While eugenic ideals were part of the common parlance before World War II, psychologists and psychiatrists were beginning to treat mental disability in a less punishing fashion. The profession was beginning to make distinctions between the effects of environmental factors (such as the alcohol or tobacco use of parents or parental/child relationship) and bodily illness. The debate about the causes of mental disability is ongoing in the fields of psychology and psychiatry but can be broadly broken down into the difference between nature and nurture, with the former focusing on inherited genetic characteristics and the latter centered on the impact of the familial environment. As an example, mental disability has been classified over time as a disease with organic causes, but also as the result of repressed childhood memories. The back and forth shifts between nature and nurture, and the complexities they raise, have greatly influenced cultural schemas of mental disability. This following section will briefly explore this debate, but before that I will briefly situate nature and nurture in the context of the medical model and the schemas of mental disability as a threat to society and mental disability as a disease that have been discussed.
Suggesting that mental disability is part of the nature of a person is synonymous with the schema of mental disability as a disease (in this case, an organic disease). It is simple to see how this view fits into the medical model. If mental disability is a disease, then it is a deficit of the individual that should be treated by professionals. However, suggesting that mental disability is a product of a person’s upbringing – the nurture side of the debate – is not the same as saying that they are disabled because of oppressive societal factors (which is what the social model claims). The nurture side of the debate is still very much within the context of the medical model in that it views mental disability as an acquired disease. It utilizes the other schema, of mental disability as a threat, and a threat that requires the involvement of professionals. Therefore, while the debate between nature and nurture has been ongoing in psychiatry, it is merely a debate over which cultural schema is most appropriate – mental disability as a disease or mental disability as a social and familial problem; a threat to greater society. Both schemas, however, are deficit-based ideas about the character of mental disability and at times are used in combination, but always to reinforce the medical model.

German psychiatrist Emil Kraepelin created a classification system for mental illness in 1896 and French psychiatrist Sante de Sanctus studied emotional disturbance in children shortly thereafter, referencing the work of Kraepelin. In their work there was some movement away at this time from theories of mental hygiene (focused on environmental factors), which were being replaced by the idea of mental illness (focused on organic factors). The mental hygiene movement pioneered by Clifford Beers, a former psychiatric patient, had originated within the movement to reform of mental institutions. Beers wrote of his experience in his 1908 book, *A Mind That Found Itself.* Its focus, and the focus of the mental hygiene movement, was on the prevention of mental disability through early intervention. It was commonly believed by those
who supported the movement that mental disability was the result of childhood experiences (such as a parent’s alcohol abuse) and could be improved through education (Robbins, 1933).

The two philosophies of mental hygiene versus mental illness existed in tension until at least the 1930s, at which point conditions such as childhood schizophrenia and autism had been documented and classified. By then it had become common to think of mental disability as a form of illness and not the fault of parents or environmental conditions. Kraepelin’s classification system had a great influence on the field of psychiatry, with the idea that different forms of mental disability could be categorized based on their symptoms. Adolf Meyer, considered a founding father of American psychiatry, embraced Kraepelin’s system and brought it to the United States in the early 1900s, championing the idea that the causes of mental disability were organic in nature. A biological model of mental disability thus held sway and patients were increasingly treated by doctors and even surgeons. In the early part of the twentieth century, Meyer was still suggesting treatment for madness that included having teeth and parts of the bowel removed in order to detoxify the patient (Shorter, 1997). By the 1940s, however, Meyer had changed his mind and put forth his own classification system for mental disability with a recommendation of psychotherapy as the best practice for treatment (Shorter, 1997). By this time, Sigmund Freud’s work commanded great influence.

Freud’s fame came from the idea that psychosis and nervous disorders derived from repressed childhood memories and unconscious stimuli rather than any biological cause (Shorter, 1997). His solution was psychoanalysis, which entailed analyzing dreams and memories in the form of talk therapy. Freud’s resounding impact on the field of psychiatry cannot be overstated. When his book The Interpretation of Dreams was translated into English, the New York Times claimed that Freud’s work was already having a significant effect upon psychiatry (New York
Times, 1913). By 1950, the vast majority of psychiatric training institutes focused on psychoanalysis and interest in psychoanalysis extended to psychologists and social workers (Shorter, 1997). This shift also extended to the treatment of children. Freud himself used psychotherapy to minister to young people with psychological issues (Alexander & Selesnick, 1966).

By the end of World War II, psychoanalysis was the preferred treatment for mental disability in the United States (the result, at least in part, to Meyer’s embrace of the discipline) (Shorter, 1997). By the 1940s, psychoanalysis was being used widely in the United States, a shift that had two major effects: professionals were once again seeing mental disability as environmental in cause; and it established the notion that all people were susceptible to the development of neurosis, thus putting an end to (at least for a few decades) the idea of mental disability as a disease. According to Alexander and Selesnick, “[Freud’s] recognition and reconstruction of unconscious motives, on which his system of therapy for mental illness is founded, substantially extended the application of psychological causality and for the first time provided a way to affect the structure of human personality” (1966, p.182). Psychoanalysts assumed that all people experienced some form of neurosis (Shorter, 1997). Freud’s work made popular the notion that children were not to blame for their problem behavior; rather there was an underlying cause that could and should be treated by a professional (Winzer, 1993).

The veneration of psychoanalysis continued in the field of psychiatry well into the 1960s. The first editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) were written based on the experience and philosophy of psychoanalysts. Mental health professionals in the United States (most of whom had training in psychoanalysis) had been heavily involved in
the classification and treatment of soldiers returning from World War II and their experiences led to the first publication of the DSM in 1952.

There was, however, eventual pushback in the psychiatric community. Robert Spitzer (who had been trained as an analyst) and others broke from the ideas of Freud and harkened back to Kraepelin. They believed that a classification of mental disorders should involve standards for diagnoses, much like any other disease. At the same time, insurance companies were pushing for more explicit diagnostic criteria to justify treatment and, in the social movement culture of the 1960s and 1970s, there were groups protesting some of the classifications in the first editions of the DSM, such as the idea that homosexuality was sexual deviance (Shorter, 1997). In addition, psychiatric medications had arrived on the scene. The first was chlorpromazine, manufactured by a French pharmaceutical company in the 1950s, and many more followed ranging from anti-anxiety medications to anti-depressants to mood stabilizers (Shorter, 1997). The invention of such medications also helped shift the field of psychiatry back towards the idea that mental “disorders” had biological causes, since they could now be treated pharmaceutically. The publication of the DSM-III in 1980, included diagnostic criteria for each listed disorder, treating them as diseases. Spitzer was quoted in the New York Times as saying, “We are data oriented and for the first time we are introducing specific criteria under each disorder. We are looking for verifiable rather than inferred symptoms” (Clines, 1978, p.8).

Now in its fifth edition, the DSM has grown exponentially in the past 60 years. While this may be considered a result of advancements in the field of psychology, it also represents a large increase in the number of people who may be considered mentally disabled, or who are receiving medical treatment for their mental health. Subsequently, it is likely that a larger percentage of the population might now identify as having a mental disability. It seems from the vastly expanded
list of possible mental disorders that while mental disability as a disease is the preferred schema in the field of psychiatry, the profession never really gave up Freud’s idea that all people could be susceptible to mental disability. And the DSM-V, published in year 2013, is very much a publication that still engenders controversy. The *New York Times* published an article weeks before the release date of the DSM-IV in which several influential psychiatrists said that the manual was outdated and expressed their wish “to encourage researchers and especially outside reviewers who screen proposals for financing from this agency to disregard its categories and investigate the biological underpinnings of disorders instead” (Belluck & Carey, 2013, p.13). In some ways, it can be argued that psychiatry and psychology are fields very much in their infancy and differences of opinion among professionals continue to occur as both fields continue to evolve. While psychologists and psychiatrists may disagree over the causes and ways of categorizing mental disabilities - whether nature, nurture or some combination of both - few professionals have moved away from the idea that mental disability is a deficiency. These fields still utilize the medical model and the schemas of mental disability as a threat and mental disability as a disease.

**Returning to the World of Education**

After World War II, there were fundamental shifts in the world of education as well. When the case of *Brown v Board of Education* was decided by the US Supreme Court in 1954, the field of special education was already in the midst of a crisis of conscience regarding the effectiveness of segregated classrooms for children with disabilities. The social movements of the 1960s focused on race, gender, and sexual orientation and the Disability Rights Movement of the early 1970s cemented a shift from what Winzer calls “qualitative to quantitative conceptions of exceptionality” (Winzer, 1993, p.380). She argued that:
The qualitative model holds that disabled individuals are different and deviant – they learn, perceive, and think in ways that are unlike the normal. The quantitative model views these differences as a matter of degree, not kind – exceptional people develop and function much as others do, but their progress may be slower and their achievements more restricted (Winzer, 1993, p.380).

When the Education for All Handicapped Children Act was passed in 1975, it was the result of this shift in perspective and required that students with disabilities be placed in the least restrictive environment that suited their needs, thus marking at least a policy change in how children with mental disabilities were dealt with in schools. However, educational practice does not always keep pace with scientific advancements or educational policy that would seek to be more inclusive. While policy was aimed at integration and inclusion, in practice special education became a means of continuing the segregation of students of color as a disproportionate number of them were placed in separate classes, as was discussed in Chapter 2. For example, according to Oswald, Coutinho, and Best (2002), black male students are five times more likely to be given the label “Severe Emotional Disturbance” than white females and Hispanic males are twice as likely as white females to receive the same label and children given such a label are much more likely to be placed in segregated classrooms. Mental disability was still being used as justification for the oppression of children based on race, despite policy decisions that, in theory, indicated more inclusive cultural ideals. Those who were deemed a threat to cultural norms, whether because of race or mental disability or both, were still pushed out of the mainstream.
Psychiatric Survivors and Mad Pride

As psychiatry has become more and more focused on finding biological causes of and treatments for mental disability, some people with mental disabilities (as well as like-minded academics and mental health professionals) have pushed back against the domination of negative schemas that have governed psychiatry for the past few decades. The idea that people with mental disabilities are not defective, but that mental disability is merely a difference, is at the heart of the arguments that have been put forward by advocates since the 1960s.

The anti-psychiatry movement in academia and the psychiatric survivor movement among people with mental disabilities both grew out of the social movements of the 1960s and 1970s. Szasz (1970), Scheff (2009), Goffman (1963) and Foucault (1988), all of whom have been previously mentioned, were influential in arguing that the field of psychiatry effectively exercised control over people who were considered deviant. The psychiatric survivor movement, in ways similar to the Disability Rights Movement, fought against a medical or deficit model of seeing and treating mental disability. The focus of the anti-psychiatry movement in academia and the psychiatric survivors’ movement was protesting coerced and inhumane treatment – e.g. involuntary hospitalization and medication and electro-shock therapy (LeFrançois, Menzies, & Reaume, 2013).

In 1978, Judi Chamberlain published her book On Our Own: Patient Controlled Alternatives to the Mental Health System, which became a key text for psychiatric survivors and others who were interested in alternative treatments to conventional psychiatry. Chamberlain herself was a psychiatric survivor, having first voluntarily committed herself during a period of depression following a miscarriage. She was later diagnosed with schizophrenia and involuntarily committed for several months (Chamberlain, 1978). She went on to join the Mental
Patients Liberation Front, an advocacy organization based in Boston. Similar organizations sprang up across the country and in Canada and the United Kingdom. The aim of these groups was primarily raising awareness about the plight of people with mental disabilities. But some groups also offered alternative support in the form of housing and crisis care (LeFrançois, Menzies, & Reaume, 2013). Ultimately, the goal of the psychiatric survivors’ movement was for people with mental disabilities to take back control of their lives from mental health professionals. There has been and still is disagreement within the movement as to whether it is possible or desirable to collaborate with like-minded professionals.

In the 1980s, many of these organizations joined together under the umbrella of MindFreedom International (MindFreedom International, 2017). Among other things, MFI catalogs Mad pride events, which range from conferences to protest marches to festivals, all with the aim of raising awareness of the fact that being mad is not a deficiency (Glaser, 2008).

Although members of the psychiatric survivor or mad pride movements agree that madness is socially constructed, much like those who use the social model of disability believe that disability is socially constructed, there has not been a seamless collaboration between the two groups. In the words of David Oaks, former Executive Director of MindFreedom International:

You have to remember our number one issue was rejecting labels. If you had walked into a meeting of Madness Network News or the Network Against Psychiatric Assault in the late seventies or early eighties and said you wanted to write an article about how we were “disabled,” I’m afraid that article wouldn’t have been published. The label itself, the word “disabled” – that alone was a big barrier for people to recognize our common ground. And it still is challenging, and people can get stuck on that (Pelka, 2012, p.301).
Rejecting labels was, for the psychiatric survivor/Mad Pride movements, the key to creating a new cultural schema of mental disability, one that framed mental disability as a difference (and sometimes a strength), which will be discussed in further chapters.

**Conclusion**

Examining briefly the intersections of the histories of public schooling, psychology, and psychiatry in the United States offers insights into the cultural schemas around mental disability that are most frequently invoked in education. As referenced in Chapter 2, Sewell (1992) defines deep cultural schemas as those that are not consciously recognized by those who make use of them but yet are extremely influential. I believe that the examination of history in this chapter highlights two deep cultural schemas that are present within the common knowledge of public schooling:

- mental disability as a threat to society (a schema that has been used to justify the exclusion of many groups, based on the idea that they are mentally disabled); and
- mental disability as a disease (which still frames mental disability as a defect, while not making it the fault of those who suffer it).

I will argue in Chapter 7 that there is a cultural schema that is more consciously used in response to or in critique of those two deep schemas – mental disability as a difference that can often serve as a strength. It should be noted that while it is useful to think of these schemas separately for the sake of analysis, in practice at all three schemas overlap and interact with each other in

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2 Mental disability as a threat has multiple meanings. Those labeled or potentially labeled with mental disability could see this as a threat because of the fear of being considered abnormal. Others could see a label of mental disability as a threat out of a fear of violence or negative influence on “normal” people. In all cases, mental disability is seen as a threat to “normal” society.
participant experiences. These three schemas should be thought of as continuously in discourse with each other.

Inherent in the eugenic underpinnings of the psychological testing used in schools to this day to determine whether or not students qualify for special education services is the cultural schema that mental disability is a threat to society. It is a threat that has been historically responded to by the exclusion of children with mental disabilities from public schooling or, at the very least, their segregation from their “normal” peers. In the more recent move toward pinning down the biological causes of mental disability, we see how the cultural schema of disease has been used. We see that there has been an effort to consider mental disability as a difference, a normal human variation. There has thus been a push for inclusion and recognition of mental disability as a possible source of strength, not always a deficit. This informed approach is clear in the intentions behind the passage of the Education for All Handicapped Children Act in 1975, even if in medicine and in public opinion generally disability is still regarded as a defect.

In the next chapters I will consider the lives of the seven interviewees who participated in this study and examine the ways in which these cultural schemas – mental disability as a threat, mental disability as a disease, and mental disability as a difference/strength – are present in the ways in which they consider their own disabilities. I will examine their experiences from the point at which they were labeled with a mental disability and look back over their years of schooling and how those years were affected by their disabilities. I will first examine participants’ knowledge of and acceptance of schemas of mental disability as a threat and mental disability as a disease in order to reproduce structures of normalcy.
CHAPTER 5: PERFORMING “GOOD”

The concept of normalcy is a social construct, what Sewell (1992) calls a structure, and schooling is a resource through which this concept is reproduced. We have seen that the cultural schemas of mental disability as a threat and mental disability as a disease also contribute to the structure of normalcy by influencing the treatment of children in school. In Sewell’s (1992) theory, resources and schemas mutually reinforce each other in order for structures to be reproduced. This reproduction is not automatic, however. Human beings also possess resources - tangible (such as financial resources) and intangible (such as knowledge of how to self advocate) - which can be put into use either to reproduce the structure of normalcy or resist it. In this chapter, I (1) examine how participants and schools reproduce/d the cultural schema of mental disability as a threat based on their success in playing the good student and (2) investigate how participants and schools reproduce/d the cultural schema of mental disability as a disease based on their success in playing the good patient, ultimately revealing how both “cases” reproduce the structure of normalcy.

If a mad person can approximate “normal” behavior through medical intervention, or treating mental disability as a disease and playing the “good patient”, then they are allowed more access to society (Scheff, 2009). Similarly, if a child can perform the role of a “good student”, then they are not labeled with a disability in school, even if they experience extreme distress in their inner worlds or social relationships. Children then have greater access to academic opportunity, as we have seen in Chapter 2 where the outcomes of students labeled with disabilities were discussed.

Children in schools who are labeled with a disability, whether officially or unofficially, often receive that label because of school failure, or in other words their inability to function as a
“good student”. The “good student” role as defined here includes being obedient, submissive, and making an effort to succeed academically, not merely reaching certain educational standards. Official labeling would mean being given a disability label whether through school (legal labeling for special education services) or by a medical professional. Unofficial labeling would mean being considered unintelligent or considered as a troublemaker by teachers, administrators, and/or peers. A child’s ability to perform the role of good student requires access to various resources, both human (such as the ability to concentrate and sit still) and non-human (such as appropriate dress) (Sewell, 1992). Based on the circumstances of their upbringing, as well as the specifics of their disability, some children will be better equipped to play the good student than others. In any case, the desire to perform the role of the good student involves recognition of the fact that the alternative – having a mental disability – is a problem whether conceived of as a threat or a disease. These are deep cultural schemas which are acted upon unconsciously by most people and, indeed, by some of the study’s participants. However, based on the resources available to them as children, some of the participants did perform the role of good student to avoid being labeled. If students with mental disabilities can “pass” as normal, or if they come equipped with other resources (both human and non-human) that can be used to convince others, namely teachers and administrators, that they are worth treating as normal (in other words, they wield power from other aspects of their intersectional identities), they then have more access to the resource of school.

**Successfully Performing the Role of Good Student**

Each of the study’s participants self-identifies as having a mental disability which affected their performance in school. For some, an “official” label of mental disability (given by a medical professional) came later in life, but they all believe that their mental disability had an
effect on their education. All participants were given the opportunity to select a pseudonym for the purposes of the study and it is those pseudonyms that are used here.

**Sean**

Sean is a white man in his 50s. He has long, dark hair and a pale complexion. He speaks slowly, telling his story in tangential anecdotes and often forgetting the question asked of him. He comes across as a little shy but on the other hand answered every question openly and at length. He does not laugh much but does smile often.

Sean attended public schools in several cities in the United States (his family moved often). He identifies his disability as creating issues for him in school from an early age.

I didn't really identify it as anything but daydreaming or creative imagination, but most of the time in grade school ... I'll say that at no time in my basic twelve-year early education did I ever do homework or read the stuff that was necessary to read. I just sort of paid attention in class and during the discussion, but when it was time to read, I would find myself drifting off and staring out the window, or pretending to read and falling asleep with my hand covering my face. More often than not, if I read a paragraph, and I got distracted for even a second or looked at the clock, when I came back to the page, I didn't know where I was at. Even if I've got my finger on my page, I'll reread what I just read and it's as if I didn't read it at all, and I know I just read it. I still have that concentration problem.

“Daydreaming or creative imagination” should be positive, but because he is unable to perform in school, it becomes a problem. However, Sean was not labeled with a disability while in school or even evaluated for one and seems to have enjoyed school, although mostly for its social aspects. In the above quote, he identifies his disability as a potential threat to his academic
life but he was able to play the good student by paying attention in class. Sean identifies some human resources that he possessed that allowed him to do this.

I've become very skilled at being whoever you need me to be in that moment to get the good grade, or be overly concerned whether you like me or not... Hypersensitive like that. The only negative comments I ever got was that I had potential to do more... pretty much always.

Sean connects this hypersensitivity to his relationship with his parents. In his words, “My folks drank. You weren't sure what you were going to get. You're always ready to go either way.” As a child, Sean learned how to please the adults around him, which included getting good grades. He played the good student and reaped the rewards by avoiding a label (whether official or unofficial) of mental disability. He did this consciously.

I feel like I spent most of my time trying to fool everybody. Nobody ever knew that I was a drug addict. Nobody ever knew that I cheated in the class. I have a gift of being able to pass a test without really knowing the information.

While deep cultural schemas, such as that of mental disability being a threat, are often acted upon unconsciously, Sean felt that he was fooling people into believing that he was “normal”. His ability as a test taker is another human resource he possessed which allowed him to do this, reinforced by schemas of what constitutes a good student, which can include academic achievement. Sean consciously played the role of a “good student”, utilizing resources he gleaned in other aspects of his life to do so.

Frances

Frances is a white woman in her 30s with long curly hair and a ready laugh. She speaks with authority about her experience in a relaxed way, leaning back in her chair, as if she does it
often. In fact, she works as a journalist and her first piece of writing in a professional capacity was an essay entitled about teenage depression. She laughed when she told me about that article.

Frances attended highly resourced public schools in what she describes as “an affluent, very white suburb of a small city”. Her descriptions paint the schools as fairly heavily exclusionary, with tracked classes and a gifted and talented program for students with high scores on standardized tests.

Perhaps because Frances recognized school as a place where she would be encouraged to reproduce structures of normalcy, her initial reaction to her mental disability was a refusal to go to school.

Yeah, so then I started [high] school and it might have been as early as the third day or something like that when I just woke up one morning and I was so…you know, now I recognize it as just intense anxiety, where I just refused to go to school. That was my real, kind of beginning to feel suicidal …yeah, that was when I was just really …I don’t have the clearest memories of it. I guess kind of like a post-traumatic response. I know I was refusing to go to school. I would basically have just like a flat out fight with my parents every morning over whether I was going to go or not. I think I was sort of going every other day but I would just find it so exhausting to be there. I think it was very confusing to me because I didn’t have any obvious problems. I had always done well in school, I had good friends there, I had classes with my friends.

Frances experienced mental distress because of her mental disability but due to her accumulation of resources, her disability was not considered a threat. According to her, “my baseline was very conforming and pleasant and so people were just trying to get me back to
being conforming and pleasant”. The human resources she possessed, in terms of her compliant and agreeable personality, worked in her favor. She also had a reputation as a good student.

The only accommodation I would say I received was because I had been such a high-achieving student I think they … in that first semester of freshman year, I was performing so badly that I think they overlooked things like me turning in assignments late or something or like, I flunked or basically I did very badly one quarter in math and they didn’t kick me out immediately.

Even when she was unable to perform the role of a good student by achieving academically, Frances was not moved from her high level classes and accommodations were made for her. Mental disability, in this case, could be a threat but Frances is not because of her generally conforming personality and her high degree of resource accumulation. In fact, Frances possessed the human resources to be able to advocate for herself in school. In her 10th grade year she was placed in a math class with a teacher she describes as “abusive” to the students.

I just didn’t function at all. I failed every test … despite the fact… I wasn’t trying to fail. I was doing the homework. I think I just had so much anxiety connected to him slash loathing of him. But again, I asked them to switch my teacher, which I don’t think they would have done normally. But that was the thing. In order to do it I had to go and make a personal appeal to the head of department and sit in a room with him and talk to him about why I needed to switch and I remember him being sort of complimentary of how articulate I’d been, which was great, but like, I was 15, I shouldn’t have had to do that (laughs), and how many kinds weren’t articulate and so they just had to suck it up? Like that was really ridiculous.
Frances reports that teachers were surprised to discover that she was depressed because she was performing well in school and was not acting out in class. Her disability was treated as a medical issue by teachers and administrators, rather than a behavioral issue. According to Frances, the “narrative of my depression was…there was nothing wrong with me except I had a chemical imbalance and so, give me some drugs and then I’d be fine”. She took on the role of the good mental patient (Scheff, 2009) as well as the good student, performing wellness while in school as best as she could. She used the schema of mental disability as a disease in her favor. As a disease, it can be overcome with the help of professionals and so is not threatening so long as the patient cooperates. Frances indicates that she wanted to be seen by teachers and peers as having overcome her depression.

Well a positive memory is actually when I was in 10\textsuperscript{th} grade I gave a presentation about depression. I mean that was sort of interesting though because I think I sort of wanted to be over it and so it was part of my narrative of… I’ve recovered and so now I can talk about this openly.

The idea that disability can be overcome is a schema that reinforces the structure of normalcy. This schema creates value for human resources that can be used in the performance of normalcy. Frances understands that she had relative privilege dealing with her disability because of her accumulation of such resources. After her presentation in her 10\textsuperscript{th} grade class, she was asked to speak to health classes in middle schools about her experience.

Here I was going on this speaking tour wearing my outfits from The Gap, and my friend A who became depressed around the same time that I did but then she was a skater, alternative kind of punk kid and so she dressed like that. She also was cutting a lot at one point and she got the visible scars. By the end of high school I think she was basically
fine but no one was asking her to be ... She didn't look like an outstanding member of the school community the way that I did. I was very conformist in every way. That totally makes sense to me that yes, in that respect I got a lot more ... I felt like there was a place for me if I could work on feeling well, and I'm sure A probably felt it didn't matter. I used to say it's like swimming through jello because it's just thick and not very clear but I was kind of swimming through it and there are all these people at the edge of the pool would be like, "Yeah, come on, Frances," reaching their arms out to me and she was just swimming.

Frances’ willingness and ability to perform the role of the good student, even in terms of her appearance, allowed her to accumulate even more resources, as it encouraged the support of those around her who were invested in reproducing structures of normalcy. This is contrasted with the story of A, whose appearance was not valued to the same extent that Frances’ was. A did receive services, according to Frances, but was not asked to be the face of mental disability in school in the same way that Frances was. Because Frances fit into so many schemas that reinforced structures of normalcy – the schema of mental disability as a disease, the schema of what constitutes a good student, schemas of appropriate dress and behavior – she was made a poster child. She had recovered from her mental disability in the eyes of those around her.

Marie

Marie is a woman in her 30s who describes herself as “Afro-Latina”. She has very short hair and dresses stylishly. She is direct (and in fact, says that about herself) and thoughtful. She comes across as self-confident and no nonsense.

Marie attended public school in New York City beginning in second grade, when she moved to the United States from the Dominican Republic. She indicated that the population of
her schools was “mostly Latino” and she was in bilingual programs until high school. She was skipped to third grade upon her arrival because there was “a different age system than in Dominican Republic for schooling” and her mother believed that she knew enough to move forward. According to Marie, her teacher agreed to the move because Marie learned English within a few months of her arrival.

Marie was labeled with a mental disability (ObsessiveCompulsive Disorder) around nine years of age, when she was sent to a therapist because she began stealing money from her mother. Although they saw a family health counselor and Marie attended group therapy with other children, Marie says that she and her mother had a contentious relationship as regards her mental disability.

Through the therapist, I guess it started coming out that I have certain rituals and certain behaviors, and she's like, "Oh, that's what this is," and my mom was like, "No, that's not what that is. She's just finicky and particular and all these things." That's kind of how that started.

Marie believes that her disability actually helped her to succeed in school, as opposed to being a detriment. In her case, the nature of her disability was such that it served as a resource to her performing the role of a good student.

My notes had to be perfect and if they weren't perfect, they would have to be rewritten over and over again. Even if I made one error or one letter wasn't in the same collective as the other letters then I would have to start over. I would have a lot of notebooks. To my mom that was communicated as like I was just being wasteful and I was just bored but to me it was just like if it wasn't all perfect then it wasn't right.
Copying her notes helped her to learn the material, certainly, but in addition, her social anxiety meant that she focused her energy where she could be successful, and that was in academics.

Because I had such overwhelming anxiety, I didn't socialize very often so I read a lot. I didn’t go to parties. I didn't do the things that I think other kids with disabilities, in my experience as a teacher, kind of interact with which is like they disconnect from school because school is just such a violent and toxic place for them because their disabilities don't let them perform in the way that school is supposed to. Where like mine made me like the hyper-student, right? I had no social skills, which is where my mental health stuff is the most impactful, but I was really smart, that's how I played it. That somehow made me equal to other people. Which further exacerbates the idea that this isn't a problem and this is just you're quirky.

Marie did not perform normalcy, instead her disability afforded her human resources, which allowed her to succeed in school. Because she was able to succeed academically, her disability was not seen as a “problem” or a threat, despite the fact that it caused her mental distress.

I'm told this is really great because you're so studious and you're so dedicated, especially when they're comparing you to people who are like African American kids, who are poor, who live in the projects, right? It's like, look at you, you’re amazing, you've become the token because your disability is just conducive to this academic environment, which isn't true for everybody. But my disability was not conducive to a social environment, so that made my life outside of school really complicated. Then I was just really difficult, right?
Eating, I was really difficult, right? Socializing, interacting with family, I was really difficult.

Marie recognizes some of the resources she accumulated, which other people may not have, that allowed her to succeed in an academic setting. She believes that her intersectional identity as a girl and as an immigrant worked in her favor.

I'm a girl, I was an immigrant, I think people wanted to be invested in my success. Where like if I was an African American boy, I don't think that would have necessarily been the same, or if I had been a white boy, then I would have been like the creepy ... Especially in this time versus before. I think that you could be the creepy loner kid and nobody really thought anything, you were just kind of like the emo kid who listened to Marilyn Manson. Now it's like that's a dangerous person.

Marie recognizes that parts of her identity, and the resources that she accumulated, played a part in her success as a student. She also recognizes that her place in history (she refers to the school shooting in Columbine, Colorado) may have played a role in the fact that she was allowed to be “quirky”, rather than considered as dangerous. On the other hand, as she mentions, she did not look like the people who might be considered dangerous, whether because of race or disability. Because she seemed to be dedicated to school, adults around her were invested in her success, another resource that she accumulated. She indicated that two of her high school teachers in particular were supportive of her.

L and F which were just amazing people and they understood that my brain just worked differently and they just thought that it was like this beautiful thing. They introduced me to the word quirky and I was like, "I'm quirky." It was amazing.
So because Marie could execute the role of a devoted student, she was allowed to be “quirky” and she was allowed to graduate early. On the other hand, she was allowed to experience distress socially because that was the realm that her disability affected, rather than her academic life. So long as Marie could perform academically, she could “pass” as normal and while she avoided an official label in school, she also did not receive services that may have aided her in her social life.

Nancy

Nancy is talkative and likes to crack jokes. She is a tiny person with a big personality. She speaks quickly and laughs a lot. Nancy was adopted at a year old from Korea by working-class white parents. She refers to herself as “a miserable kid” and “full of anger all the time”. She did receive some counseling as a child but she did not open up to the counselor and they spent their time playing games. Her parents eventually stopped having her attend. Nancy was not officially labeled with a disability as a child, although she was evaluated for a learning disability when she was in elementary school. She says it was because, “I was rebellious, I had problems with authority, I was unhappy, I isolated a lot”. Instead of being labeled with a learning disability, she was recommended for a gifted and talented program as a result of that evaluation, which she did not end up attending (as she recalls because she wanted to stay at school with her friends), but Nancy labels her child self with a mental disability because of her boredom in class. She was unable to play the good student when it came to behavior.

I would venture to guess, and I'm not a professional at this, that I've been depressed for as long as I can remember. As somebody who had difficulty in school for things like sitting still, being disruptive because I always knew the answers, being bored, helping other students with their work or doing it for them so that I'd have somebody to talk to, because
I'd be the first one done. I don't know if that would be AD- ... Or what is it, ADD? No ...

Yeah, I guess so. I'm not really sure.

Nancy was a good student in terms of knowing the material, but acted out in her behavior. In her words, “I rationalized my emotions. I pushed everything down, but obviously it manifested itself in other ways, being rebellious.” She began drinking alcohol and smoking marijuana and dabbled in other drugs. She references cigarette and marijuana smoking as a way to socialize at school.

Her freshman year she was caught passing a note in class which referenced alcohol use and she was referred to the school counselor with her family. Her mother and Nancy attended one session together but Nancy did not open up to that counselor either.

Was I depressed? Yes. Was I diagnosed? No. Would I probably have been if I had been in counseling? Yes. Would I have been medicated? Maybe. But a lot of that was just due to my flat out refusal to participate.

Nancy’s refusal to participate, combined with the fact that she performed well academically, seems to have kept her from being labeled officially with a disability while in school, though she was considered something of a troublemaker, according to her. Her academic performance can be considered a resource. Nancy did understand mental disability as a threat and says she refused counseling because she wanted to avoid being thought of as mentally disabled.

I guess more because the stigma. I didn't really know anyone else who was seeking counseling, and if they were, they weren't talking about it. Yeah, I would say that that was definitely a big piece of it, just feeling even more like a freak. Feeling even more different, feeling more broken, and having to do this as a result. I didn't think of it as
being a benefit, I thought of it more as a punishment for being different, than anything else.

Nancy understood that in the context of school, it was not beneficial to be thought of as “different”. Her words make it plain that she felt different, but that she recognized that being labeled as different was an unfavorable option. She was conscious of the schema of mental disability as a threat and acted accordingly. However, she did not completely avoid an unofficial label as a troublemaker. For other participants, this type of unofficial label caused more problems than it did for Nancy.

Unsuccessfully Performing the Role of Good Student

Lulu

Lulu is a Latina woman in her 40s, a child of immigrants, who describes herself as “a control freak, but in a good way”. She is very candid about her experiences and has an open and warm personality. The first time I met her, she wanted to hug me. Lulu grew up in Queens and attended school close to her childhood home.

Lulu identifies as having been a troublemaker in school; calls herself the “class clown”. She says that she used humor to deflect from the fact that she did not understand the material.

My being the class clown is throwing something, or looking at someone and making them laugh, and then they get in trouble, saying something stupid. Or just even making myself look ... I remember specifically going up to the board and just making a joke out of the fact that I didn't know the answer to the math question because it's easier to laugh than it is to just sit there in silence. I'm not a good silence sitting type of person. I can't, I can't.
In Lulu’s case, she allowed herself to be labeled as a troublemaker (using humor as a defense) to avoid the less desirable label of being unintelligent. Lulu did not enjoy school and believes that to be at least in part because of a mental disability, although she does place some blame on her educational environment.

I think my schooling would have been different. A lot of things would have been different, because if they told me I had ADHD, maybe they would have given me something. I would have been able to focus, and I would have done better in school. I was terrible in school, but yet if the right teacher dedicated a little time ... Two teachers, I could say that ... I could remember that really helped me focus and pay attention in school, because they gave me the attention that I needed. Other than that, it was just a nightmare for me in school.

Lulu labels herself with ADHD (which is not the medical diagnosis she was eventually given) and at first states that if this mental disability had been seen as a disease, she might have been able to succeed in school, with the help of medication. She then states that the resource of teacher attention may have accomplished the same goal. Her acting as the “class clown” seems to have been a plea for more attention from the adults around her; in an effort to address the distress she was experiencing from her mental disability. It was not until she was in high school that she received what she needed from school. Lulu says that she believes she would not have graduated high school, if not for the fact that she was allowed to take a business curriculum in high school, which included a work internship.

I remember having to change from a regular curriculum to a business curriculum, because I just ... Again, math, science, history. I could care less. That's not me. I'm not Christopher Columbus. I don't care. I'm not. I don't care about science. I'm not going to
create these concoctions. It's frustrating, because I don't get it. When I went into the business program, I excelled, and I did really good. I was like, 'Oh, okay, so I found my little corner.' I started doing good. If it wasn't for that, I don't think I would have graduated high school. It was something that was interesting to me.

Lulu’s good fortune at having attended a public school which included a curriculum that held her attention is evident. She was able to complete a work internship, which was meaningful to her and this allowed her to graduate high school and go on to college. When she was engaged in activities that were interesting to her, she could avoid being labeled as a threat. Despite that, she indicates that she experienced mental distress because of her mental disability, but did not seek help until she was an adult.

I never thought to go to a therapist or to see a doctor, because I grew up first generation American and that's just not what you do. You don't talk about your feelings. You don't talk about ... People who have a psychiatrist or a therapist are crazy, that's how we're brought up. That's what we're told.

Her intersectional identity, in this case, kept her from seeking help. Those around her utilized the schema of mental disability as a threat and seeking professional aid did not seem like an option. She believes that school could have offered her a way to voice what she was feeling, but did not.

Other than that, if I had a formal class like sex education where they told you "There will be times where you're going to feel like this, you can talk to somebody." We didn't even have a ... There was no ... Nowadays they have a therapist, a counselor, like a real therapist. We didn't have any of that. If you were going to go see somebody, you were in trouble. It wasn't about how, "Tell me about your feelings. Tell me about how you feel.
What's going on at home?" None of that, none of that. It was a much different world, you know? I think I learned about it backwards. I had a need, and nobody identified ...

Nobody knew enough to say, "I think you should see ... These are the things that are available to you. You should go get help."

“Going to see somebody” carried with it the weight of being labeled with mental disability as a threat, even if only unofficially labeled as a troublemaker. Lulu imagines another set of schemas that might have been available to her through school. The set of schemas she envisions position mental disability as something manageable because of the availability of resources, such as counseling and appropriate language for discussing her emotions. This will be discussed more in Chapter 6.

**Kevin**

Kevin is a man in his 30s, of Indian descent. He is self-assured and seems relaxed in his skin. He is often self-deprecating, and describes himself as “definitely a bit of a know-it-all, but … a good-natured, pleasant person, on the whole”. Both of these characterizations seem accurate to me.

Kevin attended public schools in the suburbs of Chicago, which he describes as well resourced, saying that his family moved to that school district purposefully so that his brother and he could attend school there. His father worked as a chemical engineer and his mother kept their home. Overall, his depiction of his upbringing made it seem ideal, but he says that this contributed to his not seeking help for mental distress at an early age.

I think what I would say is that I generally from a relatively early age I though I'm from a pretty good family that's pretty smart, whatever that means, and pretty accomplished and responsible and generally happy from what as I can see from a young kid about my
family and related family members. People seem to do well. People have jobs. I'm not seeing a lot of people with drug and alcohol problems that are obvious to me, broken homes or whatever. I think it was only natural that I would assume that I should sort of have a similar kind of development and to the extent that I wasn't, that's a problem that may or not be unique to me, which I think, at a young age, is the kind of thing that you're not likely to broadcast if you feel that way. I think having a sort of Asian/Eastern kind of family, my experience with similar families is that you're just not inclined to have a lot of conversations about mental health. It just doesn't happen. I'm sure someone's separately looked into the many reasons for that. The end result is pretty clear to me that it just doesn't happen. That's top down. I don't remember my dad coming home and saying oh man, let me tell you about how I'm feeling. I don't ever remember that. That doesn't happen now.

Although he came from a home with financial resources, he was not given appropriate emotional resources to describe how he was feeling. Also he recognizes that being different can be seen as a threat. That said, Kevin was not labeled in school because he acted within the scope of what was normal for a boy his age, saying that his disability manifested itself as “passive behavior” and so his mental disability went unnoticed, in part because of his intersectional identity. He did not have the emotional resources to make it more noticeable.

In the school I just tried to grind it out. I just tried to get through it. As I said before, I would come to school, my attitude was like, "This sucks. This is a waste of my time," or maybe just nod my head, or do whatever I've got to do, and then I'm either going to play baseball, or I'm going to eat some cookies, whatever I'm going to do.
Kevin performed fairly well academically while in school. Like Nancy, his academic performance was a resource that kept him from being officially labeled with a mental disability, although he admits that he was considered something of a troublemaker and did not conform to school rules.

Understandably, if you're the teacher, you're not going to be super focused on me, "This kid's a dick, and he got a ninety-two anyway, so why am I going to waste my time talking to him? I'm going to focus on this other kid who's not doing so well, or this kid who comes up to me and says, 'Hey, I want to do better.'" I didn't do any of those things, so I left stuff on the table.

His academic performance allowed him the privilege of not being officially labeled with a mental disability while in school, but was also a disadvantage because he did not receive any help for his mental distress. Also, according to him, he “left stuff on the table” and did not perform as well in school as he could have. Therefore, he didn’t accumulate resources that might have otherwise been available to him.

To the extent that depression would affect me at school, as I said, right, it might manifest itself in me not doing my homework, or not paying attention, or not showing up altogether, or just having kind of an attitude… Outside, I would think it manifested itself more in ways of like probably being interested in alcohol and drugs and things like that at a younger age. As I said, isolating myself from friends and family at times. School's hard to do that because you're in this ... You have no choice. I have to sit in this classroom, so it's hard for me to isolate myself and go about things in that way.

The nature of school shaped how he dealt with his depression and kept it from being more than “passive behavior”. He could not isolate or engage in substance use while in a
classroom full of students and so his depression was merely read as laziness or being a troublemaker. He was unofficially labeled as such but avoided official labels of mental disability.

**Jeremiah**

Jeremiah is a white man in his 60s. He is tall, lanky and balding. He told me during our first interview that he had spent the morning bike riding and I can picture him riding around the park everyday, in all kinds of weather. He appears youthful and has a lot of energy; moves quickly. He seems to choose his words carefully and he knows that he has an interesting story and likes to tell it. He came to our interview equipped with a written history of his life to help him remember dates and events. He cites his age when explaining his need for this aid, but also talked about how his disability affects his memory.

Jeremiah grew up in a middle-class suburb in New Jersey and attended public school from kindergarten. He recalls a feeling of “school phobia” beginning right away, in his mind a fear of being at school or of being away from home. While he could not consciously recognize on the first day of kindergarten that school would be a place where he would be expected to perform normalcy, he did recognize school as a place he did not want to be.

The first day of kindergarten, my mother took me up to the kindergarten door, and she introduced me to Mrs. L. Mrs. L walked me in and I said, "I have to time this right. I'll wait til mom clears the building." I counted to 12 or whatever, and I ran out the front door of the building. Our house was only a quarter mile away. Right across there's a cafeteria window and all the kids are looking out. I went streaming across the front yard and ran all the way home the first day of kindergarten. School phobia was already there.
When he was in first grade, he was referred to a psychiatrist because of behavior and academic issues and eventually repeated the grade. He recalls seeing his disability as a threat even at that age.

To have seen the psychiatrist, and repeat first grade, and you're living in New Jersey, and going to school with people whose parents work at B lab. The fathers work at B labs, the mothers are homemakers. Fathers work at the laboratories, and everybody's a fucking architect, including my parents. Both of my parents were really smart. This was very scary, and something was very wrong.

Jeremiah worried that the resource of his parent’s (perceived) intelligence was not transferred to him and thus that there existed the possibility that he was incapable of participating in the reproduction of desirable structures, such as the structure of normalcy. That possibility that he might be incapable of reproducing desirable structures was seen as something “very scary” and “very wrong”. The implication that he may have a mental disability was frightening to him and to his parents.

Jeremiah did not receive services in elementary school other than being held back a grade, which he describes as “traumatic”. This was true, at least in part, because he attended elementary school before the passage of the Education for All Handicapped Children Act. Despite this, he says that he finished elementary school with “comparative success” because “it was in junior high school that things just completely stopped. Everything just came to a total halt, educationally. I just couldn't function at all.” He attributes this to the new rhythm of having to change classes and deal with the personalities of multiple teachers. He had trouble staying organized and keeping on top of the material. He recalls this as being a real problem for him and
his narrative involves a comparison of himself and other people, which can perhaps be read as a comparison of his performance with the normative standard.

I would talk to people my age and express what I was experiencing, and literally none of them understood what I was talking about, literally nobody knew what I was going through. They couldn't understand. I couldn't understand that they couldn't understand.

There was one girl, my first sort of girlfriend. I was telling her about the trouble I was having and she said, "School. You're kidding, school's a game. It's just a game, don't take it seriously. It's nothing serious. Just play the game." It wasn't a game for me, it was real serious. It was a real serious problem.

For those who could “play the game” or easily reproduce structures of normalcy, school was not an issue. For Jeremiah, school was a problem because he did not possess the resources that would allow him to play the good student. Jeremiah describes his mother as “crazy” and “alcoholic” and his father as “laissez-faire”, indicating perhaps that he did not receive help at home which would have allowed him to thrive in school. Teachers, according to him, also did not support him although he did receive some support from a guidance counselor (Mr. F), although it was not academic support.

My teachers were not interested at all. I was just like wandering around. When I did show up, if I did show up, I was wandering around. There's this man, Mr. F, and Mr. F had seen me wandering by. He was this little hunched up guy, about 5'3, and he's hunched up like this. I'd walk all over and he said, "Come here," and he says, "Sit here." He says, "They won't see you in here." (laughs). I sat there, and he just let me sit there. He'd ask me questions and we became friends. He said, "Just come in here." He says, "if you don't know where you are, or you don't know what you're doing, just come in here and sit here
and we'll talk." He'd say, "Just come to school and sit in here." In the end he said, "this is not going well." He says, "Some bad things are going to happen," and he says, "You have to come to school. I'm hearing rumors." Then he came to my house to pick me up to bring me to school …Because he was really scared.

Eventually, Jeremiah was charged with truancy and then expelled from school. Other than Mr. F, he found the adults around him to be eager to be rid of him.

The principal, he finally came. The principal spoke to me all of one time, and it was to take me into his office and say, "We're expelling you and you have to go somewhere else. You're unacceptable."

In this case, the resource of school utilizes the schema of mental disability as a threat. Jeremiah’s expulsion and his labeling as “unacceptable”, as a troublemaker, prove this. The school principal worked to reproduce the structure of normalcy by excluding Jeremiah from school when he was deemed less than worthy of being there because of his mental disability. It is important to note here that being “normal” is not always enough to make one worthy of school as historically people have been excluded from school for other reasons (such as race and class) but for Jeremiah, it was his mental disability that made him unworthy of school in the eyes of the administration.

Jeremiah did not think himself capable of performing normalcy. That is, he believed he did not possess the human resources to function as a good student and eventually ceased attempting to do so. In the next chapter, we will see that eventually Jeremiah came to believe that he had a “learning difference” rather than think that anything was wrong with him. However, while he was in school he was unable to play the part of the good student and so he was labeled
as a troublemaker (a form of mental disability) and expelled from public school. He was then placed in a private school, which he describes as “the worst place imaginable”.

I ended up going to school where there were 30 kids, and of the 30 kids, ten were shooting heroin, and 28 were at least smoking pot. 25 were taking acid and all this other shit. The other two were below, they were like six and eight or something like that, autistic or something, that's why they were there… There was no food. This place had no food. They had a loaf of Wonder Bread and margarine, out 24 hours a day, so you wouldn't literally starve to death. For meals, they'd have a dinner I think. It was like Chef Boyardee Spaghetti and Meatballs, totally inedible, and that's all they ever served. It was like fucking hell. It was unbelievably the worst place imaginable. I did that until I turned 16 and I didn't have to go back.

This private school was a place where children with mental disabilities could be segregated from the general population so that they did not pose a threat to the reproduction of structures of normalcy. Contemporary categories of mental disability were still not yet fully defined at this school and the treatment of children with mental disabilities was akin to incarceration. The schema of mental disability as a threat was utilized to justify such treatment.

**Performing the Role of Good Patient**

Playing the “good student” involves some acknowledgement of the schema of mental disability as a threat. Similarly, an acknowledgement of the schema of mental disability as a disease facilitates performing the “good patient”. Acknowledging these schemas does not mean that participants necessarily agreed with them, as we will see in the next chapter, but they did recognize the power of the schemas. According to Scheff (2009), playing the good mental patient allows the person labeled as deviant (by virtue of their being labeled mentally disabled) a way in
which to regain the favor of society. All of the participants, to some extent, acknowledged the idea that their mental disability was a disease, although often they thought their mental disability could have been better addressed.

As a child, Jeremiah saw his “learning difference” as a threat and reacted to that by resisting acting as a good student, which shall be discussed more in Chapter 6. However, Jeremiah has multifaceted identity of mental disability as he also has the label of “bipolar disorder”. While, as a child, he internalized the schema of mental disability as a threat when it came to his “learning difference”, he chooses to use the schema of mental disability as a disease when it comes to bipolar disorder. He was labeled as such later in life after an episode where he experienced a “manic state” after being prescribed an anti-depressant. As he describes it, “It was like an elevator. I never even would think it was like taking an elevator. It just went from the basement to the fucking penthouse overnight.” A psychiatrist diagnosed him with “bipolar II” after seeing him in this manic state. Jeremiah says:

To me, that experience was a definitive moment like, "Okay, I've had this situation that I've been dealing with, this unknown circumstance that nobody's really been able to figure out." I have a guy who really knows his shit who really diagnosed it properly. Not like the guy who sticks a screwdriver in your radiator, but like an auto mechanic who really knows what the fuck he's doing. He goes, "Ah-ha, now I know what it is. It's the alternator," or whatever. I had full confidence.

Jeremiah fully believes that bipolar disorder is an appropriate label for him because it was given to him by a medical professional. In this case, he believes that the doctor is the expert on his experience of his mental disability. This is in line with the medical model, in which treatment by a professional is the correct response to mental disability. Jeremiah was prescribed
medication, which he believes was the correct course of action for this particular disability. In the case of his bipolar disorder, he subscribes to the idea that the mental disability is a disease with a proper course of treatment, which should be prescribed by a professional. He plays the role of the good mental patient by taking his medication. In his words, “That was eighteen years ago and I've been on the course of treatment he prescribed since then. I tried to go off it. It was not a good suggestion.” He possesses, in this case, the resources to play the good mental patient, whether they are financial (non-human) resources or experiential (human) resources. As an adult he has access to those resources. Thinking of his bipolar disorder as a disease produces positive results for him, so that is what he does. In this case, unlike when he was in school, utilizing a schema to reproduce a structure of normalcy is a choice that he makes based on experience. In contrast, when he was a child, he utilized the schema of mental disability as a threat to think about his learning disability because that is the schema that the adults around him employed. Then he had little choice in the matter, but we will see in the next chapter that he did adopt more positive schemas to think about his mental disabilities later on.

Jeremiah is not alone among the participants in vocalizing the idea that doctors are experts about the treatment of mental disability. Sean believes that his doctor diagnosed him based on his patterns of speech.

I go once every quarter to see the psychiatrist to see how I'm doing as far as this medication goes, so I've seen him like four times, and he just asks me some questions kind of like you're doing and I just spit out whatever answer it is and I guess he can tell about my answers because he's a doctor. He could tell, "You definitely have …" I remember whatever, a year ago when he was, "You've got ADHD," or whatever and just could tell that by whatever, maybe my scattered way of forming sentences.
Sean takes the medication prescribed to him, although he has doubts about its effectiveness, because of the fact that he trusts his doctor to know how to treat his mental disability. Nancy does the same, despite the fact that she blames a prescribed medication on a “psychotic break” that ended up in her being admitted to the hospital. She says, “I've always been very good about taking my medication, even when it was to my detriment”, indicating that she sees some value in being a good patient, even when it did not work in her favor.

To some extent, all of the participants had knowledge of and accepted the idea of mental disability as a disease. Lulu was first given the label of bipolar disorder when she went to see a psychiatrist and, although she did not identify with that label, she initially accepted it. She said, “I was like, you know what, I'll take it. It's a hard pill to swallow, but I don't know better. This is a psychiatrist. So be it.” Like Jeremiah, Lulu believed that a label given to her by a professional must be correct.

Marie said that her mental disability has always been explained to her as solely a medical problem.

The medical thing is just, “Your chemicals are just out of whack and all you need to do is take this medication and it'll help.” That's pretty much been the pervasive method; just, “Oh, it's just a chemical imbalance,” kind of a thing.

Frances also used the phrase “chemical imbalance” to describe her mental disability, as well as describing it as “a chronic illness” and had a similar experience with doctors telling her that medication was the key to her recovery, which she initially decided to take. All of these participants played the good mental patient by buying into the idea that they were mentally disabled and following their doctors’ advice. Kevin describes his decision (at least when he was initially given a label of depression) to take medication:
I guess, unless you're in a really severe situation, it's hard to know how and to what extent medication is working for you in that kind of situation. You just kind of have to trust that it is. I think it's very difficult, at least for me as the patient, to be able to point to something and say, "Yeah, this is working." It's not like if you have a physical issue. If I cut myself, I put a Band-Aid on it, and I can see that it's healing. These types of things, you've got to sort of have faith in this process and kind of trust that you're on the right path.

Kevin’s “faith in the process” can be read as faith in his doctor or in the idea that a medical professional knows best how to address his mental disability. It is clear that all of the participants reproduce the schema of mental disability as a disease by acting the good patient, to varying degrees.

Although all of the participants utilized the schemas of mental disability as a disease and mental disability as a threat to some extent to understand their mental disabilities, these were not the only schemas that they found useful. Kevin summed up another reaction that participants had to their labeling when he said, “I don't think anyone likes to think of themselves as a patient, or a victim, or a burden, or problem that needs to be solved.” There was some resistance among participants to both the idea that mental disability is a threat and that mental disability is a disease, which will be discussed in the next chapter.

In this chapter I have shown that participants reproduce/d a structure of normalcy (with varying success) through their performance of “good student” which required some knowledge and acceptance of the schema of mental disability as a threat. Also, I have shown that participants reproduce/d a structure of normalcy through their performance of “good patient” which required some knowledge and acceptance of the schema of mental disability as a disease.
In the next chapter, I will consider participants’ resistance to the schemas of mental disability as a threat and mental disability as a disease through their utilization of the schema of mental disability as a difference and I will examine their individualized understandings of their labels.
Chapter 6: Adopting New Cultural Schemas

Chapter 5 examined the ways in which participants of the study reproduced schemas of mental disability as a problem and mental disability as a disease, which reinforced the medical model of disability and reproduced the structure of normalcy through their performance of “good” – the good student and the good patient. Sewell (1992) believes that social structures are generally reproduced (or rather, that it is a much simpler process to reproduce structures than to resist them), however he does recognize that social change is possible and that the reproduction of structures “is never automatic” and that “structures are at risk, at least to some extent, in all of the social encounters they shape” because of the fact that individuals and collectives have agency to resist their reproduction (p.19). In this chapter, I will examine the ways in which participants of the study resist the reproduction of the structure of normalcy through a process of learning new schemas (namely the schemas of mental disability as a difference and/or strength) and incorporating those schemas into their self-narratives when they describe their mental disabilities. I would like to begin with the words of one of the participants in the study, Jeremiah, who powerfully describes the process of reproducing/resisting structures.

We all start out with this little flame of personality, this little something that makes us individuals, that make us different than anybody else, and everybody wants to keep that little flame alight, doesn’t want that flame to go out. They want it to be them. They don’t want to be somebody else. They don't want that. I think part of the growing up process is letting that flame die. It's like a really painful experience. I think that for somebody who's got it all, who wakes up at birth and they've got beautiful parents, they live in the suburbs, they go to great schools, before they know it they’re in college, they're married, they're heading the football team, drafted at a Fortune 500 company, a trophy wife. For
them, that little personality thing is just an ego, it's all getting fanned, the flame is just great. If they get a ticket or whatever, it doesn't really matter. But if you got a disability, and that's all you fucking got is you and there's nothing else there, that tiny little flickering thing, I mean, yeah, it gets really sticky when people are telling you can't do this, you can't do that, or you've got to believe in God, or whatever. "Fuck you. I don't have to. This is me." Don't mess with that.

The “growing up process” here is the process of learning cultural schemas and acquiring resources. For those people for whom acquiring resources is relatively simple, by nature of their socio-economic background in his example, then both reproducing and resisting schemas can be relatively simple, or at least less complicated than it is for people with fewer resources. People who have resources can choose to reproduce the cultural schemas (and thus structures) that benefit them and resist those cultural schemas that do not (in his example, following traffic laws). For people who are disabled, structures of normalcy are more difficult to enter and reproduce. The choice then becomes trying to “pass” as normal by attempting to reproduce cultural schemas of normalcy (as seen in the last chapter), or resisting that reproduction by finding new schemas with which to operate.

What came to light in the interviews with the participants in this study is that they were more likely to find different, more positive schemas with which to describe their experience if they accepted their label as part of their identity. Some of them continued to use the historical schemas of mental disability as a threat and mental disability as a disease to describe their experiences because they did not fully accept their label as part of their identity. I will first describe how those participants who did not accept their label thought about their labels and their identities. Next, I will explain the process of self-realization and self-discovery that some
participants expressed, which led to their adoption of new, positive cultural schemas around their labels. I will then discuss participants’ adoption of schemas of mental disability as a difference and/or strength. Lastly, I will return to an analysis of their schooling years and examine how individual teachers were instrumental in teaching some of them new schemas with which to explain their mental disabilities.

**Difficulty Accepting Labels**

Two of the participants, Sean and Nancy, resisted adopting their mental disability as part of their identity. Sean has been given two diagnoses, ADHD and Social Anxiety Disorder. He is of two minds whether these labels are appropriate for him.

I think it all stems from early childhood stuff. It appears to be that way. If I don't think about it, I don't have it. It will seep into my consciousness that I'm uncomfortable, or I don't belong. It becomes so overwhelming that I am uncomfortable, and I don't belong, and I can't participate.

Sean believes that if he avoids thinking about social participation and just does it, then he does not experience distress. He continues to use the schema of mental disability as a threat in his own identity formation process - if he does have a mental disability, then it is one that creates negative scenarios in his life. He would rather not have a mental disability and spoke about how he debates (within himself and with his psychiatrist) whether he needs any treatment. He does not identify as having a mental disability publicly.

People will write me off as being quirky or funny or a workaholic or whatever category it is, or introverted if I'm quiet or whatever. I don't happen to say, "I have this problem and that's why I act like this," or whatever, other than just using self-deprecating humor. It
usually works, by the way, "Oh, I'm just an idiot. Sorry about that. I forgot to do something."

Sean does not identify with his label personally and thus does not feel the need to identify with it openly. He does, however, still see his mental disability as a threat that can affect his work, one that he moves around by using self-deprecating humor. He continues to use the schema of mental disability as a threat to explain his disability and has not felt the need to adopt other schemas. Interestingly, he self-identified with a mental disability in order to participate in this study, however does not seem to fully embrace any of the labels he has been given. We saw in Chapter 5 that he trusts his psychiatrist to have given him a correct diagnosis, and yet he has not fully embraced the label as part of his identity. Sean and the other participants were seemingly in constant negotiation of their identities, utilizing various schemas.

Nancy has been given the label of bipolar disorder, but says that she does not know if she identifies with it. She gave the reason for not fully connecting to her label in our first interview as due to her having recently stopped using alcohol and drugs. She believes that because she abused alcohol and drugs from a young age, she does not really know who she is and thus cannot say whether the label of bipolar disorder is appropriate for her. She also believes that her substance abuse might have affected her mental state and thus her label might not be correct. Additionally, she cites the fact that she is adopted as a confounding factor in creating a solid sense of self. These factors in combination are her explanation for not having a more substantial self-narrative around her mental disability.

Well, a mockingbird knows the songs of a lot of different birds. I don't know if they actually have their own. Identity-wise, again, social chameleon. I used to joke about the fact, even when I was older, that I wouldn't necessarily put all my friends in one room
together for a party because I don't know how well it would go. In terms of like gay, trans, burlesque people, and then kids that I knew from high school with kids, and people that I knew, corporate ... Like I had the double life. I worked in financial services, I worked for a lot of conservative companies, I wore a suit, but then I went to an improv theater and hung out below a grocery store with a leaking ceiling, or I was doing burlesque type of thing, where in the morning I had to make sure I didn't have glitter on me from the night before. Honestly, that was it...Maybe I'm a robin. I don't know. Maybe I'm a cardinal. I'm like, maybe I'm a seahorse. (laughs) I have no idea! But yeah, really tough time with self-identity, especially being a Korean adult now, adoptee, I still struggle with who I am on the outside, who I am on the inside. I've been making meatballs and macaroni since I could stand up.

Nancy says that she struggles with self-identity and is not clear on how her mental disability fits into her narrative of self. She was hopeful, however, that being sober would help her to create a stronger self-narrative and also leave her better equipped to deal with her mental disability.

At this point in time, given the fact that I just have over four months of sobriety, I have no interest whatsoever in trying to explore changing medications, at least probably for another year or so, to then reassess where things are. I don't want to get into that mode of, "I don't need to be on medication!" Because that's oftentimes, from what I've read in the past, not uncommon but can also lead to disastrous consequences.

Nancy trusts her psychiatrist to know what is best for her in terms of medication, which may suggest that she is still using the schema of mental disability as a disease to explain her
mental disability. Certainly, she has not moved on to using more positive schemas to explain her mental disability as, at this point, she is not completely sure that her label is appropriate for her.

Kevin suggests that a process of self-examination, such as the one Nancy is experiencing presently, is key to accepting one’s label, but also states that such a process is not always enjoyable.

I'm not sure that I examined things as closely as I probably could have. I would guess for some of the reasons that people tend not to do that because it's not necessarily a lot of fun and you find out things about yourself that you wish weren't true or just difficult work…so I think. Being 21, I was happy to say I have some depression or whatever, but it certainly wasn't going to stop me from like doing drugs or drinking or just having the lifestyle that I wanted to have. If I had really confronted those issues, I probably would have had a hard time finding agreement in the way that I was living my life and my mental health issues. I think that's probably the reason I didn't look at it too closely.

Kevin’s words suggest that he believes that there is a certain way to live life after being labeled, certain behaviors (such as abusing drugs and alcohol) that one should no longer engage with once a mental disability has been identified. When he was younger, Kevin did not wish to engage in self-reflection around those behaviors, even though he did identify as having a mental disability. According to Kevin, then, agreeing with the label that has been given to you is not enough to create positive schemas of the disability. A process of self-reflection has to come first.

The Process of Self-Reflection

Lulu fully believes that her label of an anxiety disorder is part of who she is. She believes that this diagnosis describes her experience. More importantly, perhaps, she believes that this is
not a label that is going to change over time. The mental disability indicated by the label is something she will live with for the rest of her life.

Circumstances could contribute to how you feel at a certain time, but I think that for you to diagnose yourself with a mental illness is something that you've got, and you've got it forever. It's not going to go away. You can change your environment. You can change whatever, but it's not going to go away. I think that's the difference between somebody who's just going through some shit, and somebody who lives with it.

That said, accepting that label involved a process of self-reflection and self-advocacy for Lulu. She was initially given the label of bipolar disorder when she sought professional help for her mental distress, and she did not agree with that label.

That first day I got intake, I was like, "They put me down as this, but I don't believe that that's my diagnosis; I want to be reevaluated." Because again, these people, what, they see you for 15 minutes and then all of the sudden they know your whole history and then they stamp you with a fricking rubber stamp that says, all right, Lulu is this. You don't fucking know me. I could've had a bad day today. Maybe I didn't show you all my depression. Maybe I didn't show you all my thing. Maybe I'm acting. How do you know?

Lulu fully identified at this time as having a mental disability, but did not believe that it was bipolar disorder. She used her knowledge of self to work with mental health professionals to find a label that made sense to her. She used resources of self-knowledge and the ability to self-advocate to make sure that she received the correct label (in her mind). It is important to note here that Lulu possessed the personal resources to be able to do this as part of her intersectional identity, which may not be the case for everyone entering similar situations.
Self-knowledge was key for many of the participants who managed to adopt more positive cultural schemas to explain their mental disabilities. Kevin, for instance, describes his process of self-discovery that he began to engage in at a young age, which allowed him to cope with aspects of his mental disability.

One thing that happened, in terms of outside of school, was it was around that time…12 up, maybe, that's when I really started getting into music, and I think that depression may have had something to do with that because isolation is a lot more pleasant if you have headphones or something. Just you sitting in an empty room staring at a wall. That's kind of a downer even when you're depressed, but you can listen to music. I got really into poetry at that age. Was really into poetry in college, took poetry classes, wrote for a newsletter, you know, did all this kind of stuff. Learned to play guitar, did a little bit of singing. All those things, I think, at least in some way, the root of which was this need for expression and sort of self-discovery, which, I think, not understanding that, frankly, may have been a reason to be depressed, and in trying to find an outlet for that, may have led me down some of the interests that I still have to this day.

Self-discovery, for Kevin, was and is important to coping with his mental disability but he also believes that a lack of self-expression may have worsened his depression. For him, music and poetry were ways of alleviating distress, as well as means of self-discovery.

For Marie, the self-knowledge that she has grown into as she reached adulthood, as well as the level of command she has over her life as an adult, allow her to manage mental distress.

I try to create balance for myself. I also have control over my life, but when I was younger, I couldn't be like, "I'm going to therapy." You don't even know that that's okay or that that's healthy or that that's like ... That everybody who lives in New York has a
therapist, right? Like, you don't know those things until you're older and you've had some kind of life experiences. Having control over my life also makes having a mental health disability much more manageable.

Marie’s life experiences have taught her not to be afraid of seeking help for her mental distress and have also given her the ability to manage aspects of her life. She copes with her mental disability through a level of self-knowledge about what her triggers are and what she needs to go to manage them. As an example, she said “I need to ride the express bus home even though it costs four more dollars than taking the subway because that's the only way I'm going to make it home as a cohesive person.” Marie, like Kevin, has found ways to reduce mental distress through learning about herself.

Some process of self-discovery and level of self-knowledge seem to be key to the ability of the participants to adopt positive cultural schemas around their mental disabilities. This is not to say that they always think of their disability as agreeable, but that in the end they have learned enough about themselves to be able to create a cohesive narrative of their disability with a positive twist. Jeremiah demonstrates that point.

I think that that's probably the case, that if I hadn't been so damaged I could have done a lot better. Then there's plenty of evidence that that's best-case scenario. That's if I hadn't been damaged and everything went right. How about if I hadn't been so damaged and everything didn't go right? Not everybody turns out like that. Anyway, that's judging my insides by somebody else's outsides, which we know is the stupidest thing…There's a good possibility I'd be happier if I wasn't so damaged, but I don't dwell on it. I just don't know that that's true. There's just no way of knowing. Plus I like to romanticize and think that being weird is a good thing in some ways.
Although Jeremiah refers to his disabilities as him being “damaged”, he has also managed to create the narrative of “being weird” as a positive trait. His self-reflection involves knowing enough not to compare himself with people who might not fit the bill of being “weird”, at least on the outside. He also tries not to dwell on imagined possibilities of what his life would have been like if he had not had mental disabilities. His process of self-reflection allows him to set aside these potentially damaging thoughts in order to have a more positive view of his mental disability as part of his identity.

Frances also has engaged in self-reflection around her mental disability. Unlike Jeremiah, she sees her depression as almost positive, or at least as resulting from a strength of her personality.

My empathy is very tied to my depression and anxiety because I’m very sensitive to other people’s emotions it can trigger….so my depression and anxiety is mostly triggered by other people’s bad feelings around me and my feeling of responsibility for their bad feelings and my desire to fix them, which obviously in many cases I can’t do. I think that it stared with having a mother who… yeah, that first started with my mom. Being very aware of her bad feelings and feeling like I need to… and sometimes her being… perhaps her unhappiness in part being triggered just by the isolation of parenting.

In Frances’ narrative, she has identified the cause of her mental disability as her empathic nature. Identifying the triggers of her depressive episodes has been part of her process of self-knowledge, much like it was for Marie. This allows her to manage mental distress, but also have a positive view of her mental disability.

This process of learning about self was important for all of the participants who managed to eventually adopt positive cultural schemas around their mental disabilities. In the next section
I will demonstrate how some participants who engaged in a process of self-reflection managed to embrace the more affirmative cultural schemas of mental disability as a difference/strength as part of their identities.

**Mental Disability as a Difference and/or Strength**

Viewing mental disability as a difference and/or a strength does not mean that the participants did not experience mental distress because of their disabilities. Instead, the ones who adopted the schema of mental disability as a difference/strength found some way to acknowledge their feelings of mental distress while developing strong self-narratives that included positive qualities of mental disability. Kevin summed up the generally theme of these narratives when he said that he thinks of his mental disability as “a hurdle and a challenge”.

We saw that Frances believes that her disability is a kind of manifestation of one of her strengths of character. She thinks of herself as sensitive and empathic and for her that can lead to mental distress.

I think it's really brought on by me being a highly sensitive person. I think I'm just extremely sensitive to other people's emotions and so I think ... We were talking about performance of good behavior was driven by that sensitivity and being able to ... Almost for my own sense of wellbeing I need everyone else around me to be chill. If they're not then I become hyper aware of them not being chill and then that makes me very agitated and that makes me depressed. I think actually that part of the reason that my depression was triggered at the age that it was, was essentially being around 300 adolescents was like being in a room where everyone was screaming, for me. I can't lock it out, which is one of the best things about me but it also is something that causes me big problems. I would say depression is a symptom of this strength and that's not a good symptom. But I
think my sensitivity to people has helped me maintain friendships for 25 years that many people don't. I think it's helped me play an important role within my family, that my siblings can't fulfill. Stuff like that. I generally like the person that I am and a big part of the person that I am is having this extreme sensitivity.

It is not that Frances thinks of her depression as necessarily being a positive aspect of her life, but rather that she recognizes that it stems from positive facets of her character. She sees that the sensitivity, which brings on her depression, also allows her to build strong social relationships. Thus it is not so much that she thinks of her mental disability as a strength, but rather that she accepts it as a result of one of her strengths. She has adopted a schema around her mental disability of it being a difference, she is more sensitive than other people but this allows her to do things that other people are not able to do.

Marie also views her mental disability as a difference (which could potentially be seen as a strength). We saw in the last chapter that because of the nature of her particular disability, she was able to perform well as a student.

I think I was actually more successful in school because of the particular disability, or the disabilities that I have, versus another kind of disability. I feel that way now, especially, that I am teaching and teaching special ed. A person who's obsessive compulsive who is really focused on rewriting their notes is going to absorb that information really well, right? There's no way that if you're just rewriting the same science information and not record it to memory, which then makes it really easy to succeed on a test or to pull that information back up.

In Marie’s case, her mental disability aided her in performing the role of good student and she thus sees it as a strength within the context of school. She also says about her mental
disability, “I don't think anything's wrong with me. I think I reflect human variance.” For her, her mental disability is very clearly a difference that can sometimes serve as a strength. Her thoughts about her mental disability closely align with the social model of disability and signify that Marie does not buy into the schema of mental disability as a threat but rather has adopted the schema of mental disability as a difference.

Marie became a special education teacher after her schooling and she reflected on why she felt that was a worthy profession.

It just felt like the work was worth it because these were like discarded members of society. I just remember the sense of accomplishment that you felt when a kid could say, "Red." Like, identify red to red, that was just such an amazing feeling. Also, I didn't like kids, ever, growing up. But I liked these kinds of kids. I wonder now if I just recognized something of myself in them, like they were just different. Their way of being different was more explicit and obvious than mine was, but they were different, and I liked different.

Marie thus recognizes her students’ disabilities as differences and her own disability as a difference and this is a schema that she appreciates. She likes different, much as Jeremiah believes that being weird is a good thing. She is able to bring her positive views of her own mental disability into her work with children with disabilities and see their differences as such.

For Lulu, it is important to address stigma and misconceptions about mental disability and she does this by sharing the positive schema that she has adopted around her own disabilities. She identifies as having both an anxiety disorder and alcoholism and she sees that the schema of mental disability as a threat is widely used in the culture and that this affects
people who might benefit from seeking treatment for a mental disability. She sees it as important to address this in order for people to feel comfortable attending to their mental distress.

Depending who I'm talking to, I'll either say, "I suffer from anxiety. I see a psychiatrist."

I usually say, "I see a doctor." Sometimes medication is needed. Sometimes it's not. It's not always. You just need to talk to somebody to find out what is your situation.

Sometimes people will say something derogatory, and I'll chime in and be like, "Well, I suffer from mental illness. That doesn't make me X, Y, Z," or, "I suffer from alcoholism. That doesn't make me a homeless person or indigent or useless." That's how usually I've used it.

The schema of mental disability as a threat is what creates the image of alcoholics as always “indigent or useless” and produces stigma around mental disability in general. That stigma can prevent those experiencing mental distress from speaking about it, which can lead to disastrous consequences. Lulu believes that accepting a label of mental disability is a step “away from the ledge” for people who face mental disability (including addiction).

If you can help someone step away from the ledge, because in all honesty that's what it is, it's a ledge, especially for addiction. You might not physically be at the ledge, but every time you take a drink, every time you pick up, whatever the case may be, you're choosing to risk death so it is the ledge. It's the same thing with people who are anxious, depressed. People feel like, okay, it's okay to kill myself. It's okay, and it's not. People just need to somehow see how the box fits and how the whole fits into that box.

“The box”, in this case, is the label of mental disability. According to Lulu, those who experience mental distress need to try on that box for size in order to be able to “step away from the ledge” of addiction or suicide. To her, it is important to accept the label in order to move
away from danger. That said, she also says that people facing mental distress should see “how the whole fits into that box”. The label here is not the sole defining factor of a person but it is important to incorporate the label into one’s self-narrative in order to move forward. Then it is possible to see the experience of mental disability as a difference, as Lulu does.

If she can do it and she's got her shit together, then it's not that bad, or she's normal so ...

Everybody knows I'm crazy. You know what I mean? She's crazy, but she's not crazy so maybe it's okay.

Lulu sees herself as “crazy” as in viewing her mental disability as a difference but “not crazy” as in she does not view her mental disability as a threat. She hopes that sharing her experience can help others to adopt more positive schemas around mental disability and thus not be afraid to seek treatment for mental distress.

Jeremiah, we have seen, does sometimes view his mental disabilities as problems or as him being “damaged”. However, he also does see assets within himself resulting from his experiences of the world, which include mental disability. He sees himself as “pretty strong” as a consequence of all that he has learned from his experiences.

I go for the big picture and I fight the long game, because I'm not going to score many points, I'm not going to win too many battles. My identity. Endurance. It's like I'm a cyclist, I'm an endurance athlete, and I ride. I'm in endurance sports, I stay with it, I wear them down. That's my identity. That's a strength of mine. There is strength to my identity, and that's it. I think of myself, actually, of being pretty strong. It's that just keep at it. I know that it doesn't have to be done today. It's almost patience, ironically. It doesn't all have to be done today. I'll show up tomorrow, and I'll show up the next day, or I'll show up the day after, and I'll just keep coming back. I'll just do it over and over and over and
over and over and over again til it gets done, which isn't very sexy, and it's not winning a lot of battles here. There's not a lot of showing off. It's just showing up. That's what's great. That's where my strength lies.

It is clear that Jeremiah still incorporates negative schemas of mental disability into his self-image, as he qualifies even his strengths as not “sexy” and says he will not be “winning a lot of battles”. That said, he does see as strength those qualities which make him different from other people, thus he also integrates the schema of mental disability as a difference/strength into his narrative. It is possible, then, to weave these schemas together. In Chapter 5 we saw that Jeremiah learned from a young age (as young as six years old) that his mental disability was a threat, something “scary” and “very wrong”. According to him, it was not until he was an adult that he began to see mental disability as difference (as will be explained in the next section). Perhaps those facts account for the fact that he merges schemas of mental disability as a threat and mental disability as a difference in his self-narrative.

Jeremiah learned from the adults around him that his mental disability was a threat as they excluded him from school. As Marie says, “when you're a kid, you don't even know who you are, so when somebody tells you you're just being difficult, you absorb that as, ‘I am difficult.’” That said, if teachers are able to impart negative schemas, such as mental disability being a threat, then they should be able to convey positive schemas as well. In the next section I will explain how individual teachers had an impact on the schemas that the participants use to describe their mental disabilities.

**Teachers Informing New Schemas**

One of the ways that Sewell (1992) suggests that individual agents can resist the reproduction of structures is through the transposability of cultural schemas. This means that
schemas learned in one place can be transferred to another. I suggest in this section that individual teachers have done this and then conveyed to the participants these new positive schemas at various points in their schooling, helping participants to see their mental disability as a difference/strength rather than a deficit.

Marie speaks about two of her teachers in high school who helped her to see her mental disability as a difference by teaching her a word with different connotations from those she had been using to think about her disability.

L and F, which were just amazing people and they understood that my brain just worked differently and they just thought that it was like this beautiful thing. They introduced me to the word quirky and I was like, "I'm quirky." It was amazing.

L and F, through their life experiences as adults, were able to see difference as a “beautiful thing” and helped Marie to see it that way as well. The word “quirky” was new vocabulary for Marie and it opened up a world for her in which her mental disability was not a mark of deficiency, but rather a difference and a positive one at that. This experience was “amazing” for Marie as it allowed her to own her disability as a favorable part of her being. This is a clear example of individual teachers using their own ability as agentic actors to transpose schemas and then teach the transposed schema (in this case, of mental disability as a difference) to a student.

Not all cases of this process, as described by the participants, are as clear as Marie’s experience. For some participants, they learned from their teachers simply that their mental disability was not a difficulty in the classroom, a reversal of the schema of mental disability as a threat, which has led to the exclusion of so many students with mental disabilities historically. Kevin learned from his teacher, Mrs. D, that he could pay attention and perform in class, while
still having the space to “be late, or talk out of turn, or whatever” (the behaviors he indicated in Chapter 5 that correspond with his mental disability).

She would never yell at me, and, frankly, she was smart because that was not the type of thing that I would respond to well, and I still don't, frankly. When somebody yells at me, my attitude is just kind of like, "You're an idiot." I'm even more resolved, now, to do what I was doing before or whatever I want to do. She came at me much more like a mom, where it was like, if I didn't do something, she'd say something like, "You know, I'm really disappointed that you didn't do that," and I would feel bad. She's the only teacher who's ever made me feel bad. I remember that, and thinking like, "I can't let this woman down. I've got to read this book," or whatever, like, "I'm going to feel like an asshole if she calls on me, and I have no idea what I'm talking about because I really think that she wants me to do well, and she feels bad when I don't." When I would make these comments, or be late, or talk out of turn, or whatever, she had a way of finding a nice balance between sort of looking the other way when it didn't really matter, and when it was time for me to settle down and pay attention, she still had a way of doing it where it was motherly. I seemed to respond to that a lot better than the disciplinarian style teacher.

Mrs. D created a classroom in which Kevin felt he could be himself while still being held to a high standard of academics and behavior. She cultivated a personal relationship with Kevin that allowed him some freedom while still encouraging him to perform the role of good student. It is not clear that Mrs. D recognized Kevin’s mental disability, but rather she naturally created a classroom that was inclusive of many types of students and did not treat Kevin’s tendency to act
out as a threat that would require drastic action. Mrs. D was gentle with Kevin and respected his differences while inspiring him to achieve as a student.

Jeremiah mentioned two teachers who taught him new schemas with which to explain his mental disabilities – one from elementary school and one later in life when he was pursuing a Masters degree. The first, Mrs. B, an elementary school teacher, saw value in him where other teachers and administrators did not. Jeremiah was expelled from school at a young age (as we saw in Chapter 5) and does not have many memories of teachers who appreciated him or could view his mental disabilities as anything other than threats. Mrs. B was an exception to this.

There was Mrs. B, I think, was my first grade teacher the second time around, or my second grade teacher, I can't remember which. She had a southern accent, and she was kind. I think, as I recall. I think she said one day, "You're going to come back. Jeremiah, I get it, one day you're going to come back in a Cadillac. You're going to show us." Not so much teachers, per se, she was like the first embodiment of a persona that has shown up repeatedly in my life. I guess Mr. F, to some extent he was that. Usually it's a woman and it's usually just like, "I get you. You're okay. It's going to be okay." She was sort of like that.

Jeremiah felt seen by Mrs. B, who predicted success for him. According to what Jeremiah remembers, she recognized the fact that he was not valued by other teachers, which is clear in her (remembered) statement “you’re going to show us”, but she believed that he did have worth and that he was “okay”. Jeremiah remembers Mr. F (who was mentioned in Chapter 5) playing a similar role. For Jeremiah, these two adults are people who recognized his differences, and also appreciated them. This was the very beginning of Jeremiah being able to view his disabilities as
differences. When he was in graduate school, that schema became even clearer for him because of another teacher.

One professor at B College said, "I don't like learning disabilities. I call them learning differences." It sounds like a euphemism, you know? I actually think in this particular case ... Also he called it a learning difference. He didn't put some kind of fancy title on it. He didn't come up with some sort of euphemistic weird name. He just used plain language, a learning difference. I think that's actually more accurate than a disability. It's not that I can't learn, it's just that I learn a different way.

At this point in his life, as an adult, Jeremiah is able to recognize that “learning difference” is “more accurate” to his experience than the term “learning disability”. He sees, now as a graduate student, that he is able to learn, which is not necessarily what he believed about himself as a child because of the way that his mental disability was received while he was in elementary school and junior high (until he was expelled). This professor gave him the language to describe what he began to learn from Mrs. B and Mr. F and what he learned from his own life experience. His mental disability is a difference, not a deficit. He thus adopted the schema of mental disability as a difference into his self-narrative.

**Conclusion**

This chapter has shown that the participants who were able to describe their mental disabilities in terms other than “threat” or “disease” were those who both embraced the label(s) they had been given and also engaged in some process of self-reflection. Marie said, in one interview, “I feel like if labels are going to exist, than everybody should try to own one”, and it is that process of owning the label that seems to have allowed participants to move from seeing their disabilities in terms of the medical model (within the schemas of mental disability as a
threat and mental disability as a disease) and towards a vision of their mental disabilities as
differences and/or strengths. Individual teachers and administrators helped some of the
participants to make that shift through their words and actions in the classroom.

In the concluding chapter, I will discuss how participants of this study have used their
mental disability throughout this study as a landmark in their lives around which they built their
narratives of schooling and self and consider again how the moment of labeling is important to
mental disability. I shall also revisit the social model of disability and labeling theory and discuss
how it applies to mental disability, given what has been learned from the participants of this
research.
Chapter 7: Implications and Conclusions

The purpose of this research was to foreground the school and labeling histories of people with mental disabilities, people who are not often thought of as history makers. Through a blend of oral history and life history interviewing (with a focus on their schooling and labeling histories), I examined the ways in which cultural schemas of mental disability – mental disability as a threat, mental disability as a disease, and mental disability as a difference/strength - were used by the participants to explain their own experiences of schooling and labeling. This final chapter will discuss the implications of this research for educational theory and future research.

To revisit, the research questions that guided this study were as follows:

1. How has mental disability been defined from the inception of public schooling in the United States and how have dominant cultural schemas of mental disability been used in schools and education policy making?

2. What do personal narratives told by people categorized as mentally disabled reveal about their experiences of public schooling?
   a. In what ways do these narratives reproduce and/or resist dominant cultural schemas about mental disability?
   b. What personalized understandings are revealed through the narratives and how do they reframe how we think about mental disability?

Chapter 4 provided historical background for the study, answered the question of how mental disability has been defined for the purposes of education in the United States since the beginnings of public schooling, and highlighted cultural schemas that have been used to inform the education of people with mental disabilities. Chapter 5 was a discussion of how these dominant cultural schemas were reproduced by the participants of the study through their acting
the “good student” and “good patient”. Chapter 6 examined resistance by participants to the dominant cultural schemas of mental disability as a threat and mental disability as a disease via the adoption of the more positive cultural schemas of mental disability as a difference/strength through a process of self-reflection on the part of participants and instruction from some of their teachers.

Eisenhart (2009) claims that qualitative research is generalizable insofar as it is useful for rethinking and refining theory. With that in mind, I will use this chapter to consider the implications of participant experiences on how we think about mental disability by reexamining (1) labeling theory, (2) Disability Studies theory (specifically the social model of disability), and (3) intersectionality theory. The goal will ultimately be a reframing of how we think about mental disability in education.

**Revisiting Labeling Theory**

The participants of this study were a diverse group who had one commonality – they were all labeled with mental disability. Returning to labeling theory, we recall that Becker argued that “treating a person as though he were generally rather than specifically deviant produces a self-fulfilling prophecy” (Becker, 1963, p. 34). A label of mental disability is tantamount to calling a person “generally” deviant. In Chapter 6 Lulu commented on the tenacity of a label of mental disability. Once given and accepted as part of the receiver’s experience, there is no way of surpassing the label. It remains for a lifetime.

If Becker is correct and treating a person as “generally” deviant “produces a self-fulfilling prophecy”, then people who are labeled as mentally disabled and accept that label will act the part (Becker, 1963, p. 34). In Chapter 5 it became apparent that some of the participants had a choice of acting as the “good patient” or as the “good student” to reproduce structures of
normalcy, which put them at less risk of being labeled and/or afforded them greater social capital after they were labeled (Scheff, 2009). Their ability to choose this path was based on their accumulation of resources as part of their intersectional identities, and whether they had knowledge of the deep cultural schemas of mental disability as a disease and mental disability as a threat. Thus it is possible to resist being considered deviant, if one has access to certain resources and knowledge of particular cultural schemas.

That said, all of the participants were eventually given a label of mental disability and all of the participants believed that their mental disability had some effect on their schooling. Therefore, their label of mental disability not only affected their lives after the fact, but also often served to explain events that happened even before the label was given. The label not only created a “self-fulfilling prophecy” as participants moved forward with their lives, it also helped to structure the narrative of their past lives as they looked back over their schooling histories. Hence, as they were labeled deviant, the whole of their lives was worked into that storyline. The label of mental disability becomes a powerful means of explaining their identities.

While we saw in Chapter 5 that a label of deviance, synonymous with a label of mental disability, did encourage participants to play particular roles, as Scheff (2009) suggests, it is not given that participants self-inscribed the dominant cultural schemas around mental disability. As agentic actors, they engaged in self-reflection that led them to adopt more positive cultural schemas, such as mental disability as a difference/strength. This shift in perspective seemed to require that they accept their label as part of their identity, as those who did not do this did not make the same alteration. It would seem that allowing a label of mental disability to become part of one’s life narrative is not necessarily negative and does not necessarily mean that the person who does it is reproducing social structures of oppression. For several of the participants, it was
this acceptance of their label that made possible their espousal of more affirmative schemas around mental disability. It is therefore possible that individuals can use their label of deviance to resist cultural schemas that oppress them and that acceptance of that label is part of the process. Thus Becker (1963) and Scheff (2009) can be seen read as overly simple. While it is possible that a label of mental disability influences future actions of those labeled and that society treats those labeled as generally deviant, the experience of participants would indicate that there is a more complicated negotiation that is part of accepting one’s label. Several participants saw their mental disability as a source of strength and not a prediction of their potential. This may be considered an example of “claiming” their disability as, while done privately and not publicly, such a process of moving towards more positive schemas does allow the participants to better advocate for themselves and even advocate for others, as we saw in the example of Lulu sharing her experience with others who were in similar situations (Linton, 1998a). Participants were constantly rethinking their relationship with their label and did not always see those labels as negative or as an indication of general deviance.

While most of the participants did accept their labels and were able to create positive narratives for themselves, it is also true that almost none of the participants considered themselves to be disabled, at least not in the way they defined the term (which amounted to a loss of function). In the next section, I will revisit the social model of disability based on participant experiences and rethink the model specifically for mental disability.

Revisiting the Social Model of Disability

The social model of disability relies upon a distinction made between impairment and disability (Linton, 1998a; Hamre, Oyler & Bejoian, 2006). Impairment is considered to be a physical difference whereas people are disabled by the fact that they are denied access to spaces
and services based on deficit-based schemas about impairment. In this model, disabled people constitute a political minority based on their shared oppression. In Chapter 4 there was a description of the Mad Pride/psychiatric survivors’ movement, which included discussion of their hesitance to identify themselves as disabled. As David Oaks, former Executive Director of MindFreedom International, said, “The label itself, the word ‘disabled’ – that alone was a big barrier for people to recognize our common ground” (Pelka, 2012, p.301). Psychiatric survivors do not think of themselves as impaired, instead they consider madness an example of human diversity. They think of themselves as merely different from the “normal” standard. The participants of this study seemed to agree with this view (without, it seemed, having prior knowledge of the psychiatric survivors’ movement). Participants did not consider themselves to be disabled (aside from Marie, who took the political stance that she was disabled in order to show solidarity with other disabled people), rather they thought of themselves as different. Some also took the stance that most (or all) people are “different” to some degree. In the words of Marie, “I actually think more of us are not, quote end quote, normal.” Thus the social model of disability as includes a distinction of impairment and disability did not seem useful to the participants. This is consistent with literature in Mad Studies, which theorizes mental disability as a difference and not an impairment (LeFrançois, Menzies, & Reaume, 2013). Mad Studies seeks to understand the experience of people with mental disabilities “within the social and economic context of the society in which they live” (LeFrançois, Menzies, & Reaume, 2013, p. 2). The discipline frames madness as “emotional, spiritual, and neuro-diversity” (LeFrançois, Menzies, & Reaume, 2013, p.10). Mad studies frames people with mental disabilities as being part of a marginalized group who are oppressed by labels given by the psychiatric community
and by societal stigma, rather than seeing them as impaired (social model) or as disordered
(medical model).

What participants of this study had in common, rather than impairment, was the fact that
they were labeled with a mental disability. While mental distress is something that everyone can
and will experience due to disparate factors such as trauma, drug use, and lack of sleep, not
everyone receives a label to describe that mental distress. There are various factors that play into
whether or not a person receives a label, ranging from the intensity of degree and level of
consistency of the distress to factors like gender and race, which can influence the clinical
judgment of professionals (Biklen, 1988). As we saw in Chapter 5, the resources that a person
possesses (whether human/intangible or non-human/tangible) can have an effect on whether or
not they are labeled (Sewell, 1992). It is not the distress (or impairment) that disables a person. It
is the label, in this case, that positions the recipient as not “normal” and creates the disability and
subjects them to stigma.

Paradoxically, it is acceptance of the label that allowed participants to adopt more
positive cultural schemas around mental disability. This meant acceptance of their uniqueness. It
meant that some participants developed an appreciation for human diversity, when it came to
mental disability. We saw that, as least in Marie’s work in a special education classroom, this
appreciation of difference extended outward to include others who were labeled. It is the
acceptance of labels as indicative of difference (not deficit) that allows the espousal of positive
schemas around mental disability.

However, we saw in the experiences of the participants that schools are not always set up
to accommodate difference. Teachers, administrators, and school structures still use deficit-based
schemas of mental disability as a threat and mental disability as a disease to explain the
experiences of people with mental disabilities. People who experience mental distress may attempt to perform wellness/normalcy in order to avoid being labeled as troublemaker, daydreamer, or antisocial misfit, if not given a label of mental disability outright. Schools reflect the way we treat the vulnerable in our society and people with mental disability labels, people who are different, are still treated as problematic rather than embraced as part of a diverse population.

The participants of this study were “disabled” in the sense of the social model by the negative effects of the schemas of mental disability as a threat and mental disability as a disease as a result of being labeled. That said, for the most part they did not consider their mental distress or their labels as disabilities. Instead, as we saw in Chapter 6, these were merely “a hurdle and a challenge” for them and for many of them their label was a source of strength. This is not to say that their labeling or the mental distress that led to the labeling was necessarily a pleasant experience, but it was an experience that they did eventually think of in positive terms. Their identities as related to their label were constantly being rethought and renegotiated via the use of various cultural schemas. While many of those cultural schemas around mental disability are negative, it cannot be said the participants were disabled by all of them. Many of them managed to adopt schemas of mental disability as a difference/strength and draw power from that. Thus whether or not the participants were disabled by their label is called into question. At times they were, and at times they were not.

It can be argued that official labeling in school can provide students with services to aid their educational and emotional lives that they may not otherwise have access to. Labeling becomes oppressive, however, when accompanied by negative schemas which, as we have seen in the experiences of the participants, is almost always the case. Teachers should treat labels
(whether official or unofficial) as shifting and porous. However, teacher preparation programs tend to teach labeling as static and essential. That is, teacher education is very much still based on the medical model, where intervention is necessary to address the range of issues that students with disabilities bring into the classroom (Brownell, Sinclair, Kiely & Danielson, 2010). Teacher education programs rarely question labeling processes or the schemas that come along with labels. However, as we have seen, inherently, mental disability is fluid and dependent on context and thus there is no way to define students by their label that is fair.

Labeling is best conceptualized by teachers as a means to an end, which is services for children who could benefit from them, rather than descriptive of any characteristic of the child. While that is true for teachers, the participants of the study took on their labels as descriptive of themselves (but only if they made sense to them, as in the case of Lulu); only if it described their lived experience. Labels can be helpful in giving name to lived experience, offering vocabulary to describe what one is going through. Acceptance of the label then, as we’ve seen, can be both detrimental and helpful to the receiver. It brings with it negative cultural schemas but can also be a source of strength through adopting positive schemas. That said, while labels can be useful in describing a person’s experience, in school they are mainly used for the benefit of educators and other professionals and negative schemas are often imposed on children with mental disabilities which they then have to negotiate. Understanding labels as a means to an end (services) and one that can be fraught with negative consequences is important to not essentialize students based on their labels.

It is also worth noting that some people with mental disabilities (who have the human and non-human resources to do so) may choose to invoke their label when it is useful to do so and perform normalcy when that is useful. We saw evidence of this in the participants’ performance
of the “good student” and/or “good patient” in Chapter 5. Rather than merely being a reproduction of negative cultural schemas, such performance shows an acknowledgement of the power of those schemas and is a means of exerting some control over a situation in which one might otherwise be disabled by the label. Thus people with mental disabilities, who possess requisite human and non-human resources, can manage to some extent when and how they are disabled by their labels through the performance of wellness or “good”.

The disabling of people based on labels of mental disability is contingent on the cultural schemas about mental disability with which they come into contact. Later I will discuss how teacher education can be instrumental into bringing more positive schemas of mental disability into schools, thus breaking patterns of using negative cultural schemas around mental disability in education and thus disabling people with mental disabilities.

Revisiting Intersectionality Theory

Individuals have different experiences of labeling with mental disability based on their particular intersectional identities. We saw from the participants of this study that the accumulation of resources (both human/intangible and non-human/tangible) allowed some of them to perform the roles of “good patient” and “good student” to a greater degree than others (Sewell, 1992; Scheff, 2009). Thus based on the quantity and quality of resources that an individual accrues (whether economic or social), they may be able to avoid being labeled with a mental disability altogether or at least avoid some of the negative social consequences of that label. I would posit that the ability to avoid negative social consequences of a label of mental disability (in other words, having the privilege to be able to keep that label mostly invisible if one so chooses) may be a factor in whether or not a labeled person is able to develop a positive self-image that includes that label. If being labeled creates more mental distress for a person
based on the negative social consequences that follow the labeling, it may be more difficult for that individual to adopt positive mental schemas around mental disability. As an example, I would refer to the case of one of the participants, Jeremiah, who was asked to leave school in junior high based on behavior directly related to his mental disabilities and who has not completely given up discussing his mental disabilities in deficit-based terms, although he does make an effort to use schemas of mental disability as a difference/strength after being explicitly taught such schemas in his graduate degree program (this process is discussed in depth in Chapter 6). I would argue that it is probable that people who easily amass resources by virtue of their socio-economic or cultural backgrounds will be more likely to easily adopt positive cultural schemas around mental disability and begin to think of their disability as a difference/strength. However, we saw in Chapter 6 that individual teachers can be instrumental in helping students with mental disabilities shift their thinking from deficit-based schemas around mental disability to asset-based ones. In the next section I will discuss the implications of that finding for teacher training.

**Implications of this Study for Teacher Education and Classrooms**

Having discussed the implications of this study in relation to theories of intersectionality, labeling, and the social model of disability, I will now examine its findings and implications for teacher education and classrooms. I argue that teachers can and should provide openings for students with mental disabilities to think about their labels in more positive terms.

We saw that participants of this study were able to adopt positive cultural schemas around mental disability through self-reflection and/or explicit teaching and that managing mental distress was made easier for participants through adoption of positive cultural schemas of mental disability. That said, it is not enough to assume that students with mental disabilities will
be able to adopt positive schemas on their own, especially given the fact that negative schemas around mental disability (such as it being a threat and a disease) are embedded in the culture historically and still used by schools and medical professionals on a regular basis. Teachers can and should provide openings to positive schemas. Teacher education programs could involve the teaching of positive schemas of mental disability and the cultivation of caring and flexible attitudes around mental disability among educators. Teachers could then enact these asset-based schemas of mental disability to their students, both those with disabilities and those without.

It is possible, as we have seen, through self-reflection for people with mental disabilities to develop these positive scripts for themselves. However, given the limited cultural schemas that are available regarding mental disability (most of which are negative and grounded in the medical model), it is would be irresponsible of schools and teachers to assume that all people with mental disabilities could adopt positive schemas on their own, without explicit teaching. This is described in the book Learning Disabilities and Life Stories by Rodis, Garrod, and Boscardin (2001) by Gretchen, a young woman with ADHD, which falls under our umbrella of mental disability:

There is a part of me that would never want to change the fact that I have ADHD. I believe that this condition can be positive in many ways for the person who has it. The main setback for most people with ADHD, especially children, is that they are misunderstood. If I had been taught to believe that ADHD was a learning difference rather than a learning disability, I feel I would have had a more positive view of myself while growing up (p.71).

Being misunderstood by teachers can stand in the way of a child developing a positive self-image around their mental disability. In order for teachers to convey positive schemas about
mental disability, however, they must confront their own deeply held beliefs about the nature of mental disability and replace negative schemas with schemas of mental disability as a difference/strength (which must be explicitly taught). Only then will teachers be able to explicitly teach those schemas to their students and help to build positive self-images in their students with mental disabilities, as well as address stigma among their students without labeled mental disabilities. Teacher education should thus include self-examination on the part of teacher candidates, as well as the introduction of more positive schemas. This self-examination is not always comfortable, but some discomfort is necessary in order to shift negative views about mental disability as the schemas which cause these negative views (mental disability as a threat and mental disability as a disease) are deep schemas, often held unconsciously, and acted upon without much thought. In order for teachers to act upon more consciously held schemas of mental disability as a difference/strength, they must confront deeply held negative schemas in a teacher education classroom that uses a “pedagogy of discomfort” to gently push teachers beyond what is comfortable for them (Zemblyas & McGlynn, 2012). Because labels of mental disability are shifting and porous and because these labels can be official and unofficial, I believe that all teachers would benefit from such education as all teachers will at some point come into contact with students experiencing mental distress. For that reason, I believe the most appropriate place for such a pedagogy of discomfort would be in classes on multiculturalism and/or diversity, which are required for all teachers. Mental disability could be brought into such classes as a potentially positive identity with studies such as this one used to demonstrate how a shift from negative schemas of mental disability to positive ones can be accomplished with the help of teachers.
Schemas of Mental Disability in Teacher Education and Pedagogy of Discomfort

I have argued that teacher education could involve teaching of positive schemas of mental disability, but what could that look like? First, it would be necessary for teacher candidates to recognize the negative schemas that they utilize to describe students with mental disabilities. Next, teacher candidates could critically consider how those schemas came about. In the end, the goal would be to consciously replace negative schemas of mental disability with positive schemas and cultivate caring and flexible dispositions in teacher candidates for their work with children with mental disabilities (and, indeed, all children). This process would involve the use of what Kumashiro (2000) calls “anti-oppressive education” and what Boler (1999) calls “pedagogy of discomfort”. In other words, teacher candidates would have to confront deeply held beliefs (or what Sewell (1992) calls “deep schemas”) in order to be able to make a shift from negative to positive schemas. According to Boler (1999), confronting these deeply held beliefs allows for teachers to gain insight into the roles they play in reproducing dominant ideologies. Boler (1999) also emphasizes that hope should be a part of the process of this critical pedagogy, which will be discussed further later on.

“Pedagogy of discomfort” is an educational process of pushing the student beyond his or her “comfort zone”, which is defined as “the emotional space in which somebody feels comfortable, without taking any risks or feeling threatened” (Zemblyas & McGlynn, 2012, p. 57). According to Zemblyas and McGlynn (2012):

Pedagogically, the approach assumes that discomforting emotions play a constitutive role in challenging dominant beliefs, social habits, and normative practices that sustain social inequities and in creating possibilities for individual and social transformation (p. 41).
This means that in order to create safer spaces for the children who will be their students, teacher education cannot be entirely safe. There is a need to challenge deeply held beliefs and the practices that arise from them if teachers are to create nurturing classroom spaces where children with mental disabilities are safe from the social repercussions that come along with a label of deviance, whether an official label of disability or an unofficial label of troublemaker. As was mentioned, Boler (1999) discussed the need for hope to be a part of a pedagogy of discomfort with the understanding that justice is not inevitable, but that educators can fight for it in their classrooms. Including a pedagogy of discomfort in teacher education is done with view to supporting a pedagogy of caring on the part of new teachers in their own classrooms, here defined as explicit teaching that arises from a commitment to social justice for their students.

Theories of a pedagogy of caring arise from the work of feminist scholars such as Gilligan (1982) and Noddings (1984) and the idea that education is a relational process. Teachers build relationships with their students and through those relationships convey moral education. I draw upon critiques of this pedagogy of caring such as that of Thompson (1998) who states that these theories of care were based in White feminism and thus in political and cultural ideas that ignored race and assumed colorblindness. Thompson (1998) argues for a pedagogy that includes non-White perspectives on care. Such a pedagogy would aim to recognize societal inequality and work for social justice through a diverse curriculum that includes multiple viewpoints and histories. I would argue that a pedagogy of caring should also keep able-bodiedness and able-mindedness at the forefront if it is to be effective in reaching students with disabilities, and mental disabilities in particular. Students should not only see themselves represented in the classroom, but deep schemas about mental disability should be consciously questioned by teachers and students.
Thus, in the teacher education classroom, a pedagogy of discomfort around mental
disability specifically should refute the supremacy of the schemas of mental disability as a
disease and mental disability as a threat. A pedagogy of discomfort should also engage with
critical histories of madness and explicitly teach the social construction of mental disability. New
schemas of mental disability as a difference/strength should be introduced to teacher candidates
through encounters with research studies such as this one as well as other work and media that
highlights the voices of people with mental disabilities and their beliefs about their own labels.
Rodis, Garrod and Boscardin’s (2001) book *Learning Disabilities and Life Stories* is another
example of a text that might be used in this process. Pedagogy of discomfort is engaged in in the
teacher education classroom with the idea that in elementary and secondary classrooms, teachers
who have participated in this type of reflection can enact a pedagogy of caring aiming for social
justice. This could include actions such as questioning language (“crazy”, “psycho”) that
perpetuates negative stereotypes of mental disability and ensuring that a diverse curriculum
includes positive representations of people with mental disabilities. Teachers should also take
advantage of relationships with their students with mental disabilities to explicitly teach
affirmative cultural schemas of mental disability as a difference/strength. As well, teachers
should critically reflect on their relationships with students in order to avoid unofficially labeling
their students. This type of reflection could be done in collaboration with other like-minded
educators. In addition, a pedagogy of caring could include principles of Universal Design for
Learning, which will be discussed in depth later.

**Potential Issues that Arise with Pedagogy of Discomfort**

It is not always possible to know how students taught using a pedagogy of discomfort
would react. While the strong emotions that might come up during this process can certainly be a
catalyst for personal transformation (Greene, 1998), some teacher candidates may not be willing or ready to examine their own roles in the oppression of student with mental disabilities and may turn away from schemas of mental disability as a difference/strength. It is important to recognize that schemas of mental disability as a threat and mental disability as a disease are deeply entrenched schemas and historically rooted, likely creating discomfort for some teacher candidates to let go of those deeply held beliefs.

In addition, there is some irony in potentially creating emotional distress in teachers in order to alleviate emotional distress in students. Teacher candidates moving through discomforting pedagogies should be given emotional support in order to do so, much like the emotional support that they will be expected to provide for their own students.

Lastly, while the end goal of discomforting pedagogies is for teachers to enact pedagogy of caring in their own classrooms, it is essential to note that not all caring is demonstrated in equal ways. At times such seemingly benevolent emotions such as caring and pity are simply “hidden expressions of disgust for the Other” (Matias & Zemblyas, 2014, p. 319). Pedagogy of caring must be rooted in a desire for social justice for students rather than merely a performance of positive emotion. Teacher candidates should aim to be allies of their students with mental disabilities through creating safer classroom spaces for them built on the principles of Universal Design for Learning (which will be discussed later).

Teachers have to deviate from the script of accepted norms in order to better understand their students who have been labeled as deviant. By that I mean they must defy deeply held cultural schemas about mental disability in order to provide openings in their classroom for students who are labeled (whether officially or unofficially), openings through which these students have access to the curriculum and to emotional supports. In order to do this, they must
become allies to their students with mental disabilities, rather than acting in ways which further oppress them. Recognizing deeply held negative cultural schemas of mental disability and working to replace them with positive ones is a first step on this path, but what does this process look like in the classroom? I would argue that the pedagogy of caring (defined, again, as a commitment to social justice on the part of teachers) which arises from a pedagogy of discomfort in the teacher education classroom echoes some of the principles that underlie the theory of Universal Design for Learning (UDL). A pedagogy of caring in the classroom can learn from UDL how to provide openings for all students, both to the physical classroom and curriculum and to emotional support.

**Pedagogy of Caring and Universal Design for Learning**

Universal Design for Learning (UDL) has its roots in accessible architecture and the idea that it is possible to design buildings (or classrooms or curricula) which are available and open to everyone, regardless of ability. According to Pisha and Coyne (2001):

*UDL features that can be useful to almost everyone may be implemented in a way that makes them more openly available for general use. Just as the curb cut improves access for everyone, curricula and materials that embrace elements of UDL can be expected to improve outcomes for all learners (p. 198).*

The guidelines to teachers for implementing UDL, according to the National Center on Universal Design for Learning, are to provide multiple and flexible means of engagement of students, representation of materials, and expression of knowledge (National Center on Universal Design for Learning, 2017). The overarching idea is that everyone, regardless of ability, has a right to access the material and to demonstrate his or her learning.
A child who is labeled as a troublemaker or deviant or as having a mental disability is experiencing a challenge. The goal of his or her teachers should be to help them over the “hurdle” (as described by Kevin) rather than further disable them by ascribing schemas of mental disability as a threat and mental disability as a disease to them. We saw from the experiences of the participants of this study that helping them can be as simple as teaching a new vocabulary word (“quirky” in the case of Marie) or being flexible in terms of the behavior that is addressed in the classroom (as we saw from Kevin’s description of Mrs. D). The end goal is for teachers to open space for different perspectives and behavior in the classroom without being challenged by them. Too often teachers impose a normative standard of behavior in the classroom that assumes that children will be able to pay attention consistently and perform to a certain academic requirement without taking into account students who may be experiencing mental distress or other challenges. The labeling process for mental disability (whether official labeling with a disability or unofficial labeling of students as troublemakers) can lead to negative outcomes for students – such as disproportionate levels of disciplinary action or students leaving school altogether. If teachers recognize that fact and work to adopt more positive schemas of mental disability as a difference/strength, they could build safer spaces for student with mental disabilities in their classrooms. Using the tenets of UDL - i.e. multiple and flexible means of engagement of students, representation of materials, and expression of knowledge – can be useful here, especially developing ways of engaging learners who may be experiencing mental distress, as will be explored in the next section.

**Multiple and Flexible Means of Engagement**

Engagement of students is two-fold. Teachers must find ways of drawing in individual students, especially those who find it challenging to pay attention in a traditional classroom
environment. They must build what Danforth and Smith (2004) call “a pedagogical alliance” (p.5). In addition, teachers must engage a community of learners by building community in the classroom. If teachers are using negative schemas rooted in the medical model of mental disability as a threat or mental disability as a disease, they will inevitably create a classroom environment in which certain students are excluded from engagement in the materials because they are seen as incapable or unwilling. Viewing mental disability as a difference/strength allows for more options for engagement of students. If we look back to the participants of this study, we can see that they offered some ideas for how students with mental disabilities might be engaged in the classroom and how teachers might build community in which mental disability is not seen as unacceptable.

*Individual students should be given options for how they will engage in the curriculum.*

Lulu was considering leaving school until she was placed in business classes in high school and given a work internship. This piqued her interest and she excelled in her classes and she graduated from high school and went on to college to study her area of interest. The options provided her for how she engaged in the curriculum kept her in school.

*Individual students should be taught schemas of mental disability as a difference/strength.* Her teachers offered Marie the word “quirky” as a means of explaining her personality. This was a positive way of thinking about her mental disability that she had not considered before it was explicitly taught to her.

*Classroom communities should be welcoming of all and hold high expectations for all.*

Kevin described the caring he received from Mrs. D, who did not ostracize him for his behavior but rather tried to find gentle ways of re-focusing him when he needed it. Jeremiah discussed his teacher Mrs. B who held him to a high standard when others did not.
Classroom communities should be taught schemas of mental disability as a difference/strength. If teachers are committed to social justice for their students with mental disabilities then stigma can be addressed in the classroom by teaching positive schemas. While the participants of the study did not describe this process, it is a logical extension of the findings of the study. Bringing schemas of mental disability as a difference/strength into the classroom should not only help students with mental disabilities develop confidence and more positive self-images, it should also allow children who are not labeled to grow as allies of their peers with mental disabilities and help them to address any mental distress that they might experience throughout their lives.

The principles of UDL provide guidelines for how teachers might begin to think about how to put into practice positive schemas of mental disability in their classrooms. By considering how students are engaged as individuals and as a community, teachers can create safer classroom spaces where all children are accepted for who they are and are allowed the experience of mental distress (which most, if not all, will go through at some point) without being stigmatized and led toward negative outcomes because of official or unofficial labels of mental disability.

Revisiting Limitations

While I believe that the small number of participants in this study made it possible to explore in greater depth the experience of being mentally disabled in school, some may consider the size of the study to be a limitation. In addition, the stories of the participants of this study were taken at their word. Because the participants were interviewed as adults looking back, the study is dependent on their memories and I had no way of verifying the facts of their stories. As mentioned, the fact that they were looking back over their lives and schooling through the lens of their mental disabilities meant that the narratives were situated with the mental disabilities at
their center. It might not always be the case in the lives of the participants that they give their mental disabilities such weight. However, this process of looking back allowed me to see how the label has affected them from childhood until the present and permitted me to engage with theories of Disability Studies, labeling, and intersectionality as seen through the eyes of the participants. Wherever possible, participants were asked their opinion on the theory and engaged in the process of analysis, however, in the end the ideas put forth in this chapter are my own based on what I heard in the stories of the participants.

For future research, it would be helpful to expand this study to include more participants and, in particular, to examine the experiences of people who could be seen as “at risk” of being overrepresented in official categories of mental disability in schools (such as ED). An expanded study would allow for more in depth analysis into the processes by which labels are given in schools and the effect that such labeling has on individual lives.

**Conclusion**

Further research can and should be done into the effectiveness of replacing negative schemas of mental disabilities with positive ones in teacher education. This study begins to imagine the possibilities for this type of transformative teacher education on the lives of students with mental disabilities and, indeed, on all students. The principles behind a UDL approach to the education of students with mental disabilities is to create spaces in which all students are able to thrive and feel safe to express their emotions.

This study provided information about the schooling and identity formation of people with mental disabilities. It is clear in the words of the participants that people with mental disabilities use various available cultural schemas to negotiate their identities. They both reproduce schemas that position them in a negative light (mental disability as a threat and mental
disability as a disease) and resist those schemas which harken back to the medical model by adopting positive schemas to describe their experiences (mental disability as a difference/strength) and their identity formation involves a constant negotiation of these schemas. I have argued that teachers can and should be taught to introduce positive schemas around mental disability to their students in the hopes that this will help them to adopt those schemas as part of their identities. The goal of such an approach is to affirm the uniqueness of individual students and to teach them that it is not a problem for them to be who they are in the classroom. Perhaps if teachers can adopt positive schemas around mental disability themselves and convey those schemas to their students in the classroom environment, students with mental disabilities would not have to be segregated in an attempt to normalize the classroom environment. Students with mental disabilities have a right to be educated with their peers in a classroom environment not only appreciates their differences but thrives on that diversity. All children benefit from a classroom environment in which mental distress is treated as a natural phenomenon that can be addressed with caring and not a problem to be solved. It is my hope that this study demonstrated some ways in which teachers might work to create such a classroom.
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167


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