Expectations, socialization and safe spaces: An exploration of the

experiences of middle school students with disabilities

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Lisa Ann Johnson

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Dr. Timothy J. Lensmire, Adviser

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This work is dedicated to my husband, Jeremy, and our children,

Nevaeh, McKail, Nadirah, McKellen, Namarah and Baby Girl Johnson.

You are my everything.

Abstract

Historically, disability has been understood as a strictly individualized medical experience and considered a deficit. The person with a disability needed to be treated or rehabilitated by professionals. Recently, the social model of disability has offered a different perspective, one that situates disability within a social context. The "problem" of disability does not reside within an individual but instead within the social structures, policies and environment that create unnecessary barriers for a person. These barriers certainly can be found in our schools, and this study explored how one rural middle school, recognized regionally as "doing great things for students with disabilities," responded to the social and academic needs of its special education population.

This year-long ethnographic study began in the summer of 2011 when I began meeting with school personnel to learn the norms of the special education program. During the school year, I was present four to five full days per week. Data collection methods included participation observation in formal spaces (classrooms) and informal spaces (cafeteria, hallways, recess and field trips), individual and small group interviews and document collection and analysis. While many students and staff made this study possible, my focal participants included 18 students in grades five through eight, four parents, many teachers and aides and two school administrators.

I focused on three areas of interest. The first was related to the school's use of formal curriculum for educating "about the other" (Kumashiro, 2002) that took the form of a disability unit. Students "put on" disabilities during simulations, completed research and gave speeches related to the medical nature of

disability. This succeeded in reaffirming traditional stereotypes of disability as a strictly medical problem or personal tragedy. A second focus was on the ways expectations for students with disabilities were communicated through the students' access to meaningful, high quality instruction and in the ways staff talked to and about students with disabilities. In many instances, students experienced "dumbed down" instruction, if they received instruction at all, that did not meet their individual needs. In other situations, students were talked about in violent ways that indicated some teachers' perceptions that students with disabilities were not capable of a meaningful existence. A final area of focus explored the unlikely safe space that occurred in a detention classroom. Students gathered, by choice, to support one another and figure out what it meant to be marginalized in this school.

This work responds to a call for research done by researchers who are themselves disabled with children and teens who are disabled and has implications for how we think about and teach students with disabilities in our schools.

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Introduction

"Guys!" Ms. Lana Marks, one of the middle school's special educators, yelled over the roar of excited voices in the classroom. "Head out!" Any other day, it may have taken three or four tries to gain the students' attention, but today, with the End of the Year Valleyfair trip, these three words set the crowds in motion, and the masses pushed out into the hallway and half ran, half skipped to the front of the school to claim their seats on the awaiting coach buses. Soon I was the only one left in the room. I closed the door and walked down the hallway toward my workspace in the special education wing to get my backpack and lunch.

"Just who I wanted to see." It was Mrs. Melinda Matthews, another of the multi-categorical special educators at Cinder City Middle School. "I've got meds for you for Matt and Sabin. Give them at noon. And, would you mind grabbing Sarah's wheelchair on your way out to the bus? It is by the front doors. I guess Mom and Dad want it on the bus. Not my problem if it gets damaged is what I say! Lana will be on the trip with you, but I just saw the bus list and you've got all our kids on your bus so I figured I'd fill you in."

"Not a problem," I said, taking the envelopes of medication and zipping them into my backpack. "One thing. What if Sarah needs to go to the bathroom? What do I need to know to assist her?"

Ms. Marks, who had rushed into the room in time to hear my questions, said, "She'll be fine. She won't have to go, and if she does, she can do it herself.

She should've just ridden with her parents if you ask me. Less work for us."

"I'm happy to help. . ." I offered.

"Well, if she has to go, she'll have to hold it or crawl to the bathroom, but It is not your job to help her."

We talked a few minutes more before I excused myself and headed down the hall to pick up Sarah's wheelchair. Thinking I would just roll it out the front door, I remembered that the front doors to the middle school were not accessible. I tried to recall where I'd seen a ramp but couldn't, so I picked up the wheelchair and carried it down a set of stairs, out to the front of the building and over to the awaiting bus. Sarah's dad had already carried her onto the bus so another eighth-grade teacher and I folded the chair and stowed it beneath the bus and I got on board.

As I appraised the available seats, several students in front called my name and asked that I sit next to them, but I settled into a seat about five rows from the front. Mrs. Andrea Marshall, the eighth-grade English teacher, took the seat next to me. She and Mr. Larson, the social studies teacher, took up a conversation about the past evening's failed gubernatorial recall election in Wisconsin, a conversation I only partially listened to as I feverishly worked on fieldnotes from the morning's events.

Mrs. Marshall eventually turned her attention to me and asked what I was working on, but no sooner had she done this when we were interrupted by a student's voice, "Excuse me?"

"Oh, hey Emma!" Mrs. Marshall said. "What's up?"

"Sarah asked me to tell you that she has to go to the bathroom."

Mrs. Marshall glanced sideways at me before telling Emma to return to her seat and that we'd be right there.

"What are we supposed to do?" she asked.

"I asked Ms. Marks and Mrs. Matthews, and they told me that Sarah would be able to do it on her own."

"But how is she going to get back to the bathroom? She can't walk that far."

"I know," I sighed, embarrassed to share the next part. "They said she could crawl."

"What?!?"

"I know. How humiliating would that be for her in front of all these kids!"

"Why isn't Ms. Marks on this bus?" she asked but didn't wait for an answer. "Oh, that's right, she's here to socialize and you have to do her job."

"It is better this way," I admitted. "It is always worse for the kids when she's around."

"So, what do we do about Sarah?"

"Why don't we ask her? We can figure this out," I said with more certainty than I actually felt. We both got up and walked up front. Emma moved into a seat next to another student, giving us more room to talk to Sarah privately. "Emma says you have to go to the bathroom?"

"Yeah," she responded. Her cheeks flushed pink.

"So, can you walk on your own or do you need our help?" I asked.

"I can't do it myself."

"That's okay," Mrs. Marshall said. We whispered together for a moment, and then Mrs. Marshall said, "If we each take one of your arms and help support your weight, would that help?"

"That should work." She shifted over to the seat closest to the aisle and lifted her arms. Mrs. Marshall glanced at me and slowly we helped Sarah to her feet and began making our way, one slow shuffle at a time toward the back of the bus.

"Doing okay?" Mrs. Marshall asked. "If you need to slow down or stop, let us know."

"Okay," Sarah said. There was a strain in her voice and a look of concentration on her face. She propelled herself unsteadily, one step at a time. Five minutes passed before we made it to the bathroom.

"Are you okay now?" I asked as I opened the door to the bathroom. It had a toilet and small sink in a space no bigger than an airplane lavatory.

"I don't think I can do it alone." She looked embarrassed.

"No big deal. What do you need us to do?" I hoped that by downplaying the situation, I could minimize her embarrassment.

"Can you come in with me?" she asked. Mrs. Marshall looked between Sarah, the stall and me, a worried expression on her face.

"Sure," I pushed the door open with my elbow and began to back in. Mrs. Marshall helped Sarah maneuver through the door and let go. I pushed myself up against the wall to give us enough space to get the door closed.

"Okay, what do you need me to do now?" I asked.

"I can't get my swimsuit bottoms down."

"Okay, so I should pull them down for you?" She nodded. I tugged down hard on Sarah's bottoms and lowered her to the toilet. All along I couldn't help but imagine how I would have felt as a fourteen-year-old in this situation.

When she finished, Sarah reached up her arms and put them around my neck, and I lifted her from the seat and turned her around so she could use the sink.

"They should make these bathrooms bigger, don't you think?" I tried to joke, but Sarah didn't respond. Awkwardly we worked to get the door open, and I was relieved to find Mrs. Marshall waiting outside. We began the five-minute shuffle back to the front of the bus.

After Sarah was safely in her seat and we were back in ours, Mrs. Marshall fired one question after another. "I can't believe they told you she could do that independently! How do they get away with this? What if we would have done something wrong? Isn't this some kind of liability issue?"

I wasn't sure which question to answer so I started with, "I don't have training as a PCA [personal care assistant] so I'm not sure if we handled that correctly or not, but I wasn't about to leave her there with no help."

"I know," Mrs. Marshall sighed. "It is like what I've been saying over and over. It doesn't seem right how they make themselves out to be these saviors for kids but really, I think they make things worse."

Before long the bus came to a stop next to another bus carrying more students from our school.

Ms. Marks barged onto the bus, immediately barking orders. "Guys, listen up. You all get armbands so don't walk away from the bus without them. You all need to be with a partner AT . . . ALL . . . TIMES! Got it?" Students mumbled their responses and she went on. "Lunch is from 12:30-1:30. We will meet at the clock tower just inside the front gate. What time are we meeting?"

"12:30," the students repeated in unison, rolling their eyes and shuffling their belongings, doing whatever they had to do to get off the bus.

"We are leaving at 4:45. We will meet again at the clock tower at 4:45. Don't be late!" The anticipation of roller coasters and freedom grew by the minute. "Guys!" Ms. Marks yelled, "maybe you just want to sit here all day if you can't listen!" The students grew almost silent. "Okay, start unloading!" She moved into the row in front of mine and glanced down at me. "You still have the meds?"

"Yes, I do," I replied.

"You need to give them to a *real* teacher."

Her comment stung like a slap to my cheek. I dug into my backpack and pulled out four envelopes, each labeled with a student's name, and started handing them to Ms. Marks.

"I don't want them." She pulled her hand away. "Give them to their teacher chaperones."

I handed two envelopes to Mrs. Marshall and turned to hand the other two to Mr. Larson, but Mrs. Marshall put her hand on my arm. She slipped the envelopes back into my backpack. "Just keep them. The kids will take them better from you anyways."

By then the bus was almost empty. As Mrs. Marshall and I made our way to the front of the bus, I noticed that Sarah was still sitting in her seat and her friends were gone. I asked, "Can we help you get off?" But before she could respond, Ms. Marks yelled up that we should leave her and that her dad would carry her off.

Once Sarah was off the bus and all of the students had dispersed, Mrs. Marshall, Ms. Marks, Mr. Larson, two other staff members and I began making our way toward the entrance to the park. It was then that I noticed Natalia, one of the students with whom I had developed a strong relationship, hanging back as if she was waiting for me. She asked, "Are you coming with me?"

"Natalia, get going!" Ms. Marks barked. "Mrs. Johnson is here to be with the teachers."

I gave Natalia an apologetic look and she walked away slowly, her head down. I felt like I had abandoned her after nearly a year of sharing in her school days. I hadn't intended for it to be this way.

I followed the teachers and listened as they decided on our first ride. Just

then, Ms. Marks's cell phone rang. She held it up to her ear. "What's up? Well, when you want to ride just call my cell and I'll come help. I don't know if that one will work. Yeah, just call me. Bye." She stuffed her phone in her back pocket, exasperated. "And *that* was Sarah. If she calls me every five minutes, that is going to get old fast. I don't get why her parents are on the trip yet I have to help her."

"Yeah, why isn't she just going with her parents?" Mr. Larson asked.

"Well, because she wants to be with her . . ." She paused to make air quotes for extra emphasis, "*friends.* Plus they have Sophie to deal with."

I walked a few steps behind the rest of the group and listened as they continued to talk about students. I was hurriedly trying to type fieldnotes onto my iPhone when Mrs. Marshall turned quickly and mouthed, "Are you getting this?"

I nodded. Yes, unfortunately, I was getting every last word.

* * *

Growing up, I rarely had the sense that other people understood me. There was always a level of disconnect between how I understood the world and how others believed I understood things. While my status as the oldest daughter of two working-class parents in rural Wisconsin might not seem atypical, what complicated our life together was that I was born blind. My teenaged parents were thrust into a world of medical specialists, IEPs (Individualized Education Program) and surgical procedures that often left me sick for weeks at a time. They were socialized to believe that disability was a deficit; while my father never

spoke openly about his feelings related to having a disabled daughter, my mother openly communicated her disappointment with my imperfections. For her, the less time she needed to see me, to confront my body, the better, for my blindness was visible in more ways than just my inability to see. One of my eyes was gray. It had no color, no pupil. It was . . . ugly. People stared or turned away because it was uncomfortable to look at. One way that my mother tried to cope with this was by excluding me from pictures, or only allowing half of my face—as she called it, my "good side"—to be pictured.

No one ever specifically came out and said that something was wrong with me, but this was communicated in indirect ways that reached far beyond how I was allowed to appear in pictures. Most of my childhood days were spent with my maternal grandparents. My grandma was there to care for me after many surgeries and accompanied my mother on long trips to a well-known research hospital four hours from our home, a journey they made often in hopes of finding a procedure that could cure me. My grandparents, both very well-meaning people, even took me to religious healers. Jesus made the blind man see and so perhaps, they reasoned, the same could be done for me. I remember thinking that I must need to be fixed because I wasn't right the way I was. Even my cousins thought this must be true. One of them confronted me one weekend and told me that I was the way I was because my mother smoked and drank when she was pregnant and that this was my punishment. My parents divorced when I was six, and my mother remarried a man whom she allowed to verbally abuse

me. Beyond yelling constantly, his other favorite way to punish me was to hide things I cared about and watch me try to find them. Not being able to see, I was never successful. He would stand by and laugh.

For several years, I was the only disabled person I knew. I entered the public school system at age three and received services in a self-contained classroom for the mentally retarded. Even while in that classroom, however, I still did not see myself in my classmates, though I didn't have the vocabulary at the time to say so. Throughout elementary school I was always the odd one out with my assistive technology, modified assignments and the timidness with which I approached many academic and social activities. It took four different schools and fifteen years before I ever met another individual with a visual disability. By then I was beginning to wonder if anyone felt the same way, struggled with the same things that I did. I felt, by and large, completely misunderstood. While I was, by definition, academically successful (with almost straight As), I struggled so much in other ways, but didn't understand why.

When I was sixteen, it became medically necessary to be fitted for an ocular prosthesis which included not only removing the infected left eye but restructuring the eye socket. The experience was traumatic. I was bedridden for nearly a month; even after I could sit up and eventually walk steadily, I did not return to school for a total of two months. I can remember my family being very excited about the surgery, saying that this would be good for me. Three months after the surgery, when I was fitted with my first prosthetic, painted to match my

other eye perfectly, my mother said to me, "I can finally look at you and not feel ashamed."

These experiences as an individual with a disability growing up surrounded by abled individuals and feeling marginalized at school and even within my own family serve as the inspiration for this doctoral work. When I first met another blind person, I sat with her on a hill in the hot summer sun asking a million questions about what her life was like. My curiosity was insatiable. Having attended small, rural schools through grade eight I wondered whether if I had grown up somewhere else, things would have been different. Was navigating the school system hard for all parents, or just for mine? Was the focus of interventions always on helping students get good grades? Did anyone ever address the social challenges of being one of only a few students with disabilities in a school? I never felt as if I was very happy, and I wondered, was it just me? Was something bigger going on?

In 2003, after earning a degree in elementary/middle education, I made the shift from student to professional and began my career as a seventh grade English teacher in the third largest middle school in Wisconsin. For the seven years that I held that position, I continued to question the ways in which we raised and taught our students with disabilities. Over time, my questions began to take a different direction. I no longer focused on wondering *if* students experienced things differently when they had a disability. My own observations of and interactions with students as a practicing teacher allowed me to see that,

yes, there was a difference in the ways in which schools, teachers and peers interacted with students with disabilities. My new focus became why. Why did this happen? What does this do to students? And what should we be doing differently?

I was so troubled by these questions that I brought them with me to my graduate program at the University of Minnesota. I was determined to find answers, or, at least, to find a place and the support of individuals who would allow me to engage in my own research on the topic. Admittedly, at first I was disappointed. While I felt I had selected a program that would avail itself to the inclusion of discussions of disability within its classes, that was not always the case. Culture and Teaching, the program within the Department of Curriculum and Instruction that I had selected, seemed to focus on many dimensions of culture and diversity, with the exception of disability. While at first I was disappointed, further reflection helped me to see this as further evidence for the need for my work, because disability was being marginalized even within conversations about difference.

I began this introduction with a lengthy narrative recounting events from the very last full day of school at my dissertation site for multiple reasons. First, I did not want to wait to invite the reader into the lives of the individuals who agreed to participate in this study. The stories and experiences included in this study are emotional, complex and meaningful. I hoped that by sharing a story early on, the reader would want to learn more. Second, I want this piece to not

only allow me to share my understanding about what I learned while spending time in the field, but also to encourage readers to participate in their own processes of meaning-making. Finally, I chose this narrative specifically because it touched on many of the themes that are discussed at length in the pages that follow.

As mentioned earlier, I wasn't always certain that what I worried about in relation to disability experience was relevant or of concern to others. Through my studies as a teacher candidate, and even during my time as a middle school teacher, I came to realize that my concerns with the experiences of children with disabilities—in and out of schools—went far beyond what was tracked by traditional special education literature. In the last three years, however, I found a body of work that concerned itself with exploring the issues I cared most about. In Chapter 2, I review this literature from the fields of Disability Studies and Disability Studies in Education, which attempt to situate disability experience within a social context and push back on the traditional view of disability as a human deficit.

Realizing that ethnographic work provides a unique opportunity to become part of a research site for a prolonged period of time in an attempt to develop a complex, holistic understanding of that which was being studied, I selected this approach as the methodology for this study. In Chapter 3, I provide a rationale for selecting the ethnographic methodology, highlight my sources of data and explain the processes used for analysis. Within this chapter I also discuss the

complications that existed for me in relation to my identity as a disabled researcher.

As the reader may have recognized in reading this vignette, several processes are at work in the lives of these students. In Chapters 4 through 6, I explore three themes revealed during my analysis of data, examining a curriculum unit on disability, expectations for students with disabilities, and the transformation of a lunchroom detention space into a barred room for marginalized students.

Chapter 4 examines how this school and its staff used the curriculum as a vehicle to teach about disability in hopes of creating an atmosphere that was open to, in their words, "the differently abled." While this intense nine-week unit provided students with several opportunities to explore disability through a research project, films, guest lectures and simulations, the degree to which this unit challenged students to consider disability as anything other than a deficit was questionable.

The opening narrative introduced Ms. Marks, a special educator at Cinder City Middle School (CCMS). She was very open in sharing her beliefs about one of the students, Sarah, and her abilities. She believed it was acceptable for Sarah to crawl to the bathroom on a moving coach bus in the event that she was unable to walk to the bathroom. She was frustrated when Sarah called her to ask for help getting on some rides at the amusement park, even though this was a method that had been agreed upon prior to the trip. Ms. Marks seemed frustrated

that Sarah chose to be with her friends instead of her family for the trip. Her presumptuous commentary was not an isolated event, and in chapter 5 I more deeply explore teacher beliefs about and expectations of "differently abled" students. I provide several examples of the kinds of expectations teachers communicated to students through their words and actions. I discuss how curriculum was, or was not, used to provide students with opportunities to grow and be challenged as learners and what this in turn did to students' feelings of agency. I also examine how teachers' thoughts about individuals with disabilities (students and myself) were directly and indirectly communicated in formal and informal spaces in the school.

While at CCMS, I had the great fortune to create some very meaningful, powerful relationships with several students, among them Natalia, who was introduced briefly in the introductory vignette. Chapter 6 invites the reader to consider an interesting space that developed over the course of the year in which Natalia and several other students participated. "Lunch detention," initially devised as a punishment for a defiant student, evolved into an escape for many marginalized students in the school, a space in which conversations took place and unusual friendships were born. This place became one in which we barred the door to the outside world each day for forty minutes in order to take care of ourselves.

While this dissertation study and my findings are specific to one school district in a small, Midwestern city, what was learned here has ramifications that

reach far beyond the boundaries of this small community. Chapter 7, the conclusion, serves not only as a summary, but also discusses the implications of this work for the field of Disability Studies in Education. I also consider future directions of study.

In the following pages, I attempted to privilege the voices and experiences of the students. Drawing on vignettes and direct quotes from my participants, I invite you, the reader, into the lives of these amazing students as they help us to understand what it means to be disabled at Cinder City Middle School.

Chapter 2: Review of the Literature

Handicapped, disabled, impaired, crippled, blind, crazy, psycho, dumb, retarded: these and many words like them are sprinkled throughout our language. While many such terms are used rather thoughtlessly, their implications are nonetheless significant. But what does disability really mean? How have our perspectives of disability changed over time and in what direction is the study of disability experience moving? This chapter explores how the field of Disability Studies has served to challenge historically pervasive assumptions of disability as personal tragedy or medical deficit, as well as traces the emergence of an alternative social model of disability. Additionally, I highlight some of the major themes from the field of Disability Studies and provide a critical analysis of the limitations of the social model of disability. This chapter concludes with a discussion of the strengths and weaknesses of Disability Studies in Education and summarizes areas needing further exploration.

An Introduction to Disability Studies

In the past, it was not uncommon to encounter discussions of disability that centered on deficiencies of the body or mind, abnormality and underlying assumptions of dependence and need for charity. Beginning in the late 1960s, however, individuals with disabilities, particularly those forced to live in residential facilities, became interested in working for political and social change. At that time, disability was not yet acknowledged as a cause for social oppression (Barnes & Mercer, 2003). The voices and experiences of the disabled as a

cultural group went unexplored, even within the social sciences (Abberley, 1987; Oliver, 1996). As Linton (1998) put it: "There were no disjunctures between dominant cultural narratives of disability and the academic narrative. They supported and defended each other" (p. 1). Then, in 1972, the United Kingdom's Union of Physically Impaired Against Segregation (UPIAS) put forth a proclamation that served as one of the fundamental moments in the formation of disability studies (Barnes & Mercer, 2003; Gabel, 2005). Members of the UPIAS (1976) asserted that:

> It is society which disables physically impaired people. Disability
> is something imposed on top of our impairments by the way we
> are unnecessarily isolated and excluded from full participation in
> society. Disabled people are therefore an oppressed group in
> society. (p. 14)

Over the coming decades, individuals with disabilities set out to challenge how disability was understood both socially and sociopolitically, but this was no easy feat. By the mid 1970s, progress was being made in rejecting biological explanations of women and racial minorities as deficient. However, the same gains for those with disabilities wouldn't be realized until nearly a decade later. The pervasiveness of the "problem of disability" as individual and tragic held fast into the 1980s and beyond (Abberley, 1987; Finkelstein, 1993).

This new conceptualization of disability served as the foundation for this new discipline. Scholars within the field of Disability Studies sought to create an

epistemological foundation for examining disability, as well as to critically

examine issues encompassing anatomy, wholeness, independence/dependence,

health, physical appearance to human variation, notions of perfection and

identity. Linton (1998) wrote that while the work of scholars from many fields

informs and influences the field of Disability Studies, those at the core of this

endeavor seek to challenge the current system, leverage power for disabled

individuals and write specifically about the social situations of the disabled. While

there is no shortage of research on disability, until recently most of that work was

done within applied fields such as medicine, which viewed a disabled individual

as a deficit who needed to be cared for, corrected or rehabilitated. Disability

Studies, on the other hand, recognizes that to only consider the medical

implications of disability prohibits questioning the social and political nature of

impairment. The work being done by writers in the field of Disability Studies

seeks to trouble conceptions of "normalcy" and "deviance" that have been

established by both the applied sciences and social sciences. This can be done

by discussing forms of oppression, discrimination and advocacy within the

context of everyday experiences of the disabled (Linton, 1998). Disability

Studies, then, sets out to look toward more complex ways of examining the lived

experiences of the the disabled (Oliver, 1993; Shakespeare, 2006; Siebers,

2008).

One final characteristic of Disability Studies that Ferguson (2006) offered

is that often scholars within the field are not simply writing as a means of coming

to know and uncover understandings of disability; they are writing to promote social justice. Many Disability Studies scholar-activists are themselves disabled and have a vested interest in writing about and being involved in disability rights activities at the organizational and individual levels. By utilizing their own personal experiences with disability in combination with critical methodologies within Disability Studies, scholars are better positioned to "question the taken for granted . . . unquestioned assumptions that guide traditional policy studies" (Ferguson, 2006, p. 162). As a result of questioning the norm, it has become commonplace that the work being done by disability scholars pits individuals with disabilities against professionals and policy makers within the fields of education and rehabilitation regarding practices and policies that reinforce discrimination and social inequity.

Historical Insights and Models

One of the major roles of scholars in the field of Disability Studies has been to trouble the assumption of disability as individual deficiency which, historically, has been a widely accepted belief. Those with disabilities were understood to have flawed minds and bodies, resulting in an inability to be independent or succeed on their own accord. Because of their inability to be self-reliant, individuals with disabilities would spend a lifetime dependent on family and society for support (Barnes & Mercer, 2003; Goffman, 1963). Because of physical, emotional or sensory impairments that classified the disabled as "less than whole" (Dartington, Miller, & Gwynne, 1981, p. 126), it was often thought

that these individuals were unable to contribute to society in valuable ways.

To respond to the drain that individuals with disabilities placed on their families and society, eugenics, which represents a blend of Darwinist ideas of natural selection and genetics with heredity (Dwyer, 2003, p. 107), promoted "dealing with disability and supporting the well born. Eugenics as a world wide practice became a mutual project of human exclusion aimed to banish deviance from the trans-Atlantic gene pool" (Mitchell & Snyder, 2003, p. 845). This was accomplished through practices of sterilization, euthanasia and, in some extreme cases, genocide (Proctor, as cited in Ferri & Connor, 2006). We can find examples of attempts to rid the world of the feeble-minded, broken and disabled in Germany's Nazi T4 program which involved the killing of children and adults with disabilities (Shapiro, 2000). In the United States, the eugenics movement can be traced to the Eugenics Record Office at Cold Spring Harbor on Long Island, New York. Those in power sought out venues at which to share public service announcements warning of the "dangers posed by certain classes of individuals" (Mitchell & Snyder, 2003, p. 845). Utilizing visually disturbing exhibits at World Fairs and other events, messages compared the lives of the disabled and their reproduction patterns to those of cattle. Such messages served to educate even the "common folk" about the "problem" of abnormality.

In an attempt to validate, in scientific terms, the deficits of the disabled, a myriad of mental assessments were used to identify and label the "feebleminded" (Mitchell & Snyder, 2003). This enabled professionals to position themselves as

experts entitled to solve the problem of disability. Welfare and medical services, along with a push toward institutional living, were promoted for the good of these feeble-bodied individuals to "help" them, while simultaneously preventing them from becoming a burden to society (Goffman, 1963). Those in institutions could spend much of their lives away from family and society, and, as Miller and Gwynne (1972) wrote, were in essence "socially dead."

This "personal tragedy" portrayal supports what Oliver described as the individual model of disability, which assumes that physical limitations or psychological shortcomings are problems located within the individual. It is important to note that within the field of Disability Studies, some authors refer to the individualization of disability as the "individual model" while others simply refer to this understanding as the "medical model" of disability. Oliver (1996) clarified his word choice with the explanation that, while medical practices are one component of this model, we must consider more than just medical practices and include the psychological discussions surrounding disability and the perception of disability as personal tragedy. Many writers recognize this distinction but continue to use the terms interchangeably, myself included.

The negative consequences that can be traced to the medicalization of disability are profound. Let us first begin with disability as defined within the constraints of the medical model. Disability is "an individual deficit lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being" (Siebers, 2008, p. 3). First, to suggest that

individuals with disabilities need to be treated and cured seems to indicate that anything but a "normal" body is deviant and undesirable. The individual should, then, undergo whatever procedures are necessary to correct the body. It was not unusual (and some would argue, continues to be common) for individuals with disabilities to deliberately pursue medical interventions to correct their impairment, or make it less prevalent, even when the procedures are painful and invasive (Linton, 1998). As Foucault (1995) wrote, "A docile body may be subjected, used, transformed, and improved" (p. 136). A medicalized focus on what "normal" should look like sought to correct defects to promote the "physical vigor and moral cleanliness of the social body" (Foucault, 1980, p. 54).

However, there is value in human variation, and by moving to treat the flawed body, the medical field fails to recognize this and places a distance between what is normal and disability. Also, the treatment and medicalization of disability permits society to cast disability as an individual problem; the individual cannot keep up with societal expectations so it is he or she that must change, not society. This understanding frees society from any onus of responsibility for its own actions. Not surprising then is the particularly receptive audience this interpretation found in policy makers, professionals and individuals who ran organizations "for" the disabled because, by individualizing the problem, they were able to maintain their positionality as "experts" (Oliver, 1996).

As "experts" on the disabled, professionals were then entitled to diagnose, label and assign treatment as well as to make decisions for the disabled based

on perceived medical deficits and sicknesses (Abberley, 1987; Barnes & Mercer, 2003; Barton, 1996; Charlton, 1998; Linton, 1998; Oliver, 1996; Russell, 1998; Shakespeare, 1996). While the medical profession presumed that its "help" was what the disabled most needed and desired, these practices sent a strong message that those with an impairment couldn't possibly "want" to be disabled, just as they couldn't possibly know what was best for themselves. The entire process of labeling and treating all sorts of physical or psychological problems only served to further marginalize individuals with disabilities (Davis, 2006; Linton, 1998; Murphy,1990; Russell, 1998). This process failed to recognize individuals with disabilities as having a culture of value and did not validate the disabled as humans capable of speaking for themselves.

Social Model

While medical professionals, policy makers and other professionals and their ideas about the disabled perpetuated the individual model of disability, disabled individuals themselves forcefully influenced the conceptualization of disability as largely social. Recognizing that sociological explanations could be used to better understand and theorize disability experience, Finkelstein (1980), among others, is credited with developing a social interpretation of disability as a form of oppression. While evidence of a discussion of disability as socially constructed dates back to writings of the 1960s, including labeling theory (Becker, 1963; Erickson, 2004) and stigma (Goffman, 1963), these ideas did not find a willing audience of acceptance until decades later and by today's

standards are considered a bit over-simplistic (Gabel, 2005). Yet even these

early writers locate disability not within the individual but within society, a society

that "imposes restrictions on disabled people ranging from individual prejudice to

institutional discriminations, from inaccessible public buildings to unusable

transport systems, from segregated education to excluding work arrangements"

(Oliver, 1996, p. 33). Disability, Lemert (1962) wrote, is a deviance that is

ascribed to individuals whether they want it or not, and this deviant label, based

on deficiencies in the body, results in a socially devalued status and identity

(Barnes & Mercer, 2003). Goffman (1963) described his theory of stigma as it

relates to disability as a mark or "abomination of the body" that allows society to

justify discriminatory practices that reduce the life chances of individuals and

position them as dangerous, deviant and immoral.

Snyder and Mitchell (2006) insisted that the term "disability" has little to

do with a medical diagnosis. The identification as disabled is rooted in social

experience, and they believe that if society deems a person to be disabled, then

she is such. "Disability is not an individual deficit but a product of social injustice

that requires not the cure or elimination of the defective person but significant

changes in the social and built environment" (Siebers, 2008, p. 3). The presence

of a disability, wrote Murphy (1990), is most profound in its effect on self-

awareness and on the way one constructs the world around them and their

position in it. Additionally, the social model suggests that disability is not simply

the result of some random misfortune, but is systematic oppression that is added

on to one's impairment (Oliver, 1996).

Understandings like these have prompted the study of disabilities from sociological and sociopolitical contexts (Barton, 1996; Charlton, 1998; Davis, 2006), attempting to explore how oppressive life events and social relationships serve to constantly shape one's identity, a fluid identity that is constructed and reconstructed based on daily experiences (Glenn & Cunningham, 2004). Those operating within this model work to ensure that a disabled person develops a positive identity and a person empowered to effect social change. Individuals with disabilities should be given opportunities to develop a deep understanding of the self (Charlton, 2000; Linton, 1998).

It is important to further explain and reiterate that the social model of disability as articulated above does not reject disability as a problem, but locates the problem of disability within the constraints imposed by society. Whereas in the historically prevalent medicalized model the problem of disability is attributed to the individual, the social model points to social barriers and power differentials (Barnes & Mercer, 2003).

Critics of the social model argue that to locate the entirety of the problem of disability within society is a rejection of physical or psychological implications of impairment. Oliver (1996) countered this argument with his explanation of impairment as nothing more than a physical description of the body. The social model recognizes that there are disabling circumstances that arise from illness, but what distinguishes this understanding from that of the medical model is that,

while at times it is necessary to treat illness, disability cannot be treated. "Disability as a long term social state is not treatable medically and is certainly not curable" (Oliver, 1996, p. 36).

One of the major criticisms of medical professionals within the social model is how they use their power over those with impairments. It is not uncommon for these "experts" to attempt to treat the social problems of disability with medical interventions, and then they seem surprised when their patients do not find relief or reject medical interventions. Doctors and rehabilitation "specialists" might suggest wheelchairs for those who cannot walk, mobility training for those who cannot see and provide assistive technology in the workplace, but these treatments, while helpful to a degree, do not "solve the problem" of disability. Discrimination, inaccessible buildings and pervasively negative attitudes about disability are not solved with bandaid approaches such as these. Scholars in Disability Studies reject the tendency to elevate the expertise of medical professionals and their "right" to make decisions related to where individuals with disabilities are able to live, if and under what conditions they are able to work, how they should be educated, what rehabilitative services should be rendered and what benefits an individual should receive (Oliver, 1996). Countless attempts to "fix" an individual's broken body perpetuate the social stigma of disability because they reinforce a belief that anything less than an ideological conceptualization of "normal" is both undesirable and unacceptable.

Major Issues and Themes in Disability Studies

While I have always been curious about disability experience not just for myself, but also for others, it wasn't until I began reading within the fields of Disability Studies and Disability Studies in Education that I truly began to understand the complexity of living with such a label. While the writings on impairment and disability span volumes and touch on everything from recreation and leisure to employment and rehabilitation, particular aspects of the literature are especially compelling to me. What follows is a discussion of the major themes from the literature that have informed my thinking and that proved significant during this research.

Disability Identity and Culture

One of the most important themes that has emerged in my reading of Disability Studies literature is the recognition of disability as identity, and even more broadly, as a form of culture. Let us first examine disability as culture. Linton (1998) offered the following definition that speaks to the inclusion of disability: "disability culture is a critical conceptual framework for discussing the shared aspects of our experience, language, customs and artistic products that emerge from it" (p. 102). Barnes and Mercer (2003) noted that "disability culture presumes a sense of common identity and interests that unite disabled people and separate them from their non-disabled counterparts" (p. 522). Disability culture as defined by Longmore (cited in Johnson & McIntosh, 2008) is a redefining of disability by persons with disabilities in response to a need for self-definition and in response to social invalidation.

While these definitions differ in terms, their messages all take up a "shared" or "common" experience that unites disabled individuals just as it separates them from the non-disabled. That is not to say that the culture of disability has been fully embraced, nor is this meant to imply that the "culture" of all disabled people is experienced in the same ways. The experience of disability is very unique, but "culture" recognizes similarity in difference. Johnson and McIntosh (2009) wrote,

> a conspicuous absence of discussion about the culture of Disability
> (and Deafness) from the perspective of members of these
> communities is reported even though disability and Deaf
> experiences fall well within the definition of culture and yet is
> seldom addressed as such in courses and texts. (p. 70)

As previously addressed, the medical model treats disability as possession of a physical or psychological deficit, but Siebers (2008) contended that disability is, instead, a cultural and minority identity. This understanding acknowledges that disability is subject to the influences of social control, and as such, one's identity is constantly in flux (Linton, 1998; Zola, 1982). Because people change, culture is always changing, and thus a categorical approach to understanding, studying, and working with individuals with disabilities is not sufficient (Johnson & McIntosh, 2009).

In thinking about identity, factors of gender, race or sexuality differ from that of disability because of the instability and unpredictability of disability

(Siebers, 2008). While these aforementioned identity characteristics do not change, able-bodiedness is temporary. While one will not wake up one day and discover she is black, one can be walking one day and paralyzed the next. At some point in life, almost everyone will be forced to contend with disability's presence whether because of an accident, age or terminal illness, among other causes. This creates a sense of fear because of the likelihood that one will experience disability personally (Mairs, 1996). Further, when examining identity within the context of post-structuralism, it is also necessary to recognize that our identities are constantly in flux. As Britzman (2003) described, our experiences lead to change and as discourses shift, so do identities.

Managing the Disability Identity

While it is not advisable to assume that all individuals "manage" their disabilities in the same ways, a great deal of literature discusses ways in which people live with their disabled identity. That is not to say that a disabled identity should be presumed weak (Siebers, 2008). The psychological underpinnings of disability identity development focus on the concepts of consciousness and alienation (Garland-Thomson, 1996). Consciousness, or how one comes to know oneself, is directly influenced by the world in which one lives. This act of "being" in a social world in turn impacts consciousness, and consciousness in turn influences the act of being (Garland-Thomson, 2009; Jackson, 2006). Disabled individuals, as members of society, not only have differences associated with their conditions but also have an altered form of thinking based on their lived

experiences and social positions (Charlton, 1998; Murphy, 1990). How disabled individuals perceive the world in which they live will inform their consciousness, which could in turn lead to the development of a false consciousness or constructed normalcy which internalizes stereotypes from the dominant culture. Children and adults then come to believe that they are inferior.

Messages of inferiority are shared daily in subtle and obvious ways in homes, schools and workplaces, as well as through the media. The internalization of negative messages by disabled individuals can be alienating in that they may come to believe in their powerlessness and inability to effect change (Jackson, 2006) or can lead to the development of self-loathing (Abberley, 1987; Charlton, 1998; Murphy, 1990).

The literature seems to suggest that individuals tend to "manage" their disabilities in a variety of ways and that the way in which they choose to manage their status is dependent on the disability, the visibility of the disability to others and the degree of the impairment (Goffman, 1963). Additionally, literature suggests that how an individual chooses to portray him or herself changes given the situation. An individual with a disability may openly share his disability at one moment, attempt to "'pass" as non-disabled in the next moment and later feel pressured to overcompensate for the disability by becoming "super." Additional considerations associated with the management of the disability identity can be traced to who is with the individual and whether he or she has an awareness of the condition. In some situations an individual with a disability may act, or be

expected to act, in a particular way so as to protect the reputation of others with them.

"Passing" is not a concept unique to disability experience but is also common within the GLBTQ community (Kumashiro, 2002) as well as some racial communities. To "pass" means to participate in activities in which the disability will not be revealed, or where it can be hidden by making deliberate attempts to minimize the effects of impairment (Shakespeare,1987; Zola, 1982). In "passing" one can avoid, or attempt to avoid, stigmatization or the discrimination that often is a result of being categorized as "other." In some families, the need to pass has been supported, or even demanded, by children's parents. Disability literature is rich with examples of parents socializing their children to believe that disability was undesirable. If children could pass, they would be better positioned to lead "normal" lives (Charlton, 1998; Linton, 1998; Shakespeare, 1996; Taylor, 2006; Zola, 1982).

The need to "pass" wasn't always demanded for the benefit of the child. Disabled adults recall childhood memories of being only partially pictured or completed excluded from family photographs, as if this omission would serve to erase the impairment from existence (Abberley, 1987; Shakespeare, 1996). Individuals recall instances of being asked to undergo surgeries, not so much to ease pain associated with a disability, but rather to make them appear "more normal" to the non-disabled (Mairs, 1997; Zola, 1982). Still others feel pressure to "act normal" to protect their families and loved ones from persecution and

unfair judgment. A social relationship, whether it be a connection through family or friendship, can result in non-disabled relatives or acquaintances being treated as stigmatized (Goffman, 1963) by simple association.

For some individuals, passing as "normal" is difficult because of the visible nature of the disability. These individuals might instead try to overcompensate in order to "overcome" the disability or prove they can surpass society's low expectations of what disabled people can and cannot do (Barnes & Mercer, 2003; Goffman, 1963; Kumashiro, 2002). It is not uncommon for the media to present stories of individuals who seem to do the impossible, given their circumstances (Garland-Thomson, 1996). I've read many news stories and watched video clips that feature disabled individuals who have scaled mountains or ran marathons. In these cases, stories highlight an individual's ability to achieve some dimension of normal in spite of disability. In my case, I have been featured in several publications for being blind AND teaching, blind AND parenting five children (two of whom also have exceptional needs, how "fortunate they are to have a mother who can understand their challenges. . .") Millions of people teach or parent everyday, but my story became extraordinary because I was doing this "against the odds."

While I never felt like I was doing anything worthy of an article on the front page of our city's Sunday paper, I will not deny that I have often done things to prove to others that I, and others like me, do these things everyday. In addition to placing a spotlight on the amazing or sometimes ordinary accomplishments of

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the disabled, those who do "overcome" are often asked to act as "spokespeople" for people like them, to help others understand what it is like to be disabled. What is most ironic about asking an individual who has proven he or she can succeed despite disabling conditions is that these individuals are often more representative of "normal" than of the disabled group that they are supposed to represent. They are a minority within a minority (Murphy, 1990; Zola, 1982).

An unanticipated complication of attempting to overcome or overcompensate for being disabled is that it reinforces negative stereotypes about disability in that one wants to be distinguished from others with a similar disability who may not be viewed as brave or accomplished or outstanding. This practice can lead to discrediting the disabled, as if people need to succeed in order to give the group a good reputation and to bring credit to the group (Linton, 1998). To accept a compliment from someone is a double-edged sword because in doing so, one is acknowledging society's inferior image of the oppressed group AND asserting that one shouldn't let obstacles get one down, but instead should work harder, scale walls, beat the odds and go above and beyond to prove oneself. When some individuals are able to obtain and maintain the "super" image, this often prompts the non-disabled to ask the question, "well, if you can do it, why can't everyone? They just aren't working hard enough. They could do it if they wanted to" (Zola, 1982, p. 122). This criticism of the work of "overcoming" is not to say that one shouldn't engage in hard work, but that it should be done because it is rewarding in and of itself. Even when an individual works hard and

feels that he has finally been able to "rise above" the disabling experience, this is often no guarantee of inclusion into non-disabled society, because "overcoming is not the same as integrating" (Zola, 1982, p. 3).

For individuals with disabilities, the consequences of a decision to not identify with people like themselves can have traumatic implications (Linton, 1998). Denying or hiding the true self is unhealthy, not only in the medical sense, but in the psychological sense as well. By accepting and adopting an external definition of the selves they think they should be, by hiding a disability, by overcompensating, individuals risk experiencing "hidden injuries" that can result from internalizing negative stereotypes or even through the work of resisting traditional stereotypes (Kumashiro, 2002). Disabled individuals may develop a temporary identity or a compromised self and act in ways in which they feel are socially acceptable yet are disempowering (Shakespeare, 1996). In *No More Stares* (Carrillo, Corbett, & Lewis, 1982)*,* Missy and Elsa shared their own experiences in the identification process. Missy shared that:

> I am hard of hearing and although I can function well in both the hearing and the deaf worlds, I do not, at times, feel a part of either world. I am not totally accepted as deaf because I can talk and lip read and I am not totally accepted as hearing because there are times when I cannot hear and use an interpreter. (p. 37)

Elsa stated that "early in my disability I rejected other disabled people and have only just got rid of this. I didn't want to mix with them, didn't want to be associated

with them. I wanted desperately to be accepted as normal" (p. 38). While Missy highlighted the challenges she faced in negotiating as an "outsider" in both of her communities, Elsa's desire to deny her disability in order to "be normal" was apparent. Individuals with disabilities experience an identity dilemma that exists until the "confluence of physical, cognitive and social aspects of development and the ensuing crisis of self concept are satisfactorily resolved" (Duesk, 1987, p. 370). While Kumashiro (2002) highlighted the challenges that queer youth face when their multiple identities complicate membership within communities, the above stories seem to suggest that the same could be said of individuals maintaining memberships and relationship within their own communities.

At different moments in my life I have acted out all of these "strategies" of being. As a child I was expected to act as a "normal" and did not use a cane or learn Braille and was thrust into a visual world by my parents. My mother demanded that my "ugliness" not be pictured, and there are years of photographs in which only part of my face is pictured or in which I was left out completely. It wasn't until I was well into high school that I would even say the word blind. By then I traveled with a cane, read Braille and visibly couldn't see, but even then I did not associate with "those" people because I had been socialized by my parents and society to believe that there was something wrong with being disabled. Simultaneously, while attempting to pass to those around me, I was working to overcome my disability label by "doing it all" to prove to others that I was not worthless. Numerous times I was encouraged to drop classes in college

because professors saw me as incapable and burdensome. Instead of leaving their classes, even though it would have been the easy thing to do, I stayed, worked tirelessly without accommodations from professors and always tried to surpass their expectations. While working with determination is in my nature, in these cases I was doing it to prove my worth, to "make a good name" for others like me, to "change attitudes about disability." It was exhausting, painful work.

Limitations of the Social Model

While the social model offers a great deal for understanding disability experience as more than just a medical deficit, it is not without its criticisms. Individuals with disabilities, who once welcomed the explanatory nature of the social model and its demands to establish disability as a social problem and not a problem with the individual, are beginning to question its value, in particular the tendency for some to presume that it can be used to articulate the experiences of all disabled people (French, 1993; Gabel, 2005; Oliver, 1996, Siebers, 2008). Others are critical of how this model has taken disability experience and made it academic, devaluing personal experiences. Additionally, while the benefits of the social model are recognized, writers in the field seem to disagree about what exactly constitutes the medical and social models. The social model seems, with all of its initial explanatory benefits, to be an oversimplification of disability.

First, the social model, some believe, is an outright rejection of medical intervention and of the physical and psychological effects that, for some, accompany impairment. Siebers (2008) explained that while the social model has

highlighted the obstacles created by societal barriers, both built and attitudinal, it

fails to recognize that chronic pain, secondary health problems and aging are

found within the body and that to neglect these factors within the social theory is

to deny how the social world affects the experience of the body, just as the body

has the power to transform the social world. A failure to acknowledge the

relationship between the two is disheartening to many. Morris (1991) wrote of the

denial of impairment that

> there is a tendency within the social model of disability to deny the
>
> experience of our own bodies, insisting that our physical differences
>
> and restrictions are entirely socially created. While environmental
>
> barriers and social attitudes are a crucial part of our experience of
>
> disability . . . to suggest that this is all there is to it is to deny the
>
> personal experience of physical or intellectual restrictions. (p. 10)

Both Morris and Siebers seem to feel that the social model fails to recognize the

"personal" of disability, the trials, the individual restrictions and physical and

psychological demands associated with impairment. Impairment can be painful

and limiting in other ways, but removing social barriers will not result in

eliminating certain unavoidable social consequences of impairment. For

example, as an individual with a visual impairment, my experiences are similar to

French (1993), who cited challenges related to interpreting non-verbal cues and

recognizing individuals. Attending social gatherings at which food is served

presents challenges of identifying food without the help of someone else.

Wheelchair users have similar frustrations in their ability to navigate and interact with people at parties in the same ways as individuals who are able to walk about freely (Oliver, 1996). Additionally, individuals with disabilities are critical of the social model and its failure to recognize that medical interventions have not only improved well-being for some individuals with disabilities, but have also saved lives (Gabel & Peters, 2004; Linton, 1998). Few would argue that ongoing improvements in the treatment and prevention of life-threatening ailments is of benefit to all humans. Therefore, to not acknowledge the good that can come out of medical intervention is to deny its benefits to some individuals with disabilities.

Oliver (1996) argued that the social model intentionally ignores these consequences. The social model embraces issues that could be changed through collective action. There will always be challenges that accompany disability that the social model cannot change. Shakespeare (1993) added that, to move beyond a deficit view of disability, there was a need to "break the link" between the body and social situations. This enabled scholars to examine the real reasons for marginalization of the disabled: discrimination. He went on to say that "to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is 'really' about physical limitations after all" (Shakespeare, 1992, p. 40). Oliver and Shakespeare seem to agree that, initially, the social model HAD to deny the physical and psychological implications of impairment or society would never accept responsibility for its role in marginalization. To demand social action while acknowledging that, yes, there is

pain is to reaffirm what the medical model suggested all along. While I can certainly respect what Shakespeare and Oliver suggest here, a need to deny the bodily implications of impairment temporarily, I agree with French and Morris that there are conditions of disability that will remain, regardless of whether societal barriers are minimized. While my story of impairment is one among millions, I know that the medical implications of blindness leave me living day to day, never knowing when I wake up in the morning, what I will see. This implication of disability for me will never change, whatever the social situation.

An additional criticism disabled individuals make relates to the social model's failure to adequately address other oppressions, including racism, sexism and homophobia, and how various forms of oppression and exclusion interconnect (Ferri & Connor, 2006). Furthermore, Finkelstein, one of the original promoters of the the social model, recognized its inability to fully articulate the experience of any person with a disability, male or female, black or white. He suggested that we instead use the phrase "social interpretation," because when applying social views of disability to theorizing disability experience, authors are often utilizing multiple paradigms and theories (Gabel, 2005).

Finkelstein himself is advocating for an altogether different approach to understanding disability experience, that being the administrative model of disability, which focuses on controlling the disabled at every juncture of life. His questioning of the model he once advocated for confirms that no model can explain everything about everyone. The social "model" is not a social "theory,"

said Oliver (1996) and shouldn't be expected to do the work of a theory.

Siebers (2008), Shakespeare and Watson (2001) and Gabel and Peters (2004), among others, are critical of the limitations of the social model of disability and have even gone as far as to argue for an "eclecticism within the social model" or a dissolution of the social model altogether (Gabel, 2005, p. 7). These critics acknowledge that while a decade ago the social model provided a new and powerful way of theorizing disability, it is not an attainable way of speaking about the disability experiences of all individuals representing numerous disability types. They suggest alternative forms of theorizing disability, including resistance theory, which Gabel and Peters (2004) suggest would "provide a way out of the determinist and universalist claims of the social model by offering a fluid malleable theory responsive to particular contexts" (p. 593). Examples of resistance can be found throughout the social model in relation to resistance to stigma, disablement, social oppression and political and economic exclusion. Resistance is not one-way and utilizing a theory of resistance to explain disability experience would also capture the resistance that takes place from those who resist the disabled as well. In this way of thinking, resistance theory becomes:

> A multilevel, multidimensional dialectic within which there is
> push and pull, give and take, deconstruction/reconstruction
> between players at all levels of the social world... and avoids
> the theoretical tendency to construct abstract or rigid models

from which action and social change cannot emerge. (Gabel &

Peters, 2004, p. 8)

Resistance theory then acknowledges the fluidity of human experience and moves beyond the"one-size-fits-all" tendencies of the social model.

Siebers (2008) agreed that the social model fails to recognize the multi-dimensionality of the disabled body and that it seems inadequate to suggest that the social barriers with which the disabled are forced to reckon are "the product of a bad match between social design and some human bodies" (p. 57). Instead, he supported the use of identity politics and his ideas relate to complex embodiment as a way of exploring disability experience. Identity, as it is often written about, is frequently associated with minority groups, weakness and pain, and minority identity politics seem inevitably to be tied to disability:

It is as if identity itself occupies a minority position in present

critical and cultural theory—for those who reject identity

appear to do so only because of its minority status, a status

linked again and again to disability. (p. 11)

Siebers contended that the inclusion of identity work allows us to know more about the social worlds in which we live. As Alcoff (2006) explained, "identity is not merely that which is given to an individual or group, but is also a way of inhabiting, interpreting, and working through, both collectively and individually, an objective social location and group history" (p. 42). The inclusion of minority identity work in Disability Studies recognizes that a minority identity can be tied to

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pain and suffering but that this does not limit identity from informing the work of Disability Studies and having strong epistemological value (Siebers, 2008).

Finally, while the writers within the field of Disability Studies have worked to explore 1) ramifications of rehabilitation and medicalization of disability, 2) discriminatory practices in hiring and employment, 3) access to recreation and leisure, and 4) economic discrepancies that exist for individuals with disabilities, very little has been written specifically related to the implications of disability for children and teens (Kliewer, 2006; Solis & Connor, 2008). While eventually they will encounter transition services, employment opportunities and the need to live independently, the experiences of children in schools and other social spaces are nonetheless important and in need of exploration. It is here that we find the work of scholars in Disability Studies in Education most valuable because they take up these very issues.

A Need for Disability Studies in Education

While Disability Studies scholars made notable progress, very little of what was written was applied directly to education until recently. While Disability Studies draws from the social sciences, there is a need to apply that knowledge to applied fields, including education (Danforth & Gabel, 2006; Gabel, 2005). Disability Studies in Education seeks to fill this need by bringing together work from more traditional academic fields (including literature, art, philosophy and cultural studies, among others) and educational research. As interest grew in applying the writing in Disability Studies to education, the Disability Studies in

Education SIG (Special Interest Group) was introduced as part of the American

Education Research Association (AERA) in 1999 (Danforth & Gabel, 2006;

Gabel, 2005). The initial purpose of the Disability Studies in Education SIG was

to share information about the field, to encourage scholars to utilize core ideas of

Disability Studies, in particular the social model of disability, and to bring

together, under one name, alternative ways of talking about and thinking about

disability experience (as these ideas and concepts existed in isolation for

decades). That is not to say that all those writing within the field of Disability

Studies in Education represent a united perspective of disability experience, but

that what brings them together is a commitment to validating disability experience

and including individuals with disabilities in the process of theorizing disability

experiences in schools and society (AERA, 2007; Taylor, 2006). The current

system is ridden with examples of "facades of inclusion" or soft inclusion in which

students are put into general education situations but not expected to succeed or

held to very low expectations (Benson, Wolford, & Hyland, 2011). Disability

Studies in Education stands firm on troubling the segregating practices of

schools (Dunn, cited in Taylor, 2006) by advocating for "full and meaningful

access to all aspects of society" while assuming the competence of individuals

and rejecting traditional deficit views of incapability (AERA SIG website, 2007).

Since its inception just over a decade ago, membership in the Disability Studies

in Education SIG has increased by four hundred percent (Taylor, 2006).

Some question the need for Disability Studies in Education when we

already have massive amounts of research from the field of Special Education.

Special Education, though, in its traditional form, is problematic on many fronts,

say scholars writing from a Disability Studies perspective. Special Education

developed as a parallel system of educating "kids with disabilities" who could not

be educated (it was believed) within the general education system. Education for

students with exceptional needs had its own funding sources, different teacher

certification programs, acceptable methodologies and classroom practices (Ferri

& Connor, 2006). The difference between how Special Education and Disability

Studies in Education perceive their students and the education to which students

are entitled is also paramount. Disability Studies in Education envisions an

education system that embodies

> democratic, inclusive accessible communities where biological
>
> and cultural diversities are not construed as deficits demanding
>
> remediation, illness requiring treatment. The new purpose is one
>
> of group identity empowerment for disabled persons as disability
>
> shifts in meaning from a social problem requiring tactics of
>
> individual modification and personal adjustment to an oppressed
>
> group with a history, an identity and a just cause. (Danforth &
>
> Gabel, 2006, p. 2)

What such a goal requires, though, is critically questioning current practices and

moving beyond making disabled students fit into "normal" classrooms.

While Special Education perpetuates the exclusion of deviant persons

who do not "fit" the definition of normal, writers in the lesser known field of Critical Special Education, like scholars of Disability Studies in Education, work at "identifying, examining and questioning social and political practices that control and regulate the way we think about and through the body" (Ferri, 2006, p. 290). Critical Special Educators seek to highlight the social inequities of disability while simultaneously writing critically about the professional epistemologies that fail to acknowledge the perspectives of disabled people (Heshusius, 1982). Fundamental attempts in the field seek to question past and present discussions of power, identity and injustice and how, despite including race, gender and class, these discussions have failed to include disability as a group that can further inform and transform arguments related to power and identity (Danforth & Gabel, 2006). The tradition of Special Education privileges the expertise of the dominant non-disabled and frequently results in silencing the voices of disabled students and their families. Parents of children with disabilities report feeling unable to speak back to teachers and school counselors who prescribe Special Education services for students because the parents find it difficult to question the "expertise" of professionals (Keefe, Moore, & Duff, 2006). Children and their families need a voice or they risk being exploited by placement in Special Education classrooms that often (re)produce cultural assumptions of low expectations and inferiority of individuals with disabilities.

While discussions of power and identity are an invaluable component of the work of Disability Studies in Education, inclusion is also part of the work

scholars are doing. While most scholars in Disability Studies in Education would identify themselves as pro-inclusion, myself included, simply demanding that inclusion occur, without questioning what is being taught and how, is not enough. Frequently, Special Educators advocate for individualized education and curricular adaptations for students based on their perceived abilities and disability categories. Unfortunately, this typically translates into watered-down educational experiences that do not provide opportunities for students to excel (Brantlinger, 2005). As a result, one must be wary of how inclusion occurs because, in the end, the dominant group still controls when, how and for whom inclusion is appropriate. Even when included, exclusion can continue because, as Ferri (2006) wrote, "students can be physically included but not conceptually included in the mind of the teacher" (p. 292), exclusion within inclusion. Instead, inclusive classrooms are where

> students, regardless of ability . . . are integral members of classrooms, feel a connection to their peers and have access to rigorous and meaningful education curricula and receive collaborative support to succeed. It cannot be a surface thing. It must go beyond providing accommodations but must respond to the human need to feel as though they belong. Inclusion entails more than just getting students into regular education classrooms but also involves changing what we teach and who we think our students are. (Causton-Theoharis & Theoharis, in Ferri, 2006, p. 49)

A third dimension of Disability Studies in Education is an exploration of the roles and experiences of teachers who work in schools. It is important to distinguish between teachers who perpetuate exclusionary practices and those who, on a daily basis, witness the segregation and marginalization of students with disabilities and may feel powerless to respond. It is the teachers who chose to push back on the oppressive structures of schools who are cited as a reason for the exponential growth of Disability Studies in Education over the past ten years. These teachers recognize schools for what they are, ridden with structural and attitudinal barriers that seek to exclude students, rather than include them in classrooms. For these teachers, practices of labeling, testing and prescription of placements do not meet the needs of students with disabilities in the right ways. These practices disempower students and their families. For these teachers, Disabilities Studies in Education writings provide the ammunition needed to respond to bureaucratic practices and to work for change (Danforth & Gabel, 2006).

Strengths of Disability Studies in Education

While Disability Studies in Education (DSE) remains a fairly new field in comparison to educational research as a whole, even in the early stages, identifiable strengths of the perspective have emerged, namely in the ability of DSE to impact: 1) how teachers come to understand and work with children with disabilities in their classrooms and 2) a commitment to trouble the current deficit-based practices common in Special Education.

While teacher education programs that embrace the inclusive model of preparing teachers to work with children with disabilities are few, it is important to examine the ways in which programs have been able to impact the practices of educators in the field. Broderick, Reid and Weatherly-Vale (2006) initiated a study targeting teachers educated in a program that embraced a Disability Studies framework. The degree to which the respondents articulated how the program shifted their frame of reference of disability and the ways in which they worked with students was notable. As one teacher shared of his experiences, "I have continually changed my perception of ability/disability. I know and understand normalcy is constructed by society and hegemony. My educational plan and goals have changed for the establishment of equality and social justice of all people" (p. 145). Another teacher reflected that:

> Disability studies has helped me to separate the conventional
> (or socially constructed) idea of disability from who my students
> are as human beings. I do not identify my students by the label
> on their IEP. I see them as complex individuals with different
> needs and talents. (p. 147)

These reflections not only highlight changes in a teacher's ability to think about students as individuals and not as labels, but also illustrate a defined change in how these teachers understand disability as a socially constructed characteristic.

An additional strength is the work Disability Studies in Education

scholars are doing to trouble traditional assumptions commonly found in the field of Special Education. There has been a call from writers in the field to "restory" the experiences of both students and teachers in the field of traditional Special Education so as to challenge the current system and move forward to promote change (Ware, 2006). Scholars are advocating for changes not only in how we educate students with disabilities, but how we help everyone better understand disability experience. Ware (2006) wrote:

> Approaching disability from a humanities perspective suggests
> to some the potential for society to more fully understand
> disability and therefore to teach more rich and varied accounts
> of living with disability. This seems timely as K-12 classrooms,
> like society, have become more heterogeneous than at any time
> in the past. (p. 272)

Creating classrooms in which we do more than just teach about disability as deficit and instead focus on associating disability with pride and empowerment is key. Disability Studies in Education serves to promote education that embraces disability rather than hides it in a different part of the school or denies its existence altogether (Taylor, 2008).

Limitations in Disability Studies and Disability Studies in Education

While the work of scholars in DS and DSE is transforming how we talk about disability, it operates within the limitations of a system that continues to reify images of ability and disability in our classrooms, both in the K-12 setting as

well as in higher education. Disability is interesting in that, as Mitchell and Snyder (2001) wrote, "marginalization has occurred in the midst of a perpetual circulation of (disabled) images. Curiously, a social erasure has been performed even as a representational repertoire has evolved" (p. 6). While there is no shortage of images and societal teachings about ability and (dis)ability that seem to have become "common sense" in media, books and films (Dosch-Brown, 2011; Garland-Thomson, 1996), there is an ongoing need for scholars to trouble current understandings about (dis)ability. This remains a challenge, both in K-12 education as well as in teacher education. Foucault (1972) wrote about "discursive practices that systematically form the objects which they speak" (p. 49); images and understanding, current practices, all serve to maintain the disabled as (dis)advantaged. They continue to be categorized and classified. Unless challenged, the language we use and the placements we assign continually reaffirm a deficit image; to date, not enough is being done to counter these deficit (re)presentations of disability.

Given the possibilities that exist in targeting teacher education as a potential area of change, one of the greatest limitations to date is a lack of resources in the form of textbooks or even articles for undergraduates studying teacher education. While inclusion is no longer a novel concept, courses in teacher preparation traditionally related to Special Education are still taught as segregated courses in separate departments and seek to disseminate knowledge "about" the disabled in the form of generalizable characteristics and acceptable

accommodations (Rice, 2006). While a few institutions have embraced an inclusive education model within their teacher certification programs, notably Syracuse University and the University of Wisconsin-Milwaukee, these programs are the exception rather than the rule. Courses seldom trouble how individuals with disabilities are positioned by the dominant group, how systemically they are marginalized and how schools reproduce cultural understandings of disability as deficit. Ferri (2006) wrote of her experience teaching a Critical Special Education course in which students expected to receive practical solutions on how to work with the disabled and were often resistant to discussions that troubled their understandings of disability experience. Sadly, teacher education programs as a whole continue to reinforce rather than trouble difference (Rice, 2006).

To change the way both preservice and inservice teachers understand and work with children with disabilities, we must find ways, within teacher education programs, to teach new understandings of disability that challenge students' own views. Utilizing texts that embrace inclusive education concepts and infusing narrative writings that explore teacher identity and ways of understanding disability within curriculum are possibilities (Rice, 2006). Additionally, when engaging in discussions related to critical pedagogy, which often focus on race, gender, class and sexuality, disability needs to be part of such discussions. A critical pedagogy of disability would include "investigating the social forces that shape and maintain the centrality and power of 'ability'" (Kincheloe, 1993, p. 25). Perhaps one way in which this could be done is through

implementing disability equity training in schools. That would serve to better prepare practicing teachers to support positive images of diversity, including, but not limited to, disability. In this way, teachers would be better positioned to move beyond simply "managing" difference to engaging with it (Allan, 2006). Diversity should no longer be a separate part of the teacher education curriculum because this way of "dealing with" difference only serves to reinforce segregation in education (Tregaskis, 2006).

Also complicating the further development of a Disability Studies perspective is the need to prepare teachers for the institutional pressures with which they will undoubtedly be forced to contend. The methodological dilemma of being educated with DS in mind, but being asked to practice in a traditional special educator role, can be challenging, disheartening, exhausting and disempowering, to say the least. Resistance is needed to challenge the current deficit-based, medicalized practices of schools, but this is not easy work and often teachers who choose to challenge the system find themselves marginalized (Broderick, Reid, & Valle, 2006). One professor working for inclusion of disability studies perspectives into undergraduate and graduate teacher education programs at his university reflects that "negotiating this dissonance is a troubling and difficult enterprise. . . it is VERY difficult to need to critique a set of standards and approaches that is also what is providing me my current living" (Broderick, Reid & Valle, 2006, p. 141). This experience is not an exception. Another professor in teacher education who identifies as disabled describes his situation

as even more isolating:

> My colleagues of 17 years really don't know what to do with me.
> I'm called on to teach all sorts of . . . courses, but never asked
> to collaborate in research projects. . . I don't think any faculty
> member in my special ed program has ever read anything I've
> published. I am also rather a thorn in their side because as they
> are trying to maintain the autonomy of the special ed program, I
> am constantly working at assimilating the program into teacher
> education. . . Those events have led me to seek collegiality
> elsewhere—in other countries and in other institutions where
> disability studies scholars have positions. (Broderick, Reid &
> Valle, 2006, p. 142)

The experiences of both these professors in teacher education are not dissimilar to the experiences of teachers in K-12 settings and serve as a strong reminder of the systematic and attitudinal barriers that exist in schools and society that make change difficult. Within academia, Disability Studies scholars often share their perspectives without an established program, without the support of like-minded colleagues and in settings where Disability Studies is even more marginalized than Women's Studies or other areas like it (Ferri, 2006). This could be one of the strongest criticisms of Disability Studies and Disability Studies in Education: its inability to influence change in policy. While DS provides a framework for understanding how socially constructed assumptions about disability influence

policies within society and schools, the ability of DS and DSE to elicit change has, to date, not been fully realized (Allan, 2006; Ferguson, 2006).

Another limitation within the disciplines of both DS and DSE is in relation to who is doing the research and how it is being conducted. There is a notable lack of research initiated by individuals with disabilities about disability experience. Disabled individuals are rarely positioned as researchers because of limited access to education, discrimination in hiring processes and inadequate support for scholarly work in Disability Studies (Linton, 1998). Of the research that is being done, Oliver (1996) observed that "few of those who seek to speak for us or write about our lives take seriously the need to represent our views, our lives and our struggles accurately" (p. 20). Research needs to be conducted "with" the disabled and not "about" them. Without the participation of individuals with disabilities themselves, how does such a discipline hope to reshape the way in which we understand disability when the conceptualization of the lived experiences of the disabled fail to adequately represent the lives of the disabled individuals? If this discipline hopes to empower the disabled, some caution that we must not only have more researchers with disabilities carrying out research, but also the language of academia must not distance the disabled from stories about themselves. That which is written becomes inaccessible to those it is meant to represent. Research by the disabled, with the disabled, to empower the disabled, is necessary.

Particularly underrepresented within current literature in the field of

Disability Studies in Education is writing focused on children and teens with disabilities. There is an especially strong need for research focusing on the social experiences of children and teens (Danforth & Gabel, 2006; Taylor, 2008). Kliewer (2006) offered even more specific needs for future research, stating that disability scholarship needs to focus on "saving" the study of children with disabilities from that of educational psychology. Disability Studies in Education must also work to explore the lived experience of young children and their families and to examine how children and families can be participants and agents of change.

The knowledge that children and their families possess is often not privileged in educational settings. Parents who attempt to advocate for the inclusion of their children in general education settings are often portrayed as overly idealistic, "crazed" or "absurd" for their failure to not take the advice of the professional, knowledgeable educator (Chelsy & Calaluce, 1997). What continues to be privileged is the knowledge of educators and researchers who are distanced from the "real life experiences" of children and families who live the disability experience every day. There has been a tendency, even within Disability Studies, for researchers to position themselves above teachers who position themselves above children and families in relation to knowledge ownership. This type of hierarchical research continues to practice deficit thinking and fails to privilege the knowledge that children and families possess (Kliewer, 2006; Solis & Connor, 2006).

Recognizing that schools are primarily social spaces, it is absolutely vital to pay attention to how students with disabilities understand their interactions and conceptualize their roles and their identities in schools. The experiences of students with disabilities greatly varies based on the degree or visibility of the disability, their need for special services and the amount of time spent in general education versus segregated learning spaces, among other variables (Goffman, 1963; Keefe, 2006, Kliewer, 2006). Even students who are able to spend the majority of their time in general education classes, but may, for example, need a wheelchair to navigate in schools, may have greatly reduced access to social and academic experiences; their thoughts and perspectives on this need to be explored. The students' perspectives may aid teachers in better understanding how to facilitate the inclusion of students with disabilities in schools.

The ways in which we think and talk about disability have changed dramatically over the past fifty years and will undoubtedly continue to do so as our understandings of identity, disability culture and the complexity of the body evolve. Disability Studies and Disability Studies in Education have challenged traditionally deficit views of disability and have advocated for changes in the way we view "normal." In the future, it is my hope, and the hope of others writing within these traditions, that finally the voices and experiences of the disabled will receive the recognition they deserve. As Charlton's (1998) book title so succinctly puts it, *Nothing about us, without Us*. It is our time to tell our stories and create change in our schools, in our workplaces and in our lives.

Chapter 3: Research Methods

Exploring the lived experiences of children and adults with disabilities has interested me for more than a decade. A yearning to know more born out of my life history with disability, I've always been drawn to learn from others in an attempt to not only understand their experiences, but my own life as well. I recall being fifteen and attending summer camp for the first time, a special camp for children and teens with disabilities. Having gone to schools in which I had, with few exceptions, been the only mainstreamed student with a visible disability, I was ecstatic to finally meet others who shared my disability. I spent hours engaged in conversations with my fellow campers, trying to understand their experiences with friends, school and home life. For three years I looked forward to those two weeks at summer camp with unceasing anticipation of the sharing of stories that would occur.

I believe it was this love of learning from others who had lived the disability experience that prompted me to embark on my first (official?) research study, though when I look back on it now as a graduate student, I almost laugh at what I thought were sound research practices. The project, entitled "Proceed without caution: The social experiences of individuals with disabilities," was my feeble undergraduate attempt at an interview study in which a fellow student and I invited children and adults ranging in age from eight to 55 to talk with us about their experiences living with a disability, specifically focusing on their relationships with peers. Many of the participants spoke with great candor about

schooling, friendships, dating and the lengths to which they would go to appear "normal," by society's standards. I remember wishing throughout that study that I could just stop going to class and spend every day with the study participants, observing them, listening to them and learning from them.

I entered graduate school in the spring of 2008 not knowing the how of what I wanted to study, but certain of the what and why. I had some ideas, but wasn't, at that time, sure of their feasibility. I had read two books, *My Freshman Year* and *High School Confidential*, each of whose writers had spent one year researching the cultures of both college and high school. Through coursework, I learned that this type of research had a name: ethnography. I was intrigued by what these writers were able to learn, the relationships they were able to build and the stories they were able to share after a prolonged stay "in the field." This got me thinking: wouldn't this same method work for what I wanted to accomplish? Couldn't I spend a year "hanging out" with students so that, like other ethnographers, I could come to know, in a more holistic way, what it was like to be a student with a disability in school today?

Throughout the first few years of my graduate experience at the University of Minnesota, my interest in pursuing the aforementioned research never wavered, but my concerns about whether it would be important work, work that would matter to others, did. Never in my courses of study did I encounter work similar to what I wanted to do; in fact, disability literature in general rarely found its way into any of the courses in which I was enrolled. We discussed many

aspects of culture and diversity, such as race, class, gender and sexuality, but disability rarely was discussed. As my frustration grew, I started to wonder if anyone would feel that the type of work I wanted to do would be valuable. After sharing my frustrations with my adviser, who assured me that my work would be important, I spent two semesters engaged in independent reading focused on Disability Studies and Disability Studies in Education and found that there were others who cared about the experiences of individuals with disabilities and that there was a need for work focusing specifically on the lived experiences of children with disabilities.

What follows is the framework for this study, beginning with a justification for the use of ethnography followed by an explanation of the processes used for collection of data. Within the discussion of data collection, I also discuss the unique approaches that I used to practice "participant observation" despite my visual impairment. Finally, I discuss the processes used for analyzing this work both during the research study and throughout the writing of the dissertation.

Ethnography: A Justification

As recently as the 1980s, scholars within the field of Disability Studies have recognized the inseparability of disability from the social world that produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it (Barnes & Mercer, 2003; Murphy, 1990; Oliver, 1992). In other words, disability is socially produced (Barnes & Mercer, 2003; Linton, 1998; Oliver, 1992; Taylor, 2006). It seems reasonable

then that, to better understand the experience of disability, one must examine the social settings in which individuals with disabilities live in order to understand how disability is constructed. Herein lies the justification for selecting an ethnographic study as the basis for this research.

Writing in the field of Disability Studies and Disability Studies in Education hardly represents a picture of solidarity, with research paradigms ranging from social constructionist or interpretivist, post-modernist, post-structuralist, and legal/policy studies to name a few (Taylor, 2006). Even with a variety of research paradigms represented in the field, interpretive research does a great deal to inform theory, given its emphasis on the social construction and historical context of knowledge. While recognizing the contextual nature of experience, the interpretive paradigm also views the world as an active place. Situations and people change over time and are constantly in flux. In order to learn from the everyday experiences of individuals, it seems important to recognize that observation of and participation with research participants should take place within their natural state, without the intervention of, or manipulation by, the researcher (Hammersley & Atkinson, 1983). The knowledge of each individual is validated within the interpretive paradigm and thus this paradigm acknowledges the multiple perspectives and interpretations of single events. Reality is multifaceted and complex (Cohen, Manion, & Morrison, 2007). Writing from this paradigm invites complex stories and doesn't call for a reductionist approach to human experiences. "Thick description" becomes important (Geertz, 1973). Not

only are the knowledge and realities of the individual validated, but everyday experience is viewed as important and rich in data. There is something to be learned, even from the mundane (Emerson, Fretz, & Shaw, 1995).

While the researcher may begin a study with a particular research question and focus, what is to be found is often unknown, and therefore research questions and focus can change (Glaser & Strauss, 1967). This is contrary to the practices of positivist research. Unlike research that seeks to make broad generalizations, one of the single most important ideas put forth by post-modernists has been the rejection of social science as a universal, generalizable way of accurately discovering and describing the truth about human social activity (Richardson, 1998). There are multiple realities and to claim that there is one truth is simply not the case. Research is also the product of values of the researcher. The mere presence of the researcher in a setting changes it (LeCompte, Preissle, & Tesch, 1993; Wolcott, 2008). As a result, the researcher's values and identity cannot be independent of her work. The researcher must acknowledge her role and privilege within the study and include these thoughts in the final writing (Richardson & St.Pierre, 2007).

In the instances in which individuals from traditionally marginalized groups have been written about, they are often misrepresented in texts by the researchers who have studied their experiences. Particularly in the case of disability, what has been written has been born from the positivist approach and focuses on the individual and his or her impairment as the source of the problem

with disability which, in essence, reaffirms the individual/medical model of disability. In what Oliver (1992) called "the social relations of research production" (p. 139), the researcher lives out the privileged position of "knower" and controls the research agenda. In this process, individuals, in this case, children or adults with disabilities, are estranged from the final product. They are treated as subjects rather than co-constructors of meaning. Rowan (1981) wrote that the estrangement of participants "is usually done by putting a person in the role of research subject and only then permitting a very restricted range of behaviour to be counted . . . The person's actions don't belong to that individual but to the researcher" (p. 93). This approach thus exploits the subject: Individuals with disabilities are studied and then written about with the researcher as primary decision-maker about how to portray what has been learned. The final product lacks the elements of collaboration and sensitivity to the very personal experiences of research participants.

In response to this tendency to exploit or "write on" individuals with disabilities, there is a strong need for researchers with disabilities to write about disability experience (Taylor, 2006). I have been managing my own disabled identity in an ableist society for thirty-some years. I have been isolated, celebrated, written about, objectified, marginalized, doubted and praised because of, or in spite of, my disability. I have many stories to tell but never found a space in which I have felt comfortable doing so. I may not be alone in feeling this way, and I've wondered if others, too, search for someone who will listen and who

really wants to try to understand what they have to say. While I was under no illusion that my own status as disabled automatically entitled me to write about disability, I believed that I could be a researcher who would proceed with a commitment to privileging the expertise of individuals with disabilities, allowing their own words to be the stories.

Another of the attractions to ethnographic research was that it supported the premise of privileging the knowledge of individuals rather than treating them as subjects on which research is conducted. Ethnography, particularly critical qualitative research, focuses on social inequalities and social change. Criticalists share a concern with social theory and some of the basic issues it has struggled with since the nineteenth century. These include the nature of social structure, power, culture and human agency (Carspecken, 1996). Oliver (1992) wrote that even as interpretive research has changed the rules of research, it really hasn't changed the game, because much of what comes out of the interpretive tradition is still done by a small group of relatively powerful experts doing work on a large number of relatively powerless subjects. I hope that this ethnography can change this because I do not seek to do research "on" students, but "with" them. Richardson and St.Pierre (2007) capture the essence of my attraction to this type of work:

> When we write ethnography we work within theoretical
> schemata (feminism, critical race theory, post-structuralism,
> etc.) that challenge grounds of authority, writing on topics that

matter both personally and collectively, locating oneself in

multiple discourses and communities, developing critical

literacy, finding ways in which to write/present/teach that are

less hierarchical, revealing institutional secrets, using positions

of authority to increase diversity in both academic appointments

and journal publications. (p. 481)

Ethnographic work not only provides an opportunity to do research "with" participants rather than just "on" them, but it offers the opportunity to challenge the status quo with relation to issues that are deeply important, both personally and within the greater society.

My decision to conduct a year-long ethnographic study in a middle school, then, was a very deliberate decision. Ethnographic research recognizes that meaning develops out of social situations and that behavior, meaning and understandings are situated within the context of the social settings in which they occur. To not be present, observing the processes at work in this middle school on a day-to-day basis, would be a failed attempt on my part to explore that which happens to students, between students and within the constructs of school. Qualitative research also recognizes that we are not static beings, but rather are constantly changing, and ethnographic work in particular demands a lengthy time in the field (Spindler & Spindler, 1992). During nine months in my school site, I was able to observe and engage with students over a period of time and become part of the school culture, to the extent possible, so that I could build trusting

relationships with my participants in order to position me to better represent their dynamic experiences over the course of an entire school year.

Ethnographic research also recognizes the existence of multiple realities, multiple understandings of an experience (Lincoln & Guba, 1985; LeCompte, Preissle, & Tesche, 1993). No two students, even if present at the exact same time, in the exact same place, experience an event in the same way, nor would I expect a student to understand their experiences with disability in the same way as another student, or one of their parents or teachers. This ethnographic work allowed me to learn from not only students, both disabled and non-disabled, but from their teachers and parents as well. Multiple perspectives aided me in gaining a more holistic picture of the social nature of disability (Wolcott, 2008).

In the chapters that follow, I plan to uphold my commitment to representing these multiple realities through the use of "thick description (Geertz, 1973). As a former English teacher, I pushed students to bring their writing to life through the use of "show, don't tell"; this is something I work to achieve in my own writing. Ethnography encourages this thick description, this "show, don't tell," so the reader can experience a "you are there" quality (Silverman, 1985). To tell, I believe, assumes that I have the final say on what to communicate to the reader, that I alone know that which is true. To show, on the other hand, requires that I take the time to describe what is happening so that others can imagine for themselves the setting and what it might have been like to be there.

Thinking specifically about my own intentions for this ethnography

certainly implicates the purposes and assumptions of interpretive research. As I've discussed earlier, the individual experiences of the middle school students with disabilities are fundamental to this study. I entered the field intent on hearing their stories and learning about their own individual perspectives. Too often I believe we dismiss human experience as just being true of one person and therefore not significant. Richardson (1998) wrote that "having a partial, local and historical knowledge is still knowing. We recognize the situational limitations of the knower" (p. 348). Our human experiences are important. Additionally, even though most of the students in my study are children, I value their understandings and acknowledge that they, too, are knowledge holders. Their ideas matter.

My Work

The work for this research study began with a need to both locate a site and gain access. I knew from the onset that I wanted to focus my work on middle school students and that I needed to find a school that had a fairly large population of students with a variety of disabilities. Please note that the name of the school and names of all of the participants are pseudonyms to uphold anonymity. Geographically, my home happened to be located near a school district with a middle school that not only fulfilled these requirements but others as well. Cinder City Middle School had a population of 420 students, of whom 14% had an identified disability. Additionally, this school district had an established reputation within the region as being proactive in its practice of

inclusive education for students with disabilities. Through familial relationships with some of the staff members who worked in the school, I learned that several of the staff members of the school, particularly those who taught in the Special Education department, readily shared this perception of the good things they felt they were doing for students.

I gained access to this school with relative ease. While I didn't have a personal history with the school district, members of my extended family did. In fact, one of my family members, Michael James, has been employed with the district for 24 years, the last 12 years in an administrative role. In that time, he has established strong friendships with several administrators. Many staff members from the Cinder City School District attended our wedding and had been following my and my husband's paths through graduate school. When Mr. Frank, the superintendent of Cinder City Schools, heard through Mr. James that I was in search of a dissertation site at which to do research with students with disabilities, he happily offered his school.

While gaining access to a site with such ease was advantageous for me, it did not come without implications in the research process. Upon entering the site and meeting people for the first time, I was often introduced by my relationship to Mr. James. Many times my connection to him earned me credibility while in other instances it created a barrier. This was largely dependent on the type of relationship Mr. James had built with individuals. He had a reputation for being rigid and while some would consider this an asset for someone in his position,

some staff members interpreted his mannerisms begrudgingly. Being positioned then as a relative of his concerned some individuals because they worried that I would "report back" to him. Others, who had established a good working relationship with him, were more willing to share. Regardless, this affiliatory power (Moje, 2000) did trouble, in ways I am both aware and unaware of, the relationships I hoped to build with teachers at the school.

After being granted access to the site with relatively little effort, I made my own initial contacts with the superintendent (Mr. Frank), the curriculum director (Ms. Hibbard) and the middle school principal (Mr. Williams) to make plans. We discussed the logistics of my participation in the school environment. It was decided that I would begin attending meetings of the Special Education department in the summer of 2011 to build relationships with the its teachers and paraprofessionals. By the time I attended the first meeting in July, 2011, the department already knew I was coming, and they were very interested in hearing what my role would be. At the meeting, not only did I explain briefly the purpose of my study, but I availed myself to them as willing to work with students and support whatever work they were doing, sharing that my preference to be involved in activities rather than simply a passive observer. They were excited because not only was I an additional body, but I brought my own expertise as a former English teacher. Mrs. Matthews called "dibs" on me for fourth-hour, eighth-grade English immediately. Little did I know at that meeting when I was claimed for that fourth-hour English class that this would become one of the most

important spaces in my dissertation work.

During early email exchanges with administrators, we also negotiated how I would not only introduce myself to the staff and explain my role in the school but also how I would recruit student participants for the study. The curriculum director decided that I would attend the first staff inservice day in August and would be given a space on the agenda to introduce myself and explain my work. That did not happen because of time constraints. Instead, Mr. Williams asked me to prepare a letter to be given to each staff member that outlined my work. In the letter I explained that I was very willing to serve as an assistant in classrooms and that I looked to them to help me identify important spaces and events in which to observe students with disabilities. Letters were delivered to mailboxes at the end of the first week of school. With the letter I included a consent form that explained my interest in observing in their classrooms and asking permission to record classroom discussions. Only one teacher contacted me and asked that her classroom not be used as a site for data collection. Before entering any classroom for the first time, I always introduced myself again and asked if it was okay to observe and participate in classroom activities.

During the first few weeks of school I spent time in a variety of spaces. Using a master schedule of all students receiving Special Education services as a starting point, I began observing in different classrooms during different class periods each day to determine where I would eventually focus more intense observations. I also selected several informal spaces in which to observe,

including the corridor outside of the main office/principal's office, the grade level "wings," the lunchroom, library, playground and the bus loading zone. I also spent time observing and participating in field trips off-site. In total, for the first 18 weeks of the school year I was present at the school from 7:55 AM until 2:55 PM four days a week. This increased to five days a week for the last 18 weeks of the school year for a total of 155 days. On several occasions I stayed beyond the end of the school day to meet with teachers or attend after-school events, meetings or field trips.

These initial observations helped me determine places in which I wanted to spend more time, places in which I felt important and interesting things were taking place. Being very conscious of how my presence impacted the environment, I did not choose to stay in places in which I felt that my presence disrupted the environment or made the teacher feel as though she was being scrutinized. For this reason I eliminated two classrooms because the teachers repeatedly communicated to me that they felt "stupid" when I was there. They stumbled over their words and became easily frustrated when students acted up. By the end of the fourth week of observation, I selected six sites that I intended to focus on. They included a sixth-grade English classroom, a seventh grade math class, an eighth grade English classroom, a multi-grade Life Skills classroom, a multi-categorical Special Education resource room and the cafeteria. I continued to observe and participate in other spaces, but with less regularity, and my presence in those spaces fluctuated.

To recruit students for the study, I began with intense observation of as many students as possible in all areas of the school. By observing in a variety of spaces and by talking to a variety of students, I was able to identify individuals who could potentially become focal participants in the study. Because more than 50 students were enrolled in the Special Education program at the school, I had to establish a set of guidelines for choosing students for the study. First, only students who were able and willing to articulate their experiences independently, through the use of an interpreter or with the use of a communication device were considered. While most students were able to communicate with me, some students preferred to keep their experiences private, and I wanted to respect their decision. Second, initially only students with visible disabilities were considered. It was not my intention to draw attention to students who did not want additional attention brought upon themselves. Note the use of the word initially. Later in the study, after recognizing that invisible disabilities were made visible on a daily, almost hourly, basis by staff members, I also welcomed students with invisible disabilities to participate. Third, I sought suggestions from staff members as to which students might be most willing to participate and whose parents would be most open to their participation in the study. Finally, I recruited students by speaking with them directly about my intentions, sharing that I wanted to learn from them about what it was like to be a student with a disability in middle school.

In all, three fifth-grade students, two sixth-grade students, six seventh-

grade students and eight eighth-grade students with disabilities participated to various degrees in the study. Several students without disabilities also became significant participants. In all cases, the non-disabled students who appear later in this text experienced other forms of marginalization in this school environment. After identifying students who wished to participate, I secured consent from parents and assent from students and proceeded with my work.

Data Collection

To gain a deep understanding of this school environment, I employed multiple data collection techniques which is a common practice in ethnographic work (Carspecken,1996; Richardson & St.Pierre, 2007; Spindler & Spindler, 1992; Wolcott, 2008).

One method of data collection was interviews with individual students, parents, teachers and administrators. These interviews, I felt, gave my participants the opportunity to share stories and their own understandings related to the nature of disability experience in a semi-structured manner that often resulted in a great deal of rich, very personal information. Of the value of interview data, Carspecken (1996) wrote that

> subjects often talk during interviews in ways they seldom talk in
> everyday life . . . because very often people are not listened to
> as intently as the researcher listens to them, takes as seriously
> as the researcher takes them and supported in the exploration
> of their feelings and life as much as a skilled researcher will

support them. (p. 154)

I found this to be true in the interviews I conducted with parents, teachers and administrators insofar as five of my participants specifically shared that through the interviews they were able to verbalize things that they had never shared with anyone before. For example Marcie, the mother of a fifth-grade student in the Special Education program, shared:

I feel like I'm all alone in this big ocean of other parents, but none

of them are living the same life as me. I've never admitted this to

anyone before but, yes, I have spied on teachers here at school,

I've stood around corners and watched how they treat my

daughter. I've asked my older daughter to check in on Brinna

during the day. I don't trust that they are doing the right things for

my daughter, and she doesn't have the language to tell me how

she's being treated so this is the only way I can think of to know for

sure. Please don't think I'm crazy for doing that, but I worry.

In planning, I had anticipated that the interviews with adult participants would be semi-structured in nature and last about an hour. I would come to the interview with a few grounding questions and potential follow-up questions but had anticipated letting the participants guide our discussions. In all cases I offered to provide questions to interview participants ahead of time, and while the administrators and teachers welcomed this, all of the parents declined. As one parent noted, "I'm better at speaking from the heart." In all cases the interviews

exceeded the allotted one hour time frame, with some lasting upward of two hours. While I offered, in every case, to schedule a second interview, participants were so engaged in the interview that they preferred to continue.

I began interviews with adults by asking participants to sign the consent form. I then asked for their permission to record our session. I asked questions, the parents answered questions and the sessions ended. That is not to say that the sessions were not emotional, but the interviews were focused and I felt as though the parents took seriously the opportunity to participate in the research process.

The interviews conducted with administrators and teachers looked very different. All of the individuals welcomed questions ahead of time to craft their answers, focus their thoughts and use the time we had together effectively. However, during the interviews, whereas parents attended well to the question/answer process, teachers and administrators didn't share in the same level of commitment. One administrator invited two other individuals to sit in on the interview, took two phone calls and, at one point, left to get coffee. During the teacher interviews, one teacher brought a student with her because "he won't understand what we are talking about anyways," and another received texts during our conversation. I believe this could be in part because, by the end of the year, when I conducted most of the interviews with teachers and administrators, we had accomplished a level of familiarity. As one teacher put, she viewed me as "part of the school" and not "just a researcher."

While my initial response to some of the behaviors that took place during the interviews was one of irritation, I also acknowledge that individuals were stepping away from their lives to share their thoughts with me and that I wanted to respect their time as well. In the case of the administrator who invited participants to "sit in on and learn from" the interview, I do believe this impacted the quality of the information he was willing to share. He seemed very confident in the school's handling of situations related to students with disabilities, until my questions turned to specific instances of injustice. Then he turned to the individuals he had invited in and said, "this information cannot go anywhere because I don't want this to get out." Was he being honest before that point? I am not sure. In the case of the teacher who wanted to carry on with her interview in the presence of a student, I felt this action only reaffirmed some of the deficit-thinking that I witnessed on a daily basis in the school. To say that it didn't matter if we talked about students in front of other students because they wouldn't understand "anyways" made me uncomfortable because I do not subscribe to this belief.

The interviews I conducted with students were very different in structure to those I completed with their parents and teachers. As with the adults, I began by seeking assent from the students and consent from the parents. When seeking permission from participants and their guardians I also sought permission to record interviews as well. Not wanting to create an uncomfortable atmosphere for students in which they felt pressure to "perform" in a certain way if I called our

conversations interviews, I tried to make our interviews feel more like casual conversations. I realized the importance of being sensitive to the individual and the need to establish trust before expecting individuals to share potentially emotional information with me. Thus, establishing trust and finding a comfortable environment in which to conduct interviews were key. Fine (1994) wrote, "If you want to hear it, you have to go hear it, in their space or in a safe space" (p. 15). In this way I felt like I was doing "interviews" almost all of the time, during study time, at the lunch table, at recess and walking in the hallway between classes, but always in their spaces. That being said, I was also cautious about discussing issues that could be considered sensitive in situations in which we were able to talk one-on-one. Most often my conversations with the students centered on engaging them in conversations about situations that were immediate and relevant.

In certain situations, I was able to engage students in group interviews. These most often took place at the lunch table, during detention or in the sixth- and eighth-grade English classrooms. Typically the discussions weren't entered into with the intent of being "interviews" per se, but when the conversations turned to topics of importance to my research or when students seemed particularly eager to answer my questions, I would ask to record our conversations for use in my work. One of the group interviews that occurred in an eighth-grade classroom was particularly fruitful in that one of the students made a comment that I knew to be untrue, given my observations in the lunch room. I

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asked the student if he was sure, and that one question sparked a 40-minute discussion on who was and was not visible in the school, even resulting in diagrams and "naming" of spaces in the lunchroom and where students sat. These happenstance data collection opportunities proved very beneficial for my work.

Another form of data that I relied on for the purpose of this study was the collection and analysis of documents, including student work, emails, teacher-produced documents and official district policy handbooks. To gather documents related to district policies and communications, one of the most simple ways I accessed information pertinent to the day-to-day functioning of the school was through the middle school all staff email listserv. An administrator added my name to the middle school list so that I'd be aware of changes in schedule, upcoming events and information on student concerns. I also, through this avenue, received copies of minutes from all middle school team meetings. I was able to request hard copies of handbooks for both students and teachers related to policies that governed the structure of the school.

Documentation in the form of student- and teacher-created artifacts also became sources of data for my study. While in classrooms, I asked for copies of handouts. I found this practice important because not only could I participate more fully in classroom activities when I followed along with the students, but I also had the opportunity to think critically about what teachers were creating and distributing to students. Student work also was valuable, particularly in the

English/Language Arts classrooms. It was in these rooms that students did some of their most reflective work in the form of personal narratives, journals, essays, poems and speeches. Often students are able to express themselves in very personal ways in their writing or other creative forms of art. Two of the most powerful sources of student-rendered data came first in the form of speeches that students wrote and delivered on the the topic of disability in their sixth-grade English class and second, in eighth grade, in artifacts placed in a time capsule representing their middle school experience, a capsule that would be opened when the students were about to graduate. Examples of data collected from the sixth-grade speeches are highlighted in Chapter 4 while samples of eighth-grade students' time capsule submissions are featured in Chapter 6.

While interviews and document collection were both important in the data collection process, I believed there was much to be learned that could only be done through observation of the processes of socialization, the processes of schooling over time. Interviews, for the purpose of this study, were not enough. Scott (1992) cautioned the researcher about equating the stories that individuals tell to the actual experience. To do so, "as if they are the events per se, rather than stories about the events, is to dehistoricize and decontextualize the very experiences being reported" (p. 26). This seemed to suggest to me the necessity of placing stories within social contexts. In being committed to participant observation, that is what I hoped to do. Recognizing that participant observation may be interpreted by different people in a variety of ways, I feel it necessary to

define what it meant for me.

Participant observation, for the purpose of this study, meant not merely being present in a space, passively observing, but being active in that space, engaging in teaching and learning along side my research participants. Depending on the space, however, there were times when I did slightly more observing than participating, and in other spaces, more engaging, depending on the circumstances and the expectations for me as an adult in that particular space. Every time I entered a new site (a classroom I hadn't been in before, for example), I would spend a day or two coming to know the environment. I would be more passive at these times, watching what took place, asking questions about expectations and determining how I could participate in the classroom. I made note of findings in small composition notebooks or on my laptop or iPad. For example, while in classrooms I frequently made notes on my laptop because I could be both recording conversations and making notes with time stamps in a document. In some environments I used both my computer and iPad together so that I could record conversations in two different areas of the classroom. When participating in lunchroom activities, however, I used only a small notebook because the laptop seemed out of place at the lunch table. In all cases I made jottings that were later transposed into full-length, word-processed documents.

While the data I collected while engaging in participant observation was some of the most valuable information I collected, my perceived ability to even take part in that process had been questioned. How could I, as an individual with

a visual impairment, really observe? How could what I thought I saw be trusted when I had such limited sight? In my first foray into writing fieldnotes for a course on ethnographic methods, I was told that my notes were ineffective and not done correctly. They relied too heavily on that what could be heard and not enough on what could be seen. I felt abashed, disheartened and shocked that, in a program that focused on respecting and understanding diversity, what I wanted to do was being dismissed as an impossibility. To accomplish effective fieldnotes, this professor informed me, would require the use of a sighted research assistant.

Scholars in Disability Studies write of the need for researchers with disabilities to write about disability experience (Taylor, 2006). If that was the case, I wondered, then why was my interest in ethnographic study being discredited before it was even written, simply because of my visual disability? I knew that I could not and should not enter the field with a non-disabled research assistant, because it would defeat the purpose of what I wanted to know. I sought comfort in the research and found it in Carspecken's (1996) words on visual perception: "Forget visual perception when searching for a rote metaphor upon which to base a theory of truth. Visual perception is, in fact, a secondary sort of experience rather than a primary one" (p. 17). "It is often less perception than recognizing a situation in a culturally typified way" (p. 19). To not draw on other things beyond visual perception is to neglect the holistic experience of everyday activities. When we foreground visual perception, we background the value of the meaning of our activities, the reasons why we are focusing on something and

noting its properties.

Communication is also a major component of the field. This is not to say that observation is not an essential piece of ethnographic work insomuch as it is not the only piece. Further evidence of what can be accomplished in relation to studying a culture without sight can be found in the work of the blind anthropologist Gwaltney and his praised work on ordinary black culture—*Drylongso* (1980)— and river blindness—*The Thrice Shy: Cultural Accommodation to Blindness and Other Disasters in a Mexican Community* (1970). Gwaltney's work supports that which I hope to accomplish as a researcher with a disability. Culture is not just what can be seen with the eyes.

Before discussing other forms of data collection, I digress here to explain further how I was able to complete observations in the classroom and include some visual detail. In the introduction, I shared that I was born blind. This remained the case until I was 22 years old. At that time I learned that I was a candidate for a cornea transplant. The transplant, I was told, might result in some residual sight. My name was put on a transplant candidate list, and I waited for four months before a "match" was found; in my case, the tissue (the cornea) needed to come from a healthy young person, preferably a child. The procedure was uncomplicated, and only a day after the surgery my doctor removed a patch that covered my eye and I was introduced to real sight for the first time. While it took several months for my vision to stabilize, after it did, I was able to see colors, shapes, print, people and millions of other things for the first time.

It has taken years (and additional transplants because of rejection) to train myself to "see." I had previously known my world through sounds and touch. I had to learn to see people and to identify them by what they looked like and not only by the sounds of their voices. I had to train my eye to read print. I had to learn to put a visual image with what, previously, had been just a concept in my mind. Once I had young children, often we would be learning things together. For example, my oldest daughter was two when I first saw a squirrel. We learned together what that brown furry rodent was.

Now, 12 years later, I am still learning. My visual acuity is measured at less than 20/400 on a good day. I can see facial details if I am within a foot or two. I can read print in12-point font if I hold the source close to my face and only do so for short periods of time. I can read hand-written items only if written in pen and if done so legibly. I have no depth perception and therefore curbs, stairs or even reaching for something is more challenging because I am unable to gauge where things are in space. Lighting, weather, fatigue, stress: all of these things impact what I am able to see.

For this study, then, I spent some time familiarizing myself with the school before the study began so I wouldn't have to use my cane to travel through the halls. I enlarged student work on a photocopier. There were times when I didn't see something that happened so on occasion I would ask a teacher or student to describe what happened. I relied heavily on my hearing. I also found that I could use the camera on my phone or iPad to zoom in on things happening across the

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classroom or to see items on the board.

To return to discussion of my data collection, memoing about my fieldnotes was particularly beneficial. While this type of writing is analytical in nature, Richardson and St.Pierre (2007) shared that writing is a source of data collection as well. Often times while in the field something might trigger a thought that we simply do not want to lose because it may be significant at a later time. Recognizing that connections would manifest themselves in the writing of daily fieldnotes, each day I would memo as well. These memos included a short description of the day's events but also my own commentary and interpretation of what happened. As time progressed, these memos began to reference other similar and dissimilar events from the field. In this way I was able to recognize patterns in the data. Through the use of in-process memos, I was also able to make progress toward identifying and exploring themes (Emerson, Fretz, & Shaw, 1995).

I have thought extensively about my positionality as researcher, both in becoming a part of the setting as well as my own identity as a woman, a former middle school teacher and as an individual with a disability. It is not uncommon for qualitative research studies, including those in education, to be tied to a strong autobiographical interest (Marshall & Rossman, 2006). When I first started thinking about my research, I was very concerned with how I would remove myself from a research problem that was so close to my person. Through my coursework and participation in the research study, I have come to understand

that the researcher need not be distanced from the work; in fact, it is impossible, with the kind of work I hoped to accomplish, to distance myself. A widely held assumption of interpretive work is recognizing that neutrality is not feasible. Fine (1994) argued that all research is, and should be, political and that the researchers who represent themselves as detached only "camouflage their deepest, most privileged interests" (p. 15). Research should "unearth, disrupt and transform existing ideological and/or institutional arrangements" (Fine, p. 17). To acknowledge my positionality, however, requires transparency about my subjectivity within the writing process and disclosure of practices and biases. Researcher identity and subjectivity are implicated from the onset of research to its conclusion. If researchers fail to systematically monitor their role and biases, they "run the risk of presenting a study that has become blatantly autobiographical" (Peshkin, 1988, p. 20).

As previously discussed, my lived experiences as an individual with a disability as well as those of my disabled peers are implicated in this study. Without the violence I experienced in my own schooling as well as the stories others have shared, I would not have begun to develop personal theories related to socialization and identity development of children with disabilities. I began thinking about disability as situated in a social context before I even knew that others felt the same way. I was relieved to learn of Disability Studies and Disability Studies in Education and even more affirmed to find that much of what scholars in these fields have written supported my own theories. I found that,

even though Disability Studies had taken to exploring how social and socio-political structures serve to oppress the disabled, there remained a strong need to explore the lived experiences of students with disabilities in schools (Taylor, 2006). As is the case with my research, then, I entered the field with ideas about what I might observe, but with few certainties. The data, as they say, would make the theories known, and the stories, the definitions and the theories provided by my participants would be important (Glaser & Strauss, 1967). At first, perhaps, I was looking for instances to confirm my own experiences, but after a very short time, I didn't have to look elsewhere on purpose. The things that were happening in this school, I realized, were their own story.

What I didn't fully appreciate upon entering the field were the implications that my own disability would have for this study. What I mean by this is that I believed I would enter the field and witness how students with disabilities were being stigmatized, isolated and marginalized because of their disabilities, but I don't think I ever considered that I would experience some of those same things because I shared the status of being disabled. Smith (1999) wrote, in relation to her work with indigenous people, of the multiple ways of being both insider and outsider simultaneously. While I was, arguably, an insider on disability experience, I was an outsider within the context of this school and an outsider of the non-disabled population of this school. Smith also wrote that "one of the difficult risks insider researchers take is to 'test' their own taken-for-granted views about their community. . . It can unsettle beliefs, values, and relationships" (p.

139). As I student, I had felt the discrimination and stigmatization that can be associated with being labeled Special Education though at the time I didn't have the language to name what I was experiencing. As an adult, I have come to recognize the societal repercussions of being disabled, whether that be in the form of tokenism, charity, invisibility or oppression. For whatever reason, though, I thought that I would somehow be immune to or protected from these things as a researcher.

That was not the case. I "felt" my disability more so than usual. In part it was because every time I witnessed violent things happening to students, I personalized them. When I saw a student sitting alone at the lunch table day after day, I was taken back to the days when that was me all alone at the lunch table. When teachers used deficit language to talk to or about students in the Special Education program, I was left wondering if my own teachers had not talked to me in the same way.

I was surprised by the ways I was treated and talked to throughout the study. Individuals were "amazed" that I had overcome my disability and that I "somehow managed to be successful." I was told I was "lucky" to be where I was today, given that I could have been institutionalized like most kids like me would have been in the 1980s. I was asked to speak on behalf of students and parents with disabilities. I listened to conversations in which disabled individuals were referred to as unable to think a coherent thought, who would be lucky to work at Walmart someday. I was told that most students in this program were not like me

because they wouldn't ever become anything, and while this may have been meant as a compliment to me, it stung like a slap to the cheek. I cried a lot for myself, for every student in my study and for their parents who felt disempowered by the system. This process of observing, of learning from and of writing about individuals with disabilities has been painful. I felt angry and violated that I was witnessing in schools everything that I worried I would but had hoped that I wouldn't see.

Analysis

With the amount of data that I began to gather even early in the research process, analysis needed to begin immediately. In engaging in the analysis process, while many topics intrigued me, I proceeded with my research questions constantly in mind. What does it mean to be a student with a disability in this middle school? What is the school doing/not doing to support students both in their educational goals but also in their development of a positive identity? How do students theorize these experiences? In their own words, what do students say is happening in schools to students with disabilities? Keeping this questions at the forefront served to focus my attention in the face of totes and boxes of data.

As I moved through the analysis process, I was committed to reflexivity, a desire to engage in data collection and data analysis simultaneously. Glaser and Strauss (1967) reminded us that data analysis not only aids in theory development, but also drives further data collection. I found this to be true with

this work. As I began to analyze my work through writing fieldnotes and memoing about what was happening, I uncovered more questions, wondered about different things and identified situations that I needed to explore further, and in a way, to "funnel" my attention. I realized that before I was able to put forth an idea, I needed to validate the frequency of particular trends as well as to explore cases that would stand in contrast. In this way, my data collection went hand-in-hand with analysis; they drove one another.

My analysis process went as follows. I tried to write fieldnotes as soon as possible after completing observations. I transcribed classroom sessions and interviews shortly after they took place. I kept files by grade and subject area of any documents collected. While most of my writing took place during the evenings and weekends, I scheduled two short "write and reflect" periods into my school days, one in the morning while students were at snack break and one in the afternoon when students were engaging in silent reading. I will acknowledge that this did take me away from students for a period of each day; however, I found value in these periods. While these writing breaks didn't allow me to get all of my fieldnotes written, they provided time to get important things down on paper, to transfer jottings into thoughts that I could expand later and to memo about insights. I also found this was time valuable for self-care, particularly as the study went on and I became more unsettled by what I was seeing in the school. The supervisor of maintenance provided me with a key to a dimly lit closet in an out-of-the-way hallway, and while it wasn't comfortable by any means with its

freezing temperature and piles of clutter, it was an escape, a place where I could step away, with my writing and my thoughts.

Only a few weeks into the school year, I began revisiting my fieldnotes by engaging in close readings of the texts. These close readings (Emerson, Fretz, & Shaw, 1995) enabled me to reacquaint myself with my work and begin the process of "thinking with" the data about what was happening (Hammersley & Atkinson, 1995, p. 211). I was looking for patterns, things that surprised me or that reaffirmed commonsensical ideas that I had or that had been formally represented in the literature. I then began to ascribe some initial codes and categories (Bogdan & Biklen, 1992, Miles & Huberman, 1994). Some of the initial coding terms I used included physical barriers, formal curriculum, access, low expectations, isolation, friendship, relationships and frustration. These represented what Blumer referred to as a sensitized concept that lacks specificity but "provides a general reference and guidelines for approaching empirical instances and can provide a focus for further data collection" (Blumer, cited in Hammersley & Atkinson, 1995, p. 212). I also used the following (paraphrased) questions offered by Emerson, Fretz and Shaw (1995) to guide my reading and categorizing efforts: 1) What are people doing? 2) How do they do what they do? What strategies or means do they use to accomplish this? 3) How do members talk about and understand what is going on? 4) What assumptions are being made? 5) What did I see going on here? What did I learn from this entry? (p. 146)

As my time in the field extended from weeks to months, I found these questions particularly fitting for the purpose of this study because they kept my focus on the social processes and everyday happenings of students at this site, highlighting the "whats" as much more important than the "whys" or causes (Becker, 1998; Emerson, Fretz, & Shaw, 1995). What was happening to students? How did they understand their roles? What rules, routines or backgrounded assumptions were at work in the day-to-day goings-on in the school? What was happening in the classroom to reinforce or challenge traditional views of disability? I also believe that these questions brought focus to the often taken-for-granted aspects of everyday life that may seem insignificant but are, in actuality, very important in explaining students' experiences. In this study, the everyday experiences and, in many cases, the mundane, became most informative. I realized that "real life" cannot be understood by simply looking at situational exceptions or dramatically different events. My work instead attempted to stay focused on "the *practical* concerns, conditions, and constraints that actors confront and deal with in their everyday lives and actions" (Emerson, Fretz, & Shaw, 1995, p. 147).

As time unfolded, I observed a shift in my writing, one that focused more on looking for information to confirm or refute developing theories. I also used fieldnotes to inform interview questions. If there were things I wondered about, things that happened to students, teachers or parents, I included questions that asked interview participants to share their own explanations and theories.

My analysis going forward took on a constant comparative analytical approach (Glaser & Strauss, 1967). I began to look for similarities and differences across the data with relation to those early categories. As this process continued over the course of months, through further research and comparison, I found my categories became more clearly defined and that I was able to identify relationships between concepts across multiple spaces and participants. For example, I understood early on that the term "expectation" was used frequently by students and staff. What became important in the analysis process was understanding how this term was used to mean different things in different spaces.

Trustworthiness

While there always seems to be an interest in knowing "the truth" about what has been witnessed in the field, ethnographers acknowledge that truth itself is subjective and situated within a particular context (Kincheloe & McLaren, 2002). To honor this concern, however, and as a means of holding myself accountable for what I wrote, I committed to using systematic measures to promote the meaningfulness of that which I represented in this text. When appropriate, I engaged in member checking. Member checking gave my participants the opportunity to read texts in which they were written about and provide either verbal or written feedback related to how they were represented (Ellis, 2004). After completing vignettes and analyses, I invited individuals to review the texts. One such example was after I had completed the opening

vignette for this dissertation, when I asked Ms. Marshall, the eighth-grade teacher, to read the text. I wanted to be sure I was telling the story in a way that honored not only how I experienced the events on the bus, but how she felt as well.

This process of member checking, however, was complicated by the nature of what I found while collecting data. In certain situations I did not invite participants, particularly staff members, to review what I had written. I feared that if staff members read vignettes that portrayed them in negative ways, they would ask for them to be removed or ask that I change the ways in which they were portrayed. In doing that, however, I felt I would be compromising the data. I felt that, in many instances, the data spoke for itself, and I didn't want to have to alter that to make individuals feel better about themselves.

Presumably, ethnographic work aids in trustworthiness because of the length of time in which a researcher is in the field. LeCompte and Goetz (1982) suggested that, with ethnographic studies, time spent in the field is usually, at minimum, six months and can last as much as several years. This long-term engagement allows for ongoing data analysis and a prolonged opportunity to compare and contrast events over a long period of time. Not only does the extended period of time support validity in the resulting manuscript, but participant observation in the subjects' natural setting allows the researcher to develop a sense of what the everyday lived experiences are really like and minimizes the likelihood that the researcher's presence is affecting participants'

performances. What this implies is that, though I did not engage in member checking with all of my participants, the amount of time I spent in the field, the extensive use of fieldnotes and the care with which I coded and recoded the work, did still allow me to share the story of this setting and these participants in a truthful manner.

To also attend to presenting a text that is trustworthy in nature, I utilized multiple data sources as a means of presenting a holistic account of this setting. In this case, my dependence on the use of sociological observations, interviews and document analysis were advantageous in the crafting of a multifaceted account of the lived experiences of individuals in this study (Duncan, 2005). In what some refer to as triangulation and what Richardson and St.Pierre (2007) refer to as crystallization of data, multiple methods of collecting information about participants' experiences and understandings served as a means of identifying patterns and commonalities that cross-cut more than one source of data (Cresswell & Miller, 2000).

For instance, I found triangulation happening naturally between my fieldnotes, interviews with students and students' writing in the eighth-grade English class. During a two-day period in March, Ms. Marshall and I crafted an activity called "The Line" in which students were asked a series of questions related to things they had experienced in their lives. Some of the prompts were very personal, but also served to reveal very powerful relationships between students. My fieldnotes on these two days spoke to the way that the activity

served to bring the class together. I wrote about the silence in the classroom during the activity and about how, later in the day, I watched a student sit down next to another student and begin a conversation about one of the prompts related to losing a family member to suicide. My perception and notes suggesting that the activity was an important step in this teacher's plan to create community in her classroom were confirmed in many of the students' journal responses after the activity. Of the 55 entries I read on the topic, all but one commented on how the activity made them feel closer to their classmates. Many were surprised to learn things and felt that they had gained a new understanding for what others were going through. Many students hoped that the activity would be repeated again and suggested that the teacher make it a regular weekly event. The teacher, Ms. Marshall, spoke at length about the success of the activity in our interview, saying that she felt it put a face to the many things with which people struggle and that it created a deeper level of respect between students.

Beyond triangulation, audio recordings of classroom discussions and interviews served as confirmation of how things "really" happened within a setting as well. I relied on these heavily when writing dialogue and retelling events from classrooms. In writing, I also attempted to practice the use of "thick description" (Geertz, 1973) to enable readers to experience the setting for themselves, rather than relying on a reductionist portrayal of what might have happened.

Throughout this work, I was constantly mindful of my participants. While I am the one telling this story, it belongs to my participants. I have tried to honor

the students, teachers and parents who shared their lives with me by using their words and their theories of their experiences whenever possible. My fieldnotes, interview recordings and transcripts, classroom recordings, district documents and student work resulted in a complex understanding of disability experience in this school. They were essential pieces in crafting the data chapters that follow.

Chapter 4: "We Have a Unit for That":

The Sixth-Grade Disability Experience

From the time I began my tenure at Cinder City Middle School, I was told that the sixth-grade disability unit was NOT to be missed. The unit and the teachers delivering the instruction were credited with helping in the creation of a sense of belonging and community at the school. This interdisciplinary series of lessons began in early April and wrapped up in early June, with instruction taking place in students' Reading and English classes. While my involvement in the activities and experiences of sixth-grade students for the first three quarters of the school year was limited to occasional classroom observations and interactions with students in the Special Education rooms and the cafeteria, in order to fully experience the work being done in this unit I committed to being present in the sixth-grade English classroom for a minimum of two hours a day, but often spent nearly half of each day observing, co-teaching and engaging in conversations with these students for the last nine weeks of the school year.

I open this chapter with an overview of the sixth-grade Disability Unit that includes a description of the assignments, learning activities and assessments. I provide minimal analysis to allow the reader to focus on how the the individual pieces of the unit fit together. Following the overview, I move into an in-depth examination of the activities and experiences of the students.

Several data sources inform the overview and the vignettes shared in this chapter. I collected all classroom handouts distributed to students during the unit.

I also had access to selected students' writing. Anytime students engaged in classroom discussions, I audio recorded the sessions. Additionally, I used audio recordings of interviews with students and the teacher to support my work. My fieldnotes were an additional source of invaluable data. I frequently took notes even while audio recording class sessions or directly following conversations with students that would occur in the classroom, lunchroom or library. Students delivered speeches as part of the final project for the unit and I was able to record nearly all of these projects. I also engaged in an analysis of available disability literature, both fiction and non-fiction, in the school's Library Media Center. As I share vignettes, I communicate to the reader the data sources used to inform each one. To denote transitions between stories, I use a series of asterisks to cue the reader to shifts in time, place or idea.

Ms. Ana and Her Classroom: An Overview

Ms. Ana, the sixth-grade English teacher, began her tenure with Cinder City School District as a long-term substitute, after which she spent several years teaching fifth-grade Title I. When the position of sixth-grade English became available, she eagerly posted into it. Throughout my time in her classroom and during an interview I conducted with her at the end of the school year, she repeatedly shared how much she loved both the content she taught and the age of the students she served. She strove to make her content meaningful to students and, in addition to highlighting the Disability Unit as a key component of the sixth-grade English curriculum, she also frequently referred to a Bully Unit

taught during October. Both units reflected her passion for promoting and supporting acceptance for all students.

Ms. Ana worked hard to create a space in which all students felt welcome and valued. She often greeted students as they came in the room and during lessons she made connections between content and specific students in the room. Students told me they liked that Ms. Ana seemed "real." When she made mistakes, she took responsibility and poked fun at herself. While Ms. Ana effectively used humor in her classroom, she capitalized on the relationships she built with students over the course of the year. Students seemed to want to engage in her class because they felt respected and valued. Conversations with both current and former students of Ms. Ana's revealed that they recognized her as someone with high expectations. She expected a lot but she also made learning fun and meaningful. One such example of Ms. Ana's relationships with and expectations of students is from an interview with Danielle, a former student of Ms. Ana's. Danielle shared,

> What I loved about Ms. Ana's class is that one minute we could be joking about her latest shopping trip to T.J.Maxx and how she's a "maxxinista," and we could give her a hard time about that but then the next minute when she asked us to get down to work, we knew she meant it. And we worked hard in that class. She was the kind of teacher you didn't want to disappoint because she expected our best.

Ms. Ana designed the Disability Unit based on her own passion for the topic. Prior to her taking the position, there was no such learning experience for sixth graders at this school. She shared that her Special Education minor from her undergraduate degree was useful initially, and she spent most of her time in Special Education placements. These experiences, along with an employment opportunity in which she worked as a personal care attendant for a girl with Cerebral Palsy, pushed her to consider the implications of life with a disability. She wanted to use her position as an educator to help non-disabled students build empathy for and come to understand and respect individuals with disabilities. In creating the unit, Ms. Ana found the internet and both the school and public libraries invaluable in her search for resources that allowed her to share her passion for this topic with students and meet English/Language Arts state standards. She also shared that she read many articles written by individuals "in the field" of disability to be sure that she was "doing things right."

Of the four sections of English that Ms. Ana taught, two were "inclusion" hours. During hour one, Ms. Gilbert, a fifth/sixth grade special educator was present in the classroom. During instructional periods she usually stood at the back of the room but occasionally walked around, using proximity control to stave off disruptive behavior. She whispered reminders to students to "pay attention," "open your notebooks" or "stop talking."

The desks in Ms. Ana's classroom were organized into pods of four that allowed students to face one another during work time. Ms. Ana's work station

that included a desk and computer were at the back of the room. Her room was equipped with a LCD projector that was used frequently to project computer images or videos on the screen at the front of the room. When Ms. Ana was teaching, students were expected to face forward. When students worked independently, Ms. Gilbert traveled between groups, providing support to her students. During fourth hour, Ms. Ana's other hour in which students with disabilities were included, Ms. Hanson, a Special Education aide, provided support primarily for one student diagnosed with high-functioning Autism. She typically sat next to or very near the student and assisted by reading to and writing for the student and giving verbal reminders to stay on task.

The Disability Unit

Ms. Ana opened the unit with a series of readings intended to expose students to terminology and disability concepts that she felt were important to build a common understanding. Students read about "person-first" language that demands that language choice privilege the person and not the disability. Instead of saying "a blind person," students were taught to say "a person who is blind" or instead of "Autistic child" they would instead say "child with Autism." Students also read a brief history of disability during which they learned that students were not always educated in schools but may have been institutionalized or have attended schools and spent their entire days in special classrooms. These readings were mainly read during class, and Ms. Ana led a discussion to check for students' understanding. Students then watched short clips from prime-time

news programs that highlighted well-known personalities who had experienced disability. Film clips included Christopher Reeve's story of his horseback riding incident and Bethany Hamilton's perseverance as a surfer after a shark attack that took her arm. They viewed an interview with motivational speaker and teacher Brad Cohen, who shared his experiences with severe Tourette's Syndrome. Students also watched a full-length film on the life of Temple Grandin, a woman who has helped the world better understand the experiences of Autism.

Another component of the Disability Unit asked students to create an artifact in support of the "Spread the Word to End the Word Campaign" that takes place each April. The premise of this national project, sponsored by the Special Olympics, Best Buddies and several other advocacy groups, is to educate individuals to stop using the "r-word" (retard) which has been used to denigrate individuals with intellectual disabilities and non-disabled individuals as well. The campaign encourages people to "stop saying the R-word as a starting point toward creating more accepting attitudes and communities for all people. Language affects attitudes and attitudes affect actions" (r-word.org). Ms. Ana required that students make either a public service announcement (PSA), poster or t-shirt in honor of the campaign. To facilitate the brainstorming process, she shared examples of videos posted on Youtube from students around the United States, as well as videos collected from her former students. Students worked alone or in groups outside of class to design their projects and prepared to share them on April 27. After presenting their creations, students were required to log

on to www.r-word.org to take the pledge to end their own use of the r-word.

Literature was also an important part of the unit. As part of Reading class, each student self-selected a realistic fiction novel in which a main character had a disability. Ms. Ana gathered several dozen texts from which students could choose, with stories representing numerous disabilities and reading levels. Titles included *Al Capone Does my Shirts, My Name is Brain Brain,Things Unseen, Close to Famous, Wonderstruck, Rules* and *Freak the Mighty*. Students read books, completed packets and met in literature circles to discuss the texts. Additionally, Ms. Ana selected a book to read aloud entitled, *Out of my Mind* by Sharon Draper (2012). This text shared the story of Melody, a teenage girl living with Cerebral Palsy, and her struggle to demand respect from the adults and classmates in her life who were unable to recognize her brilliant abilities. Ms. Ana read a chapter to students when class time permitted.

In an attempt to help students understand what a disability might feel like, Ms. Ana included disability simulations throughout the unit. For one class period, students experienced what it might be like to have various levels of hearing loss. Through use of an audio cassette that attempted to emulate mild, moderate or profound hearing loss, students took a spelling test, listened to a short reading and answered questions that tested their comprehension. On another day, students spent time completing tasks in wheelchairs to know the challenges that one might face without use of the lower extremities. In still another experience, students, one blindfolded and one sighted, were paired together and asked to

travel through the hallways of the middle school and the outdoor grounds.

Ms. Ana also invited guest speakers to address her students. While each year the guest speakers were different, this year's speakers included a doctor who works with individuals who have experienced Traumatic Brain Injuries (TBIs) or other neurological disorders, a woman who trains service dogs and me. The woman who trains service dogs brought in the dog she was currently training and explained the purpose of a service dog and the appropriate ways for the general public to engage with an animal at work. The doctor shared general information on how our brains work, discussed a variety of neurological conditions including strokes and epilepsy (among others) and set up stations at which students were asked to complete tasks while having their dexterity and fine motor abilities impaired by weights and vibrators.

I addressed the class at the beginning of the second week of the unit. By this time, students had been introduced to the enduring concepts that the instructor had selected to explore through film and texts. I was deliberate in sharing my message that my life with blindness was a single story and that everyone with a visual impairment, and everyone with a disability for that matter, experienced the world differently. I focused on the things I had accomplished while including stories about the challenges I had encountered and continue to face in accessing educational opportunities, transportation, employment and entertainment. Very little of my message included talk about why my life was difficult physically because of my limited sight. I tried to share the message that

attitudinal and societal barriers were often the most difficult to navigate. I did also share many of the technologies that I used in the past or currently that enable me to more fully participate in life's activities. My presentation did not include a simulation component because I find these activities to be unrealistic and counterproductive in helping students view individuals with disabilities as capable persons.

The largest component of the disability unit was a research project for which students self-selected a disability that they wished to explore in depth, gathered research, wrote and delivered a speech with a required visual aid. The work for this portion of the unit alone stretched for more than six weeks and included at least 15 days spent in the middle school's library media center. While there, students used books and computers to gather research that they used to respond to prewritten prompts in a packet prepared by the teacher. Once students completed their packets, they used that information to prepare a written speech. The instructor led mini-lessons on various topics, including how to write strong introductions that used a story, surprising fact or other hook to capture the listener's attention. Students then were advised on preparing a speech body that was organized and used transition phrases to support flow. Finally, students were taught about writing conclusions that brought together all of the information from the speech. Other mini-lessons focused on preparing effective visual aids and the appropriate use of notecards. The speeches were delivered during the last two weeks of the unit.

The unit's culminating event took the form of a field trip to the local university's ropes course. For an entire day, students were encouraged to step beyond their comfort zone and challenge themselves on the various obstacles on the course. The "take away" message to students was supposed to be that we all might encounter things that are challenging, but with courage, we can all accomplish great things. The day began with some team-building activities facilitated by trained facilitators from the university. Parents and several staff members also shared in the day. To maximize the time at the course, the sixth-grade class was divided into two groups based on their homeroom assignments, each attending the course on a different day. It is worth noting here that regardless of homeroom assignment, all students with disabilities attended the ropes course on the same day. School staff explained that this was done for ease of scheduling support staff.

Having provided an overview of the unit and all its components, I now move into my exploration and analysis of what unfolded in Ms. Ana's room during the Disability Unit.

Analysis of the Content

Kumashiro's work on ways in which we use education to respond to the "Other" can be helpful in understanding what Ms. Ana was attempting to do with her disability unit. Kumashiro (2002) defines the term "Other" as

> those groups that are traditionally marginalized, denigrated, or
>
> violated in society, including students of color, students from under-

or unemployed families, students who are female or male but not
stereotypically "masculine," and students who are or are perceived
to be queer. (p. 32)

Kumashiro believes this same "Othering" extends to other traditionally marginalized groups, including students with disabilities. In his work, he analyzed what he saw as four ways schools can conceptualize and respond to oppression: education for the Other, education about the Other, education that is critical of privileging and Othering, and education that changes students and society.

The sixth-grade Disability Unit used a variety of methods for exploring disability, but the overarching approach to instruction drew on what Kumashiro referred to as "Education about the Other." In thinking specifically about disability experience, this unit attempted to educate students with and without disabilities about the Other and in this case, the "Other" was those with disabilities.

The unit seemed to suggest that thinking about and respecting the "Other" was something that could be accomplished in nine weeks. I felt this personally on my first visit to the sixth-grade English classroom. Ms. Ana had invited me to begin participating in her course on the first day of fourth quarter. On that day, I waited outside of her room until it was time to enter for first hour. She met me at the door and said, "Oh, we are not ready for you yet." She explained that the unit preceding the disability unit took longer than expected, and the kids would be watching *Honey, I Shrunk the Kids* instead of beginning their disability work. I was invited to come back in three days.

Even when efforts are made to work against oppression, Kumashiro (2002) explained that it is necessary to consider two types of oppressive knowledge. The first type of knowledge focuses on how society defines normal and normativity. Within this unit, the exploration of disability was often dependent on contrasting "their" experiences with what an able-bodied person might experience. Questions to exemplify this included, "how might your schooling experience be different if you were disabled? What wouldn't you be able to do if you were in a wheelchair? What challenges did Bethany Hamilton face after her accident that she didn't face before?" While the intent of the unit was to recognize difference as acceptable and valued, the way in which it was done focused on ways in which those with disabilities are not "normal" in their physical, emotional or cognitive abilities.

The second kind of oppressive knowledge that Kumashiro (2002) discussed draws on stereotypes and myths about the Other that further misunderstandings about marginalized populations. Students bring their own presuppositions and experiences to this unit that have been formed by past experiences in school and from informal exposure to disability outside of school. Films, books and media coverage often present a skewed picture of disability, rarely depicting individuals as in control of their situations.

> Disabled people are depicted as pained by their fate or, if happy, it
> is through personal triumph over their adversity; adversity that is
> not depicted as lack of opportunity, discrimination,

institutionalization and ostracism; it is the personal burden of their

own body or means of functioning. (Linton, 1998, p. 25)

What results is only development of a partial understanding of a particular

marginalized group.

In this unit, the teacher selected material that she felt provided valuable

information about the "Other," but in doing so, she exposed students to a limited

perspective of disability, one that heavily favored a medicalized perspective. Very

little of what was shared challenged the misrepresentation of disability. While

they did read books, most were not written by authors who were, themselves,

disabled. I quantify this specifically later in the chapter. Had students been given

the opportunity to read firsthand accounts of disability written by disabled

authors, they may have been able to realize disability as something other than

deficit. Additionally, this would have also allowed students to realize that

individuals with disabilities can, and do, contribute in meaningful ways to the

world through their writing. Additionally, the teacher's requirements for speech

topics focused heavily on defining medical conditions and exploring treatments

that may have had the implicit consequence of confirming disability as a strictly

individual, medical problem. In attempting to simulate various disabilities with her

students, she reaffirmed particular stereotypes and, as we see later, may have

even pushed students further into equating disability with hardship and loss. I

found evidence of this in interviews with eighth-grade students who had

completed the disability unit two years earlier. One female student shared,

The disability unit helped me because I went through that class

with Sophie and Sarah. We learned what it was like for people like

them, you know, kids with CP [Cerebral Palsy] and how they can't

use their hands well and some can't walk or talk. It is hard to be

like them. It made me realize how lucky I was. But now I'm more

understanding of that and I, like, help when I can.

Thinking about the critical work that Ms. Ana said she was attempting to

do, her intentions reminded me of the words of Giroux and Simon (1988) with

regard to the purpose of critical pedagogy:

Pedagogy refers to a deliberate attempt to influence how and what

knowledge and identities are produced within and among particular

sets of social relations. It can be understood as a practice through

which people are incited to acquire a particular "moral character." As

both a political and practical activity, it attempts to influence the

occurrence and qualities of experiences. When one practices

pedagogy, one acts with the intent of creating experiences that will

organize and disorganize a variety of understandings of our natural

and social world. (p. 12)

While I do believe that Ms. Ana intended to influence the knowledge base of

her students in a positive way by helping them accept individuals with

disabilities and seeing them as capable, valuable members of the school

community and society in general, the degree to which this was

accomplished is an ongoing focus as this chapter continues.

The Speech

When the instructional period for the speech portion of the unit began, each student received a 15-page pink packet entitled "Understanding Our Differences." The cover page depicted a symbol of an person in a wheelchair. An opportunity to depict individuals with disabilities interacting with one another, engaged in everyday activities, was lost. The first page provided a list of 17 possible research topics ranging from Blindness and Attention Deficit Hyperactive Disorder to Paraplegia and Epilepsy. Ms. Ana allowed students to self-select their research topics. She encouraged students to choose something that interested them because they would be spending a long time completing research and working on the speech. Also included in the packet were a rubric, pages to track sources and information on accessing online information databases. The final pages of the packet were devoted to guided note-taking. Students were expected to gather information on the following questions and prompts:

-Describe the disability.

-What can cause this condition?

-Describe the symptoms and characteristics of the condition.

-Discuss the varying degrees or types of the condition.

-How and when is the disability detected?

-What are the medical considerations for people with this condition?

-What adaptations need to be made for people living with this condition (home, school, community)?

-What can a person with this disability expect in terms of their education and employment?

-How did the unit change your thinking about people who are differently abled?

Looking at these guiding prompts, it is difficult to ignore the emphasis placed on exploring disability as a medical condition. After students are asked to define disability, and by define, the expectation was to provide a medical definition of the impairment, students were asked for causes, symptoms and characteristics of "the condition" as well as detection and medical methods for treatment. These six prompts focused on the physical, emotional or behavioral manifestations of an impairment, the ways in which individuals deviate from what is considered normal ability. The emphasis on this information supports the historically pervasive medical model of disability that does not distinguish between impairment as a medical condition and disability as a socially constructed experience (Abberley, 1987; Oliver, 1996). These questions suggested to students that what is essential to know about disability is that it is a medical phenomena and one situated in the individual (Linton, 1998). Additionally, disability is something for which we must seek treatments.

Two prompts required students to consider accommodations that might need to be made to ensure access for individuals with disabilities to their homes, schools or work environments and to consider implications for education and

employment. These prompts did require students to consider disability within a larger societal context by asking them to think about ways in which people with disabilities may not have the same access as the non-disabled. Students were encouraged to include examples of how the built environment, technology or teaching strategies might need to be changed to create an inclusive environment for individuals with disabilities.

Students' responses to these leading questions, as a whole, represented an overly optimistic and surface-level understanding of access. I read and heard many student responses as they prepared and delivered their speeches and have included several of their answers here. When multiple students shared a similar answer, I have indicated this with a number following the statement.

-"If we build ramps for people in wheelchairs, they can get into buildings and have normal lives." (4)

-"We need to make sure that doors have the button you can push so that they open automatically so people in wheelchairs can get in a building."

-"We have elevators for people to use who can't use stairs." (5)

-"People who can't see can learn to read Braille, and then they will be able to read like everyone else." (2)

-"Blind people can get a talking computer so that it can read them things that they can't see." (2)

-"We can make sure that people who can't hear learn how to use sign language so they can talk to other people." (3)

-"People who can't hear can get hearing aides to help them hear like the rest of us." (2)

-"People can get a service dog that will help them do things safely." (4)

-"We can label things like room numbers and elevator buttons in Braille."

-"Students with disabilities can get extra help in school from Special Ed teachers." (8)

-"There isn't really anything that needs to be done with buildings or technology to help people with this type of disability." (7)

In reading their ideas on access, I was struck by how students seemed to believe access could be achieved easily. Building ramps, installing automatic doors, creating accessible signage: these things require a great deal of financial investment. Teaching an individual how to read Braille or how to use sign language is only helpful if Braille texts are available or if other individuals also know sign language. Hearing aides are often not seen as a necessary medical expense and therefore are frequently not covered by insurance, making them difficult for families to afford. Accessibility software for students with visual impairments or learning disabilities is also very expensive and requires training on the part of both the students and the teacher. So, while students were able to identify some of the ways in which we might make spaces and experiences more accessible, they may not have fully realized the systemic circumstances that make achieving universal accessibility difficult to accomplish.

Students also failed to identify the attitudinal barriers that make full

inclusion challenging. These are manifested in discrimination in the workplace or in places of education. For example, at CCMS, during the time that this unit was going on, three of the eighth-grade teachers were unwilling to use school funds to pay for an accessible coach bus for the end of the year field trip. They expected the parents of two students who used wheelchairs to drive their children because they didn't see it as their responsibility. While Ms. Ana could have explored these challenges with students or included an additional prompt asking students to think about why inclusion of individuals with disabilities is so challenging, this was not taken up.

The rubric outlined specific elements on which students' speeches would be evaluated. A close reading of this document and its juxtaposition with the prompts used for guided note-taking raises concerns about the emphasis placed on the medicalization of disability. Within the body of the speech, students were expected to discuss causes, detection, symptoms and characteristics as well as varying degrees of the condition. Students were to spend two-thirds of the body, accounting for 20 out of a possible 30 points, discussing the deficits associated with disabilities. The students did have an opportunity to discuss the social implications of disability when they were required to speak to what daily life might be like for people with disabilities, but this accounted for only five points in the overall grade and, at best, asked students to make predictions based on the impartial knowledge they had gained about one particular impairment. These expectations communicated an emphasis on "treating the condition and the

person with the condition rather than 'treating' the social processes and policies that constrict disabled people's lives" (Linton, 1998, p. 11).

To bring the speech to a close, students were *required* to make a statement about how this unit changed their way of thinking about people who are "differently abled." It was not an optional statement. Making this a mandatory point of assessment implied that students *must* have had some sort of change in the way in which they viewed individuals with disabilities to receive the five points. Demanding a statement like this, while possibly of value for students if indeed they had come to some new understanding about disability, could and did prompt students to say things they did not truly believe, simply because the objective being communicated was that they should have changed their thinking. Additionally, this requirement perpetuated a dichotomy between the "normal" and the disabled in that it was what "we" (the "normal") were going to do or how "we" now feel about "them."

Figure 1: Evaluation Criteria for Understanding Our Differences Oral Report

Was the report presented on time?	0 5

Introduction:
      Used an interesting attention getter   0 1 2 3 4 5
      Introduced disability   0 1 2 3 4 5
      Included definition/description of disability   0 1 2 3 4 5

Body:
      Described what causes the disability   0 1 2 3 4 5
      Told how and when this disability is detected   0 1 2 3 4 5
      Explained symptoms and characteristics of condition   0 1 2 3 4 5
      Discussed the varying degrees of this disability   0 1 2 3 4 5
      Told about daily life for people with this condition   0 1 2 3 4 5
      Utilized people first language   0 1 2 3 4 5

Conclusion
      Stated how this unit changed your way of thinking

about people who are "differently abled"   0 1 2 3 4 5
An interesting closing was used   0 1 2 3 4 5
<u>Visual aid:</u>
    Time and effort were evident in creating poster   0 1 2 3 4 5
    Visual aid was used during speech   0 1 2 3 4 5
<u>Presentation style:</u>
    Information was well organized   0 1 2 3 4 5
    Note card did not distract from speech   0 1 2 3 4 5
    Speaker's voice was easy to hear   0 1 2 3 4 5
    Rate of speaking was neither too fast nor too slow   0 1 2 3 4 5
    Speaker had good posture   0 1 2 3 4 5
    Speech was at least 3 minutes long   0 1 2 3 4 5 6 7 8 9 10

While this requirement was done with the best of intentions, the long-term and even short-term effectiveness of the statement was questionable. While this project was one of the defining units of the sixth-grade year, eighth-grade students viewed it as a negative learning experience. While conducting focus groups with eighth-grade students, I asked them to share their perceptions on the effectiveness of the unit. During one group interview, Danielle, an eighth-grade student, shared:

> I think the idea behind the unit is good but I think everyone just
> kind of wants to get the speech over with and to get a good grade
> so they say what they know they are supposed to say. Then,
> when the unit is over, or even when the class period is over, kids
> walk out in the hallways and things go back to normal. They sit by
> their friends in the lunchroom and the disabled kids still sit alone
> even though in speeches people say things like, "I'm going to
> invite them to sit by me at lunch or hang out with me and my

friends." And maybe we understand a little bit more about different

kinds of disabilities, it doesn't really change the way we are.

She went on to say that many students looked back on the unit two years later

and thought of it as the worst part of sixth-grade because of the work required

during the unit. Several students nodded in agreement as Danielle shared her

perceptions. While some students seemed able to recognize that it was the act of

giving the speech that made the unit so awful, others associated that experience

of giving the speech with the content and viewed it all negatively. This came out

clearly when, as part of an English assignment for an eighth-grade time capsule

project, students were asked to complete a poem about the best and worst parts

of each year in school. The Disability Unit appeared as a negative memory in

90% of students' poems. Only two students listed it as a positive memory from

sixth grade.

And how was this unit to make students who already identify as disabled

feel? Were they, too, supposed to change the way they thought about disability?

Eric, an eighth-grade male student who received services in the school's Special

Education program shared a different reflection on how his thinking was changed

by the unit. He said:

It is funny to me that we had to talk about how we were changed

by this unit. I have a disability. The unit didn't really change my

thinking at all. I already believe that people with disabilities can do

a lot of things. They don't always get to because of the way life is,

but it isn't like I could say that because then I wouldn't have

gotten a good grade so I said the same kind of things that

everyone else did just to get the grade.

This student communicated something that I observed happening in several speeches delivered by students with disabilities. Repeatedly, their closing statements mirrored those of their non-disabled peers, with comments like, "I now believe that people with disabilities are just like us" and "I will try to spend more time with people with disabilities." By using the term "us," the students with disabilities seemed to align themselves with their non-disabled peers. There seemed to be an attempt on the part of the students with disabilities to align themselves with their non-disabled peers and establish a sense of "us-ness." In an attempt to get the points on the rubric, they had to work to create a sense of social unity and commonality between their experiences and those of their peers.

Sarah, another eighth-grade student who identified as having a disability, had a slightly different response, saying that:

I actually found the disability unit to be really embarrassing because I

do not like to talk about my disability. Even though I know people know

because they can see it, I still felt weird. I felt like I had to talk about my

disability [CP] too because I just felt like . . . it was . . . expected. That if

I didn't, it would be like I was pretending it wasn't there. I mean, most

of the kids I had spent my whole life with already, and this seemed to

be making a big deal out of something that was just part of who I was.

Sarah's experience mirrored one that I had when I was in eighth grade. As part of an assignment in our science class, we had to write a research paper on a medical condition. When I told my teacher I thought I'd write mine about strokes, he was shocked and said he assumed I would write it about my own condition (glaucoma). And so, even though I didn't want to, I did it because it was expected. It was almost as if it was incomprehensible to be able to think about conditions other than the one with which I was diagnosed.

Because Sarah's thinking reminded me so much of my own, I asked her to say more about her feelings about being disabled. She shared that she felt like her disability was just part of who she was and that having to make a speech about it was making it the most important thing about herself, something she'd tried to work against for a long time. While her disability was very visible in the way she walked and used a walker or wheelchair, she still made attempts to "pass" and her experience with the disability unit made "passing" impossible in her opinion.

To assist students in the act of information gathering, Ms. Ana and the middle school librarians had pulled all of the books in the middle school library with a disability focus and organized them on tables throughout the Library Media Center. Each table became a specific disability. Tables included Epilepsy, Traumatic Brain Injuries, Learning Disabilities, Blindness/Hearing Impairments, Autism, Dwarfism and Spinal Cord Injuries, Tourette's Syndrome and Cerebral Palsy. When students spent time in the library conducting research, they filed in,

took a seat at the table matching their topic or logged on to the computer to conduct online searches. While the practice of dividing books among tables based on disability category may have been a common-sense organizational practice, it also also reinforced the labels associated with disabilities and reaffirmed what labeling theory suggests about the label as *the* defining characteristic of a particular group of people.

As part of my analysis process, I examined all of the texts that students were encouraged to use to gain a deeper understanding of their selected topic. What I found was that of the more than 250 books made available to students on the day that I conducted this text analysis, 96% were written by doctors or medical professionals about a particular condition. Books written by individuals with actual impairments numbered two. The number of books written by a family member or close relative of someone with a particular disability totaled six. Given the time and effort that went into pulling books from library shelves and ordering additional resources from the public library so that students would have a wide selection of materials to explore, it is concerning to note whose voice was privileged in the texts, namely, that of the medical professional. As a result, the texts on which students were left to rely provided a limited view of disability. Very few of the available texts prompted an exploration of social or personal experiences of disability.

* * *

The month of May was ushered into Ms. Ana's room with a flurry of activity

as students worked to transform their notes into a well-organized speech. Class time was devoted to writing a catchy introduction, a coherent body and a conclusion for the speech. Most days began with a mini-lesson that moved students through the process of writing, followed by work time. Students worked independently, and the Special Education teacher and I worked with students while Ms. Ana met with students at her desk, checking off their work and providing feedback. As with all class periods, I audio recorded the entirety of the class period using an iPad and my computer to pick up conversations in multiple areas of the classroom.

One sunny May morning during first hour, I was walking around the room, checking in with students and reading students' introductions. I noticed Alex, a student with a learning disability, sitting at his desk with a blank piece of paper in front of him. He clicked his pencil absently and watched the peers in his pod chatting as they worked on their speeches. As I watched from across the room, Kim, the Special Education teacher who supported Ms. Ana's first-hour class, told him that he couldn't just sit there; he needed to get to work. As she moved on to another student, I made my way to his side and knelt down next to him.

"How's your speech coming?" I asked.

He shrugged, "I don't know what to write."

I asked if I could help, and he reluctantly agreed. I asked what his topic was, and he told me that it was learning disabilities, specifically dyslexia. I reviewed some of the ways in which we could catch our reader's attention and

asked which one he thought would work the best. He shrugged.

"Why did you choose this topic? Let's start there." I suggested.

"Someone told me I had to pick this," he admitted.

"Really? Why?"

One of the other students sitting at the table who'd been listening to our conversation interjected, "Ms. Gilbert (the fifth/sixth grade special educator) told us we all had to do the same topic."

"How come?" I asked. I suspected I already knew the answer but wanted to hear it from the students.

"Well, because we all have it so she thought we'd want to do it. Plus she said it would be good for us to know about it," said Matt, another of the sixth graders served in the Special Education program.

"Did you want to do this topic?" I questioned him further.

"I don't mind. I know some things about dyslexia already so I am going to talk about it in my speech."

I turned my attention back to Alex. "But you didn't want to do this?"

"No! I don't want to talk about it in front of other people."

In this situation, it was brought to my attention that the Special Education teacher encouraged several of the students to do speeches related to the impairment with which they had been diagnosed. Further questioning of the students revealed that they theorized this was done because the teachers thought they'd want to talk about their disabilities, because it would give them the

opportunity to explain things to their peers and help others without disabilities understand their impairments better. One student was so distraught about being forced to talk about his experience with Autism that his mother contacted the teacher. The mom was furious that her son was being put on the spot. While the teacher assured the parent that students were able to pick whatever topic they wanted, she later confessed to me that sometimes students were coached into a topic by Special Education staff.

Ms. Ana and a former sixth-grade teacher shared that they believed students were encouraged to research their own impairments because it was "easier" for the special educator supporting the students. The teacher could work with all of the students with learning disabilities at one time when searching for information. What typically resulted from this support was what both teachers referred to as "cookie-cutter speeches" because they all sounded remarkably similar and used the same sources. While I would have liked to question the special educator involved in supporting these students to explore her understanding, she declined to participate in an interview.

Regardless of the reasoning underpinning the special educator's decision to strongly encourage students to research their own disabilities, several points are clear. First, many students felt they lacked the agency to make their own choices about research topics. While some students wanted to research their own disabilities and felt comfortable discussing their experiences with others, this was not the case for all students. However, their preference for sharing was not

considered by the educator. The act of being the primary decision-maker, an opportunity extended to all of their non-disabled peers, was not fully extended to them. Moore (2006) responded to this need to honor students' perceptions and to grant them decision making opportunities: "Students' perceptions contain valuable information that should be used in determining what works in a classroom. . . what is surprising is that their voices are too often omitted" (pp. 24-25).

In Alex's case, I asked if he had shared with Ms. Gilbert that he didn't want to do this topic. He explained that he didn't tell her because he didn't think it would have changed the outcome. Through further questioning, I learned that he felt like his opinion often didn't matter to his teachers and that decisions were made for him because adults just assumed that they knew what he wanted. He didn't feel "brave enough or smart enough" to tell people how he really felt. He seemed to feel disempowered by the adults in his life.

Unfortunately, Alex's experiences, as well as those of his disabled peers, were not unique. Professionals often position themselves as experts on those with disabilities, a tendency that is steeped in the medical model which posits that it is the doctors, therapists and other experts who know what is best for individuals with physical, emotional or learning impairments and that if one is disabled, that this also must impair one's decision-making ability. This same understanding seems to extend to one's right to disclose and discuss personal information about themselves or their impairments. One's private self is made

public in very exploitative ways.

A second point to consider in this situation is that supporting the students became an act of convenience rather than the practice of recognizing students as individuals. It was viewed as "easier" to have all students with learning disabilities research learning disabilities. Eleven students doing one topic was preferable to 11 students potentially writing on 11 different topics. In this situation, what was best for the teacher, and not the students, drove decision-making.

This situation was particularly challenging for students with learning disabilities. It seemed as though they felt that in doing their speeches about learning disabilities, their "invisible" disabilities would become "visible" because classmates would know they had them. Students' comfort levels with their disabilities were varied in this sixth-grade classroom. Some students were very public and open about their different learning needs. Those who weren't "out" to their classmates would be after giving their speeches. A 20-year longitudinal study of students with learning disabilities conducted by Higgins, Raskind, Goldberg and Herman (2002) found that individuals with learning disabilities struggled with the stigma and negative attitudes associated with being learning disabled and that the actions of both regular and special educators had a significant role in how students' attitudes and perceptions about themselves and their abilities developed both as children and adults. Whether these sixth-grade students recognized it or not, the attention they were paid by the special

educators supporting them during this and other classes had already "outed" them. However, they seemed to still feel that if they hadn't come right out and said it to their classmates, they still weren't officially recognized as disabled, that they were somehow still "passing" (Linton, 1998). But once they said it out loud, in a speech, they couldn't "un"identify as disabled going forward.

The Field Trip

On the day of the sixth-grade ropes course field trip, I was about to board the bus with the students but one of the Special Education teachers, Mrs. Melinda Matthews, invited me to ride with her. "This way we can talk," she offered. Her comment alerted me that there must be something she wanted to discuss, and so I agreed to keep her company on the 15-minute drive. I audio recorded the conversation on my phone for later transcription. I had barely gotten my seatbelt buckled when she handed me a few sheets of paper on which were listed the groups for the day's activities.

"Notice anything?" she asked.

I scanned the list, noting which students were in which groups and which teachers were assigned as supervisors. After reading through all of the groups, I returned to the names of the students in Group A. "Did you do this?"

"No!! Can you believe it? After a unit completely devoted to including students with disabilities and then we get this!" Her anger radiated. Nearly 60 students had been divided into five groups. Each group was assigned a letter and one or two adults. While the groups were nearly equal in number and

gender, all of the students with disabilities had been placed in one group and would be chaperoned by the Special Education teachers and me.

"I can't believe it! I would have thought that this would have been the perfect opportunity to practice the inclusion that this unit tried to show students and then the teachers put together something like this? How sad!!!"

Inside I was boiling. This, for me, was personal. This grouping betrayed everything that the teachers had preached for months; this was exactly what they said was NOT happening in their school, but here it was, in print, a teacher-created document isolating students with disabilities.

"Did you say anything?"

"I tried," Mel admitted, "but the response from the teachers was, 'this is just easier.'"

In the face of blatant exclusion, the day was nonetheless full of triumphs and celebration for the group with which I was placed. The ropes course experience was designed to challenge students to take risks and that was exactly what happened for the nine boys and two girls in my group. For the first challenge, students were buckled into a harness and lifted 30 feet into the air by the team of classmates on the ground. The suspended student then had to pull a cord before being released, head first, to swing over a ledge and the river below. Many of the students were frightened, but the supporting words of encouragement their classmates provided were often the extra push needed to convince students that they could let go and take the risk. Of the 11 students, ten

completed the task. Other tasks included climbing a rope wall and walking across a high rope. Students returned to school feeling empowered and proud of their individual victories.

In an attempt to understand the reasoning behind the segregated grouping, I questioned Ms. Ana, the sixth-grade team leader, a few days after the trip, during our prearranged interview. I explained that, given the emphasis placed on inclusion of all students, regardless of ability level, I was surprised by how students were grouped at the ropes course. She let out a defeated sigh before providing the following explanation:

> That should have never happened. This was Ms. Peters's first year in sixth grade and so when I gave her the task of making the groups, I told her that Ms. Gilbert and Mrs. Matthews should each have a group. She interpreted that as meaning that they should be with their own kids. I don't think it was good that they were all together because none of them required any special harnesses or needed any special physical needs. But seriously? The two of them had 11 kids between the two of them, and they were whining about it. When they talked to me about the trip though, all I heard was, "we had such a great day, the kids were awesome!" It is ironic, though, that they pointed out our mistake ,but they group kids by ability in classes all the time. Double standard.

What was most troubling about the day's experiences, in addition to the failure to fully include students with disabilities with non-disabled peers, was a

missed opportunity. What could have been a powerful experience for non-disabled students to see their disabled peers taking risks and successfully engaging in physically challenging tasks didn't happen. If we, as a society, fail to include disabled individuals in recreational and leisure activities, they will remain invisible and their full potentials will never be realized (Barnes & Mercer, 2003). The tasks that students engaged in on this particular day were frightening for almost all students. Students without disabilities engaged in their own groups and because of a failure to include disabled peers, it was almost as if they were not participating at all, furthering supporting the perception that they were not able to complete this activity and not able to have fun.

Inclusion can be powerful for students with and without disabilities, and in this case, regardless of whether the segregated groups were created because of a misunderstanding or intentionally, both groups suffered. As part of an interview study conducted by Keefe (2006), one teacher attempted to explain why situations of exclusion occur for students:

> Often perceived barriers are not real barriers at all. They are
>
> contrived by professionals. In an attempt to act in the best interest
>
> of the kids with disabilities, we inadvertently exclude them from
>
> having normal experiences. We limit independence and
>
> opportunities for relationships to occur by putting up obstacles that
>
> are manufactured from our own fears. (p. 73)

There are times when, in an attempt to protect children from perceived dangers,

we only perpetuate exclusion. While the focus of this chapter is on the sixth-grade Disability Unit specifically, an almost identical experience happened during an eighth-grade trip to a local university for a STEM (science, technology, engineering, and math) career exploration event. All of the students with disability were put in one group. This time, however, the staff member who created the groups admitted doing it deliberately. It was "easier that way." While on the trip, students in this group were only able to visit three stations instead of four and the station missed was considered by the other students to be the "coolest." Students got to visit the nursing building in which they saw mannequins operated by computers that controlled their breathing, heart rate and other functions. One mannequin could even go through the stages of child birth. This station, however, was "too much" (intellectually) for the students with disabilities and "too far" across campus for students to quickly make the trip. Students in this group were extremely disappointed. One eighth-grade male student with a disability shared:

> This sucks because, geez, just because we had two kids with
>
> wheelchairs in our group doesn't mean we should miss out on the
>
> cool stuff. This happens all the time with field trips. A lot of times
>
> we get put together even if we have friends who aren't disabled.
>
> The teachers don't even give us a chance to be in a regular group
>
> with regular classmates.

So, while I cannot say for certain why the sixth-grade students with disabilities were grouped together for the ropes course trip, it was not an isolated event,

and, after several years of being put in segregated groups, the students knew it and didn't like it at all.

Simulations

"Would you mind going last so we don't lose anyone?" Ms. Ana asked over the roar of chattering voices. I waved to her indicating that I was fine, and she opened the classroom door and began leading students out into the hallway. The excitement and anxiety was palpable, for the class had just been broken into 12 pairs, each pair consisting of a student wearing a blindfold and carrying a stick (playing the role of a blind person) and the other acting as their sighted guide. I had provided a very short orientation on how to appropriately use a cane when blindfolded. Ms. Ana reminded them that the experience would be more powerful if they didn't cheat, because in real life, you don't get that chance. Meanwhile, the sighted guides had been provided with instructions on how to appropriately guide someone who could not see. The room was abuzz with nervous giggles from the sighted and unsighted alike. To capture the students' comments, I carried my iPhone with me to record the experience. Nervous comments dominated every conversation. "Oh my gosh, I'm going to fall!!!" "I'm so scared!!" "I think I'm just going to stay in the room." One student barked at her guide, "Stop laughing. This is not funny!!"

At first, as the students walked down the hallway, the sighted guides tried to walk forward at a moderate walking pace, but their unsighted partners begged them to slow down. Several blindfolded students reached their free hand forward

grasping for a wall or any solid object to hold onto for security. Many students scuffed their feet along the floor rather than lifting them up as one might typically do. In two minutes' time the herd of students had barely progressed ten yards.

There remained an element of joviality in the experience, but this faded as students requested that others be quiet so they could "hear" where they were or so that they could question and listen to their sighted guides providing instruction.

As the exercise continued, Ms. Ana led the students out of the school building and onto the sidewalk in front of the school, through the parking lot and up and down sets of stairs around the school grounds. Throughout the activity I was actually feeling grateful that I was in the back of the line, not just to monitor the stragglers, but for my own security. I had never walked most of this terrain myself and, without my cane, even I was having difficulty making my way around uneven pavement and oddly spaced stairs. I internally dialogued with myself, trying to understand my own decision to not use a cane for my own safety, realizing that I was resisting making my own disability more visible to students even though they all knew about it. I could have modeled an appropriate use of a cane. Should have, could have, but didn't. I was so mad at myself!

After about 15 minutes, the students reversed roles, the sighted guide becoming the "blind" person and the blindfolded student becoming the guide. The exercise then continued for another 15 minutes before Ms. Ana gathered students on the playground to debrief. I recorded students' responses on my iPhone. Students took their seats on the ground while Ms. Ana stood in front of

them. Reactions were varied, but could be categorized into three distinct groups: comments unrelated to or dismissive of the activity itself, comments about the challenge of the assigned task and comments suggesting an affirmation of disability as horrific.

The first group of comments, which accounted for approximately a quarter of all comments made, were tangential to the activity. One student twirled his blindfold on his finger a few times before sending it flying at a friend. He said, "Phwew! That was too tight on my head!" Another student pulled her blindfold off and sighed, "Ugh, that was too hot! It feels good to get that off!" One female student said to another student, "Does my hair look okay?" Another student asked if he could just stay outside on the playground instead of going back into the school because the weather was so nice. These comments were expected from a group of sixth graders on a hot day in early June. They do not affirm aloud that the activity had either positively or negatively impacting their thinking. They may have been internally thinking through the exercise but used these comments instead of sharing aloud.

A second group of students made comments related to the specific challenges of the activity. Their thoughts included the following: "I had a hard time hearing because some people were being really loud!" "My partner was walking too fast and I was scared I was going to fall!" "I kind of knew where I was when we were in the school but when we got outside I didn't really know where I was as much and then it was harder." These and similar comments accounted

for another quarter of the total responses students generated. Overall, these represented a focus on the embodiment of disability, the physical challenges that they encountered. These obstacles would have been partially mitigated if students hadn't been thrown into an activity without any prior training. If students had received training in mobility, they would have known how to accommodate these challenges but, because this simulation positioned students as blind individuals but did not equip them with techniques for accommodating the physical challenges, the students became stuck on the physical nature of disability. They were not able to conceptualize how travel might be made easier with appropriate training.

The final category of responses included those made by students for whom this activity only seemed to reaffirm negative stereotypes of disability. One male student boldly stated, "God, I'd rather be dead than blind." Other students reflected, saying: "I don't know how blind people do it!" "That is the worst thing I've ever had to do. I could never live without seeing!" "How can someone stand to never see? I'd be afraid to do anything. I'd never leave my house!" "I'd make someone else do everything for me because that was just way too awful!"

These students' comments lead me to question the purpose and benefit of what Ms. Ana tried to accomplish. While she had hoped that this exercise would be an experience in building students' empathy for individuals with visual impairments, for some students the experience only reaffirmed the belief that the experience of disability is so horrific that death might be preferable. This speaks

to one of the challenges associated with the use of simulations. Nearly half of the students in Ms. Ana's class responded with comments most closely tied to the disability as person tragedy (Oliver, 1996) and reaffirmed the positionality of being able-bodied as superior to being disabled.

Ms. Ana was not ignorant of the problems associated with simulation exercises and shared:

> I don't know what to think about simulations. I've done a lot of reading online and this year, for the first time, I'm learning that some people are really against them because they are unrealistic. But then you have Easter Seals and our regional education service organization putting out kits and materials that encourage simulations to foster understanding. I am not sure how else to help students really understand. I hope that they take more away from it than pity, though I am sure for some that is the only thing they gain because you do feel bad, but I hope it is more of understanding and appreciation for what daily life is like, but I never know what will happen.

Ms. Ana went on to explain that when she used to teach a similar unit to elementary students in a different district, she required students to spend an entire day with a simulated disability. She built in opportunities that required students to grocery shop, eat lunch and go out to recess. This, she believed, allowed students to better experience how everyday events become more

challenging in an environment that is created for able-bodied individuals. She reported that after a few hours students were tired and frustrated. While she didn't want students to learn that life with a disability wasn't worth living, she felt that these longer experiences were "more painful" and a "more meaningful way" to help students understand more fully the challenges that individuals encounter in society or in schools. The 20-minute simulations that Ms. Ana employed as a teaching method are logistically more feasible with 100 students, but they turn out to be more fun (in the case of wheelchair basketball) or completely unrealistic (sending students in blindfolds out with walking sticks but no training). Despite her uncertainty with the value of simulations, these remained a central part of the Disability Unit during the following school year.

Many within the field of Disability Studies offer reasons why the use of disability simulations are ineffective and, in some cases, counterproductive. One of the strongest critiques recognizes that when students are asked to pretend they have a disability, they do not get a sense of "the embodied knowledge contained in disability identities" (Siebers, 2008, p. 28). Students are not given the opportunity to know about the actual experience of being disabled. They are not given time to develop ways of being in that particular identity, and more specifically, of being successful in that role (Burgstahler & Doe, 2004). Pfeiffer (1989) wrote that, "by reproducing the frustrations of being deprived of sight, hearing, or mobility without the training and socialization that minimize these problems, these exercises reinforce harmful attitudes about disability and

disabled people" (p. 53). This often results in feelings of loss and pity rather than empathy: "Students experience their body relative to their usual embodiment, and they become so preoccupied with the sensations of bodily inadequacy that they cannot perceive the extent to which their 'disability' results from social rather than physical causes" (Siebers, 2008, pp. 28-29).

Simulations like those done in Ms. Ana's classroom focused exclusively on the bodily or physical experience of disability, on how the individual's body would be impacted by an impairment, paying little attention to the larger issue of how society creates disabling experiences through the built environment, attitudes and social structures. For some students, this had the consequence of reaffirming stereotypes they may have already harbored about the tragedy of disability.

Disability theorists also suggest that simulations, whether intentionally or not, result in the development of a hierarchy of disabling experiences. What Siebers referred to as "What is Worse?" occurs when students begin ranking minority identities. This was certainly one of the unanticipated outcomes of the simulation exercises in the sixth-grade unit. Without solicitation from the teacher, several students made comments like, "I'd rather be deaf than blind" or "It would be the worst to be blind, but being in a wheelchair wouldn't be so bad." Students even went further to rationalize why they "ranked" certain disabling experiences lower than others. More than a dozen students expressed that they'd rather be deaf than blind. They gave reasons that included no longer having to listen to

irritating siblings or teachers' directions to being able to turn off hearing aids when they just didn't want to hear anything at all. Other students thought that being in a wheelchair would be the least inconvenient disability because they wouldn't have to run the mile in Physical Education class or they could use elevators instead of stairs. Their ideas represented a very simplistic understanding rather than an embodied knowledge of the experience of having a disability.

Despite these critiques, Disability Studies scholars remain mixed in their opinions about whether or not to use disability simulations. Some, including Finkelstein (1991) and French (1993), argue that simulations should never be used because of their arbitrary nature. Others in the field disagree. Siebers (2008) suggested that it might be valuable to

> send students off wearing sunglasses and carrying a white cane, in the
> company of a friend, to restaurants and department stores where they
> may observe firsthand the spectacle of discrimination against blind
> people as a passerby avoids and gawks, a clerk refuses to wait on them
> or condescend to ask the friend what the student is looking for, and
> waiters request, usually at the top of their lungs and very slowly (since
> blind people must also be deaf and cognitively disabled) what the
> student would like to eat. (p. 29)

Burgstahler and Doe (2004) found that creating opportunities for individuals to have ongoing exposure to individuals with disabilities is most effective in allowing

time to observe how individuals navigate their physical and social environments.

What seems to be most important to several scholars in the field is creating

meaningful ways for students to experience disability in ways other than the

"what is worse" game. Instead of attention focusing on which minority identity is

worse off than another,r we should welcome discussions of universal design and

ways in which we can remove systematic and physical barriers to access.

Exercises that expose students in social situations in which discrimination can be

felt through the barriers, both attitudinal and structural, may be more powerful in

helping students identify the social experience of disability. Arguably these

experiences are also more difficult to do logistically in schools.

I believe that there are instances in which simulations can be used

effectively. Several years ago, I was invited to participate in an exceptional needs

working group facilitated by NASA. The function of our group was to evaluate

educational materials for accessibility before they were endorsed by and

distributed through NASA's education resources centers. Members of this group

included NASA scientists, individuals with disabilities who had been identified as

"experts" on accessibility, teachers, administrators and product designers. We

were presented with various materials and those who were not disabled were

assigned a disability. We then worked through activities. After, we debriefed. The

focus of our discussion was not on the debilitating effects of impairment, but on

the ways in which our classroom materials should be designed and delivered in

inclusive ways. As part of our meetings we also visited two education centers,

U.S. Space and Rocket Center and the Pacific Science Museum and provided feedback to the management on ways in which their museums could be made more accessible to all attendees. Non-disabled attendees learned from those attendees who were disabled as we helped them understand ways that the built environment can complicate access.

I have also used a simulation to encourage teacher candidates to consider disability as something other than a physical experience. Prior to a lecture I lead on using culturally relevant pedagogy to guide our work with students with disabilities, my colleagues and I identified students in our course who would unknowingly participate in the simulation. On the day of the lecture, I began my instruction and, with the help of a colleague, partway through my teaching, another college interrupted me, calling out several students' names and requesting that they leave the room because they had been identified as individuals who would benefit from participation in an alternate activity. I then went on with my instruction. The students who were "pulled out" by my colleague were given a reading and engaged in a short discussion while the students who remained in my lecture participated in partner work and discussion. The "pulled out" students were reintroduced to the regular classroom environment at a moment in which the students were completing an activity directly related to the information I had delivered in my lecture. The "pulled out" students were not able to fully participate. Eventually I disclosed to the students that the activity was a simulation of what students might experience in school, when disabilities are

made visible in regular education classes. We finished the activity by exploring together the experiences of the different stakeholders, including the special educator, the general educator, the students pulled out and the students who remained in the regular education classroom. I've used this activity successfully with both practicing teachers and future teachers. I believe this serves as evidence that carefully designed simulations that move beyond the physical defects of disability can be used effectively.

Conclusion

This Disability Unit is celebrated as one of the most important ways in which Cinder City Middle School validates the diverse experiences of individuals with disabilities; however, the events described here and the many others not included in this chapter suggest otherwise. While the teacher frequently reminded students that individuals with disabilities are "people first" and "more than their impairments," her prompts for the speech unit as well as the assessment value assigned to discussing those medical implications sent a mixed message. Why, if individuals are more than the impairments they experience, must students spend the majority of the unit studying the symptoms and treatments and methods of rehabilitating those with that condition?

The unit may have also reaffirmed stereotypes related to disability in other ways. Students read texts written by professionals about the disabled, and very few instances existed for students to read literature produced by the disabled or engaged with those with disabilities in positive ways. Had students been given

the opportunity to read texts produced by those with disabilities, this would have exposed students to a different perspective of disabled life, one that extended beyond the medicalization of impairment. Reading and interacting directly with individuals who were disabled would have also allowed students to recognize that individuals with disabilities can and do contribute to society in really important ways.

I believe there is value in exploring disability in classrooms. Students with and without disabilities can be empowered to work for change if only they come to know the "problem" of disability as not existing within the individual but instead, in the ways individuals with disabilities are positioned within and oppressed by our society. I do know that my presence and participation in this sixth-grade unit did impact Ms. Ana's thinking. She realized that more attention needed to be given to students' social experiences. She also recognized that her disability simulations were problematic. And while she wasn't ready to abandon them, she was thinking more critically about her work with students. There is potential here. It may take time, but there is hope.

Chapter 5: Great Expectations?:

Teaching and Talking to Students with Disabilities

Schools are places in which many elements are constantly at work. Crosnoe (2011) suggested that while many pieces come together to result in the act of schooling students, these pieces can be categorized into formal and informal processes of schooling. Formal processes involve things like staffing, curriculum, instructional materials, class offerings, grades, test scores and graduation rates, those things that are, "most concretely linked to the official mission of the educational system, which is to shape children and adolescents into skilled, well informed adults who can take their places in and contribute to the labor market and the larger polity" (Crosnoe, 2011, p. 37). The informal processes of schooling include the social and psychological aspects of the school system, recognizing the importance of relationships and how individuals develop within the context of a school. These informal goings-on are not specifically part of the public mission of a school system (Crosnoe, 2011). This organizational structure assisted me in thinking about this chapter and moving forward. I discuss an aspect of both the formal process of schooling as well as one rooted in an informal process of schooling.

According to scholars in both Disability Studies in Education and Critical Special Education, the practices of deficit thinking and use of developmentally inappropriate curricular materials in Special Education classrooms are rampant in schools. Special Education has essentially become a service offered to deficient

students to enable them to be normal, or in other words, to achieve at a level

more aligned with group norms (Brantlinger, 2005). It operates under the positive

guise of "meeting the diverse needs" of all students (Henley, Ramsey, &

Algozzine, 1999, p. 39). Unfortunately, in an attempt to achieve "individualized

instruction" to meet the unique abilities of students, Special Education

classrooms and resource rooms across the United States often face high

teacher-to-student ratios, making one-on-one time challenging, if not impossible.

What often results is the use of ineffective teaching practices. Instead of

supporting that which is taught in general education classrooms,

> it is more typical for the curriculum in special education classes to
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> be watered-or dummied-down versions of the mainstream
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> curriculum. Resource rooms are "supervised study halls" rather
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> than places for remediation or intensive tutoring. Thus,
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> individualized instruction has been a "theoretical practice" that, due
>
> to constraints . . . rarely has been realized in schools. (Brantlinger,
>
> 2005, p. 127)

And while scholars from both Disability Studies in Education and Critical Special

Education call on schools to "include disability lessons informed by pride and

empowerment" to enable students to become empowered, high-achieving

individuals, this is seldom the reality for many students (Ware, 2006, p. 14; see

also Gabel, 2005).

I unfortunately found many of the above observations related to the

"service" of Special Education to be true at Cinder City Middle School. Throughout the data gathering portion of this study, I was struck by how teachers communicated, or failed to communicate, expectations to students. While there were exceptions, I frequently heard teachers directly and indirectly communicating messages of hopelessness and disempowerment to students.

These daily interactions between students and teachers caused me to worry about the futures of the participants in my study. I was keenly aware of the dismal prospects for individuals with disabilities as they make the transition from school to adulthood. According to the U.S. Census Bureau's 2011 American Community Survey, the current unemployment rate for individuals with disabilities stood at 68% with an even higher rate of unemployment, 78%, for those with developmental disabilities (U.S. Office of Special Education Annual Report, 2011). In 2012, nearly 37% of students with disabilities dropped out of high school. Thirty percent of those with disabilities were living in poverty and, on average, were making nearly $10,000 less than non-disabled employees (Annual Disability Compendium, 2012). In the face of so many challenges, I had hoped to observe actions by educators to prepare students, to empower them, to support them. By and large, this did not occur.

This feeling of hopelessness and powerlessness felt by the students, and to a different degree, by parents and some staff, was revealed to me early in the study. As I began an analysis of my data, I noticed that their emotions and, at times, frustration seemed to be tied to "expectations," expectations that were

made visible in two main ways. Expectations were communicated to students directly through things that were said to them. Secondly, expectations were communicated to students through the curriculum to which they did or did not have access. As this chapter unfolds, I first examine how curriculum was used to instruct students and prepare them for their futures. The second half of the chapter examines how expectations were communicated to students directly through the things that were said and done to them, primarily by their instructors and aides. I conclude with exceptions: with educators working *for* students.

Before doing this, however, I want to first introduce you to participants, starting with several students who were key participants in helping me explore this topic. I provide a short profile of each student, profiles I have crafted through observations of and interviews with these individuals as well as written assignments completed by students in English class. For parent profiles, I crafted sketches based on their interviews and in the observations I made during visits to their child's classroom. Teacher profiles were born from months of observations in their classrooms, many informal conversations and formal interviews. I am providing these profiles at this point because I wanted their stories to be fresh in the minds of the reader in this chapter. Additionally, these students and parents were not participants in the Disability Unit highlighted in Chapter 4.

The Students

Sarah, Stephanie and Sophie are triplet sisters who are in the eighth grade at Cinder City Middle School. They've been students in the district since

early childhood. When the triplets were born, two of the three girls, Sarah and Sophie, were diagnosed with cerebral palsy while the third infant, Stephanie, was born without an impairment. The family lived within sight of the school grounds and, during the winter, the maintenance staff was known to clear a path from their home to the school so the girls could safely travel. The home in which they lived was not an accessible space, making it necessary for Stephanie (the non-disabled triplet) or a parent to be home at all times. Sophie needed to be carried from room to room, and Sarah crawled to her bedroom on the second floor. The triplets had a younger brother who attended the elementary school.

Sophie described herself as a little shy sometimes but also confident. She enjoyed hanging out with friends at lunch time, writing stories and joking around. She got irritated when her sisters or teachers told her what to do. On the weekends she spent most of her time at home. Some of her best friends are Tara, Emma and Cara, three eighth-grade students in the Special Education program, her sisters and Natalia, another eighth-grade student who came to Cinder City 18 months ago from the Philippines. Sophie received nearly all of her education in a self-contained Special Education classroom but was able to attend an elective course with an aide during the last period of the day. As a result, she didn't really have a favorite class in school but did really enjoy lunch and recess because she got to be with friends. Because of the cerebral palsy, Sophie spent her days in an electric wheelchair that she operated with a joystick. The chair was equipped with a neck brace that supported her head and neck. Stephanie,

her sister, frequently, without permission, adjusted Sophie in her chair, and as Sophie put it, "bossed her around." Sophie required the assistance of a teacher to use the bathroom and also requested help from a student or teacher in the lunchroom to obtain her food and open packaging. In February, Sophie underwent surgery on her legs and missed several weeks of school. Doctors' visits, surgical procedures, Botox shots and ongoing physical and occupational therapy were routine in Sophie's life.

Sarah was usually very shy. She did not like it when people looked at her because she worried about what they were thinking. She, for the most part, enjoyed school and had two close friends, Emma and Cara, who shared her experience of being in Special Ed. Sarah liked going to the mall and being with friends. English and math were her favorite classes. One of her least favorite classes was tech ed because she found the teacher to be completely unfair. She dreamed of going to college and then law school and becoming a defense attorney. Sarah's experience with Cerebral Palsy differed from her sister's in that she was able to walk, albeit slowly and unsteadily, with the use of a walker. She kept a manual wheelchair at school and used it on days when walking was more difficult or if an extensive amount of walking was required. Sarah left each of her classes about five minutes early to allow time to travel to her next class while the halls were empty. More than 80% of her school day was spent in general education classes, though she did attend a Special Ed study hall in the afternoon.

Tara, also an eighth-grade student at CCMS, was a new student and started attending classes during the second week in September. She lived with her mother, whom I was told was blind, her grandfather, who Tara shared was an alcoholic, and her younger sister, Lyla. Tara's father was killed in a truck accident three years ago. Tara described herself as pretty shy when she is around "normal" classmates but more fun and confident in Special Ed classes. Tara had an affinity for helping and volunteered in the elementary Special Education room during her study hall four days a week. In particular, she spent a great deal of time with a kindergartener who was blind. When she had free time, she liked to just hang out, cook and write. When she wrote, her stories often focused on her experiences with disability or the loss of her father. Tara received services through Special Education because she had frequent seizures that reportedly impacted her cognitive abilities. As Tara described, "people tell me that my Epilepsy makes me think more like a third grader than an eighth grader." She was included in science, English and an afternoon elective but spent the remainder of her hours in pull-out classes and Life Skills. Her favorite class was English because she liked the teacher, and she also liked it that I was always present in that class. Tara was sometimes unable to participate in school events because her mother either didn't allow it or didn't have the money to fund her involvement. For this reason she was unable to attend the end of the year trip and on the day of eighth grade graduation, came to school without dress-up clothes.

Addy was another of the eighth-grade students who became a central participant in this study. She described herself as kind of moody at times but helpful. She loved caring for others and several times expressed interest in doing some babysitting for me. She was an avid reader with a sharp tongue and a witty sense of humor. She "called things as she saw them" and this often got her in trouble with teachers. Addy's social studies, science and Life Skills teachers described Addy as challenging and unmotivated. She often did not complete assignments and needed many reminders to do what was expected. Transitions between classes were difficult for Addy, and she was often the last to arrive for class as well as the last to leave. She was frequently late for school as well. Her English teacher, however, recognized that Addy was very creative and could do remarkable things if she felt she was being treated with respect. Addy shared that she did not appreciate teachers talking to her like she was stupid, telling her what to do like she was two years old and expecting her to be respectful when they weren't very kind to her. Addy lived with her mother, father, twin sister and younger brother. Addy attended social studies, science, English, math and elective courses with her classmates while also being enrolled in Life Skills and an afternoon study hall for Special Education students. She received services because of a medical condition known as Turner Syndrome (TS). For Addy TS manifested in her short stature, curved back, difficulty with spatial processing and attention. She walked slightly hunched over and shared that it was difficult for her to write small and interpret maps and some math.

The Parents

Sandra was mother to the eighth grade triplets and was known for her strong presence at the school. When the parking lot was not immediately clear of snow, she notes this and called an administrator. When she became aware of a ridge on the edge of a piece of sidewalk in the parking lot in which she picked up her daughters, she called the District Office to let them know that it needed to be fixed. Another time, when the automatic door on the entrance her girls used to enter and exit the building wasn't working, she spoke directly to the superintendent about it. She said, "Anytime the school is not doing what they are supposed to be doing when it comes to accessibility, they hear from me." There were several times during the school year when Sophie, and to a lesser degree, Sarah, would argue with something one of the Special Education teachers or aides would want them to do, particularly related to their wheelchairs. If the teachers became too frustrated with the girls, they would threaten to call their mom. The girls would immediately become more compliant because they didn't want to get in trouble at home.

Marcie, a former middle school teacher, was the mother of three. One of her daughters was an eighth grader at CCMS while her youngest daughter, Brinna, was a fifth grader there. Brinna received services in the school Special Education department because of a genetic disorder known as 1p36 which presented itself in Brinna as a moderate intellectual disability, limited speech, gastrointestinal issues, weak muscle control, seizures and limited growth of

bones. Brinna was able to walk independently, though after walking long distances, she did become more unsteady. Marcie reported that Brinna's curiosity and love of learning were genuine and that she had always been eager to experience new things. She enjoyed eating lunch with her friends, watching TV and going places with her mom. Marcie shared that before Brinna was born, she had been a teacher, but after learning of all of the special care that Brinna would require in her early years, Marcie left her job to make her daughter her priority. Marcie believed this did result in some jealousy because Brinna's older sister often felt neglected. Marcie thought that once Brinna entered middle school, she might be able to step back and give her more independence but she instead felt that "after dropping Brinna off in that Special Education room every morning, I feel like I have to be more of an advocate now than before!" Brinna started the year included in science and social studies but by the end of September, she'd been removed from all her regular education classes and only was allowed to join her classmates for holiday parties and at lunch. Marcie was both relieved and troubled by this and worried about her daughter's future all of the time.

Anna was the mother of a fifth grade student. Her son Eric was born blind and received services through the school's Special Education department because of both his blindness and a suspected diagnosis of Autism. Anna was a single mother. Her husband was intermittently involved in her son's life. Eric spent a few nights a week with him, but Anna said that most of the time, Eric was with her. She reported that she tried to do "normal" things with him because she

wanted him to be like everyone else. Anna and the teachers admitted that Eric

was a handsome boy, and the teachers said that they thought Anna dressed him

in brand-name clothes to make up for his behaviors. Anna shared that Eric often

rocked back and forth and cried out, yelling the same thing over and over again.

It was hard for Anna because she wasn't sure what she should be doing for him.

The school encouraged her to send him to the residential school for the blind but

she refused. She wanted her boy with her, but she also felt like the school wasn't

really doing anything for her son, to move him forward. She didn't feel listened to

by teachers. She wanted her son to have a future, but she worried that she didn't

know how to best support him. She felt that the school had already given up on

him. Repeatedly during our interview Anna said this statement in a variety of

ways, but always with the same premise: "Look at you. You are successful. You

give me hope that my son can be something, too!"

The Teachers and Aides

Valerie was a middle school Special Education aide and mother of four.

While she spent several years devoting her time to her own family, when her

children were grown, she took a position as an aide with the school district in

2003 when Sophie and Sarah entered kindergarten. She followed the girls

through the years and had an undeniable soft spot for this year's eighth grade

students, even though many other staff members found them challenging. She

took the position to work with Sophie and Sarah because of her experience as

the parent of twin daughters with Cerebral Palsy. She shared with me that she

often felt very disempowered by the "system" of school. She felt that her daughters needed her to be their advocate because they were often silenced by the professionals in their lives. Working with Sophie and Sarah gave her an opportunity to help them develop their advocacy skills and, when she needed to, to protect them from injustice. I felt she was isolated from other staff members because she failed to conform to the norms of low expectations, something I explore in depth later in this chapter. Unlike the other aides, she did not maintain a workspace in any of the Special Education classrooms, did not join staff members for lunch conversations and was known to speak out against some behaviors displayed by other staff members. When providing support in classrooms, Valerie sat back until she saw a need, which allowed students to be independent and socialize without adult oversight. She often reached out to help any student who needed assistance. As she said to me once, "all of the students are mine."

Mrs. Andrea Marshall (whom you met in the introduction) was an eighth-grade English teacher and had been in the district for twenty years, though not always in her current position. She spent several years in the elementary school before moving to sixth grade where she spent two years as a reading teacher. She was in her second year teaching eighth grade at the time of this study so she enjoyed the unique perspective of having taught this year's students as sixth graders and again as eighth graders. As an educator, Mrs. Marshall valued connections with students and worked daily to create a safe space in her

classroom. We developed a very close relationship over the course of the year, and she frequently shared her feelings of inadequacy as a teacher. She felt very uncomfortable with the ways students with and without disabilities were treated by other staff members but she also felt powerless in her own ability to effect change. During the course of the year Mrs. Marshall disclosed to me that she was particularly drawn to those students who struggled because of many of her own life challenges. Near the end of the year she shared with me that she had an invisible disability, something she finally felt empowered to share given the nature of my study. She also shared that she had plans to leave the teaching profession within the next year or two because she couldn't continue to participate in a system that did so much violence to students.

Communicating Expectations Through Curriculum

Prior to examining the use of curriculum, I begin with an introduction to a self-contained space in the school. "Life Skills" was a class available to both male and female students with disabilities in grades 5-8. Typically, the course slots were reserved for students with significant disabilities who were perceived to need a pull-out classroom experience during the first hour of their days. Some students were assigned to this class because they arrived late to school daily. Although the school day began at 7:50, Eric's bus delivered him to school between 8:10 and 8:20. Sophie had personal care needs that occurred during first hour, and Addy was perpetually late for school for unspecified reasons. One aide shared that another reason students were enrolled in Life Skills was "to

explore skills necessary for independence in life." Life Skills began at 7:50 and released at 8:37 and was held in a Special Education room near the main doors of the school and away from both the fifth/sixth grade and seventh/eighth grade academic classrooms. The Life Skills classroom included a fully operational kitchen, washer and dryer, bathroom, four computer stations, rocking chair, several desks, library area, a stander (used for students in wheelchairs to build muscle strength) and several assistive devices for students with a variety of needs. Cabinetry filled most of the wall space, with the exception of a whiteboard that spanned the front of the classroom and a teacher's work station.

Mrs. James, a fifth/sixth grade multi-categorical special educator with the middle school, was the instructor of record for Life Skills but had additional support available to her for the course. Mary, a part-time bus driver in the district, also served as an aide for the Special Education Department and was (unofficially) the primary first hour Life Skills instructor. Additionally, Ms. A, a non-traditional student (who held an early childhood degree but, as an older student, was returning for a K-12 Special Education degree) from the local university, was completing her student teaching practicum; one of her assigned responsibilities was leading the first hour class for the first semester. On the first day of school, nine students were enrolled in the class: three fifth graders, Jessa, Brinna and Eric, one sixth grader, TJ, two seventh graders, Alli and Amanda, and three eighth graders, Tara, Sophie and Addy. On that first day only six were present; Tara, Brinna and Alli were not there. By the end of the second week of school,

the sixth grader would leave due to a change in guardianship in the foster care system.

On the opening day of the school year, I sat in the back of the classroom observing the first Life Skills lesson. Ms. A, the student teacher, sat perched on a wooden stool at the front of the room. In her booming voice she introduced herself to the students and asked them to remind her of their names. (She'd met them at orientation the day before.) She then invited them to answer the following question: What do you need to learn to be independent? At first, no one answered. Ms. A offered the idea of needing to know how to cook simple things. As students made suggestions, the student teacher recorded their answers on the whiteboard. I recorded this and most class sessions and transcribed their comments directly from the recording. I also took a picture of the items listed on the whiteboard before they were erased. The students' list included the following:

> *-Learning to cook things like macaroni and cheese, pancakes, chili, my grandma's mashed potatoes and cookies*
> *-Going grocery shopping*
> *-Learning to ride the bus and to actually go somewhere*
> *-Call a business and ask questions*
> *-Make a menu plan and then go shopping to get the food*
> *-Do a fundraiser*
> *-Make a meal for the teachers*
> *-Do a cooking contest between us and the principal*
> *-Volunteer at a nursing home or daycare center or somewhere like that*
> *-Go to the elementary and help in a classroom*
> *-Learn about different jobs and what people do at work and maybe get to watch them do their jobs*
> *-Make a recipe book*
> *-Make blankets or sew something*
> *-Bake things to give to teachers*
> *-Learn how to take care of a baby or young child*

After about twenty minutes of idea generating, the student teacher asked the students to decide what they'd like to do first. Amanda suggested that they begin with a cooking unit. Ms. A explained that she would talk with Mary, the aide, to see how they would go about getting food needed to cook. Amanda said that they should make a recipe book like they did last year in Life Skills to keep track of all the different foods they made. All of the students liked this idea. The class was then abruptly interrupted by an announcement asking all students to report to their homerooms for Positive Behavioral Interventions and Supports (PBIS) activities.

Once the students left, Ms. A turned to the board and began to erase the students' ideas. I noticed she hadn't written anything down, and I wondered how she'd remember what the students had said. I was about to ask her when Mary came out of the kitchen. She'd been in there doing I'm not sure what, while Ms. A had been leading the class.

"The kids want to do some cooking," Ms. A said. "How do we go about getting supplies?"

"I heard their ideas. The kids will have to find a recipe so I know what I need to get. A lot of the stuff we probably already have here or I have at home. I do all the shopping anyways. Mrs. James doesn't really do much to help."

"They have some other really good ideas too!" the student teacher shared. "It would be great to get them on the bus or to take them shopping, wouldn't it?"

"Most of those ideas will never fly. I mean, really, can you IMAGINE taking

these kids on the bus?"

"But most of these kids won't ever be able to drive. The city bus might be the way they are able to get around," Ms. A. turned to me. "You take the bus don't you? Don't you think this would be a great activity?"

"I actually took the bus here this morning. I ride it all the time. It was probably one of the better things that I learned in my Life Skills class in high school."

"Yeah, but you're not like these kids," Mary responded. "You're in school, you have a family and you work. These kids will never have any of that." She turned back to the student teacher, "And we will NOT be taking these kids on the bus."

I didn't respond to Mary's remark because I didn't know what to say. While I had met the Special Education staff members once over the summer and had spent two inservice days with them before this, the first official day of the school year, I wasn't yet prepared for the candor with which she spoke.

And that was only the beginning. As the school year went on, while I was horrified by what was said and done in that classroom, Mary nevertheless grew to like me, not ever as an equal, but she did seem to respect my homemaker skills. I cooked and baked from scratch, kept a garden, canned many of the foods we ate and "had my wits about me." Because we shared a common interest in baking and cooking, she was quite open with me. So one day I asked her about what she imagined as futures for the students in Life Skills. She said:

I don't believe that most of these kids are ever going to live

independently. Most of them will probably end up like my (disabled)

daughter who lives with me and who can't do a thing for herself. She

is why I'm stuck in this job, because I have to work to support her

and my mother. Half of them can't even get themselves to class on

time much less read a bus schedule. I'm just being realistic.

So, while Ms. A had opened the school year with the best of intentions, she

repeatedly met Mary's resistance. While she had her own philosophy of teaching,

she fell victim to the power dynamics present in the classroom. As she put it, she

was "just a student teacher" and felt powerless to push back on Mary's criticism

of her attempts to create a student-centered learning environment. In an

interview that took place after she'd left CCMS and had secured a full-time

teaching job, she shared:

I had my own ideas of what would make Life Skills a valuable class for

the kids and I tried but I also was just a student teacher and Mary had

been there for years. She was very set in her ways and made her

ideas very clear to me and to everyone else about what she thought

about the kids. I felt like I had to do what she wanted me to do

because she's very intimidating and I needed to do well in this

placement so I could get a job. Looking back, I know that I may have

contributed to what was already a really bad situation for the kids.

Mary's belief about students and her power combined with Ms. A's feelings of

helplessness set up a classroom in which, academically, so little was accomplished. Ms. A felt like she had no choice but to participate in a broken system.

* * *

"Guess what day it is?" Ms. A asked in a singsongy tone. Around the room Addy turned a page in the book she was reading, not bothering to acknowledge the question. Eric rocked in his seat, crying out every few minutes for the key (a toy key that Eric often asked for and liked to hold on to), and Alli tried to soothe him by patting his back and telling him it would be okay. Jessa appeared to be asleep, her head resting on her arms on the desktop. Amanda's back was to the group and her fingers tapped at the computer keys as she searched for a recipe for potato soup. Sophie flicked the joystick on her wheelchair and started heading for the door, and Tara called out to her from her place in the rocking chair that she'd see her at lunch. Mrs. James, the classroom teacher, was at her desk reading an email. Brinna nibbled cereal from a Gerber snack saver while her mom stood in the doorway, arms crossed, looking at what was intended to be the day's Life Skills lesson.

"Guys!" Mary yelled from the kitchen where she busied herself getting a cup of coffee. "Ms. A asked you a question!"

"What?" Brinna asked finally, looking at Ms. A.

"It is Cleaning Day!" she announced with the excitement of someone who had just won the lottery.

"Ugh," Addy groaned without looking up from her book. "That's what you're excited about?"

"Everyone needs to know how to clean! It is an important skill." She began listing the names of everyone in the class on the board and assigning them a task. Eric would finish his breakfast, Brinna and Jessa would wipe off the desk tops with a dust cloth, Addy would sweep the kitchen and Amanda would put dishes away. Alli would make ice packs and then she and Tara would deliver them to the office.

"This isn't a skill. This is stupid," Addy responded, making no attempt to move from her desk.

Ms. A encouraged her, "I remember feeling like that when I was your age but now I use my cleaning skills all the time. Every Saturday I bust out my supplies. I dust, I vacuum, I do laundry, I . . ."

"Your story is not helping," Addy interrupted her. "Why can't we do stuff that really matters?"

Mary stormed into the classroom, approached Addy's desk and grabbed her book out of her hands. "This belongs to me until you can learn who is in charge here. I've had enough of your backtalk."

"You're stealing!" Addy protested. "That's not fair."

"I will tell you what's fair: you doing what we tell you to do."

Addy dropped her head to her desk and mumbled, "this is so stupid. It is not like we were learning anything anyways. At least when I had my book I was

learning something." She continued to mumble and, despite repeated attempts by Mary and Ms. A, Addy remained in her seat, head down, talking to herself. Her refusal to clean earned her an after-school detention.

The scene that unfolded in Life Skills on that late November morning was not an anomaly. Cleaning the classroom and attached kitchen was part of the "lesson plan" one day per week. With little variation, the Life Skills curriculum followed a predictable pattern. Two days of each week were spent cooking and another day was spent counting and packaging fluoride treatments for the elementary students. Because the city's water supply did not contain fluoride, elementary students had to drink fluoride treatments weekly to prevent tooth decay. Boxes of fluoride treatments were delivered to the Special Education room each week, and it was the students' job to sort packets, place them in plastic bags accompanied by one napkin for each elementary student, place a label on each plastic bag and deliver them to classrooms.

On fluoride day, an adult would announce a particular number, for example, "Mrs. Smith's class, 12." Students would then be assigned to one of the following tasks: counting napkins, counting fluoride packets, placing labels on plastic bags or loading napkins and fluoride into plastic bags. Adults would assist by recounting work done by the students, tying bags closed or breaking apart the sheets of fluoride into individual packets. The fourth day of the week would be spent counting box tops, Campbell soup labels and milk caps. Collections of these items were delivered to the Special Education room from all over the

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school. The students would then either count box tops and milk caps into piles of fifty or would glue Campbell's labels onto a piece of paper. Once counted, these items were turned into the office and would eventually be submitted to companies in exchange for money that would be used to fund purchases that included playground equipment or activities like guest speakers, purchases that did not directly benefit the Special Education students. The fifth day of the week would rotate between cleaning, cooking and more counting.

Included below is a sample of the weekly "lesson plan" for Life Skills. This chart was posted on the wall in the kitchen. Each day a teacher would record a point value ranging from one to three in each student's box. If students showed up but refused to participate, they earned a one. If they came and did what they were told, they earned a three. Two's were reserved for the gray area on the days in which students hovered between being compliant and being resistant.

Figure 2. Weekly "Lesson Plan" for Life Skills

	Monday	Tuesday	Wednesday	Thursday	Friday
Brinna	cooking	counting fluoride	counting labels	cleaning	baking
Eric	cooking	counting fluoride	counting labels	cleaning	baking
Jessa	cooking	counting fluoride	counting labels	cleaning	baking
Anna	cooking	counting fluoride	counting labels	making and delivering ice packs	baking
Amanda	cooking	counting fluoride	counting labels	cleaning	baking
Tara	cooking	counting fluoride	counting labels	making and delivering ice packs	baking
Addy	cooking	counting fluoride	counting labels	cleaning	baking
Sophie	cooking	Adaptive PE	counting labels	Adaptive PE	baking

The activities in Life Skills did deviate slightly from this schedule at two different times during the year. Between Thanksgiving and Christmas, instead of cleaning and counting box tops, students worked on "special projects." According to Mary's assessment, the "bigger, (more capable) girls," which included Addy, Amanda, Anna and Tara, received instructions on how to make "tie" blankets. Mary precut fabric for the girls and instructed them on how to measure, mark and eventually make one inch cuts into their fabric pieces before tying them. Because it was determined that Sophie didn't have the dexterity to participate in this, she was given scraps of fabric and instructed to use the scissors to make cuts. This would, she was told, be a good strengthening activity for her hands. All of the students also "made" ornaments to be given to the parents as Christmas gifts. I placed "made" in quotes because what actually transpired is that Mary and Ms. A primarily used hand-over-hand techniques with the students during the creation process, or Mary did the projects herself, wrapped the gifts and put the students' names on the packages as if they did the work themselves.

Students were also involved in an extensive amount of baking. As part of a school-wide reward, two homerooms in each grade won a cookie party, and Mary volunteered the Life Skills class to do the cooking. For three weeks, students were in the kitchen mixing cookie batter, making cutouts and decorating cookies at least three days per week. It is important to note that while students were in the kitchen, the degree to which they were allowed to actually participate in the preparing, baking and decorating was limited. Mary seemed to have an

ideal outcome in mind and when the students were moving too slow, when their cutouts were sloppy or when their decorating wasn't how she had imagined it, she took over and completed these tasks herself. When the completed cookies were presented to the students and staff of the school, the Special Education students received the credit, as was the case with the holiday gifts sent home with the students. Mary justified her efforts by saying that she didn't want to be embarrassed to present "slop" to other students and staff.

The second period during which the activities shifted was in April during a "chili cook-off." I learned from the students and staff that in previous years the Special Education students were involved in a chili cook-off between Mary, the aide, and Mr. Williams, the principal. Special Education students were divided into teams, some supporting Mr. Williams and some supporting Mary. On the day of the event, both contestants arrived with their arms full of grocery bags of ingredients. Mary assigned the students to one of two teams. While Mr. Williams immediately got busy giving his team members, who included Tara and Addy, tasks of opening cans, browning the meat, pouring the contents into a stock pot and monitoring the contents. Mary provided very minimal participation opportunities for Alli, Brinna and Jessa because she didn't want them to "mess up her chances of winning." They were instead asked to put crackers into bowls and set the bowls onto the tables that had been set up in the classroom. Later, Mary allowed them to greet people as they came into the classroom to sample the chili. The "big girls" were allowed to hand out and collect ballots from

teachers and student council members who taste tested the chili.

Revisiting the Life Skills lesson from the first day of school, students communicated with the instructors that they had learning objectives of their own in mind. They wished to learn how to use public transportation, a skill that can be invaluable for individuals who may not be able to obtain a drivers license. They wished to learn how to grocery shop, complete meal planning and engage in career exploration. One student mentioned that she would like to learn how to care for a baby so that she'd be able to do babysitting. Beyond cooking, however, nearly all of their other ideas were dismissed. Instead the students were, as Addy described to me one day, "stuck doing the same meaningless crap every day."

Discontent with the "curriculum" in the Life Skills class was far-reaching. Marcie, Brinna's mother, dropped her daughter off every morning. A self-proclaimed "helicopter parent," Marcie walked her daughter into the Life Skills class and often waited by the door until she saw that her daughter was engaged in what she referred to as "some sort of work." When asked about her perception of the curriculum in the Life Skills class she commented:

> What curriculum? Most mornings I have to literally drag my
> daughter out of the house to come to school because she hates
> going to that class. I know the teachers think I'm over protective,
> but I hang around in the classroom some mornings to make sure
> that she gets to do *something*. But then, when I see her given the

task of counting box tops, I get so mad because she is capable of
so much more, but they don't even give her a chance! And when
I've said something, I feel like my concerns are dismissed. I mean
let the kids DO SOMETHING for God's sake!

She went on to apologize for what she refers to as an outburst, but she said she
gets really emotional about her daughter's experiences in school. She felt as
though her hands were tied. She worried that if she kept pushing the issue, the
teachers would take out their frustrations on Brinna, and she didn't want that to
happen.

Anna, Eric's mother, shared similar concerns about her son's access to a
quality education. While she had asked repeatedly that her son be taught Braille,
he hadn't, at the time of our interview, had any exposure (though he was taught
five letters by the end of the year). She shared:

As a parent I feel hopeless. I have asked that Eric be taught
something, but most of the time I think he just sits in that room. I've
been told I need to be realistic, that he's not just blind but autistic
too and that maybe he needs to be in some residential school or
something and that really, he will never function independently.
But I want him to at least be given a chance. It is like, they've
already decided that my eleven year old is not worth the effort.

And it wasn't just the parents who expressed their frustrations with the Life
Skills classroom and lack of curriculum. I was surprised to learn that even Ms.

Hibbard, the Director of Special Education and Curriculum Development for the district, was disappointed in the lack of meaningful instruction in Life Skills and other Special Education classrooms in the middle school. We met several times over the course of the study, and in January she called me into her office and asked me to give her an update on my research. I told her that much of my work was confidential and that I wouldn't be able to provide specifics, but that I could share some general observations. I offered an overview of a typical week in the classroom including the "lesson plans" that were typically used. I felt comfortable doing this because they were posted on the wall in the kitchen so I considered this visible to anyone who entered the classroom space. She interrupted me halfway through my description with the following comment:

> What you are telling me is exactly what I was worried about. I have
> told Mrs. James repeatedly that I wanted to see actual lesson plans
> and a meaningful curriculum in place in that room. Counting labels
> and making ice packs is not what I consider a curriculum. The kids
> are being treated like servants rather than students. And is Mrs.
> James even teaching? No. She still is leaving most of the work to
> the aide. This is so frustrating!

After making this statement, I watched Ms. Hibbard make a note on a legal pad. As she wrote, she spoke aloud, saying that she'd be making a visit to the classroom within the next few days. At that moment I felt a mix of horror and elation. Would the teachers assume that I was the reason for the visit? What

would this do to my relatively uninhibited access to the students and staff in that classroom? On the other hand, I was relieved. Could this result in the change for which the students and parents were hoping? But I also couldn't help wondering, why, as Curriculum Director, Ms. Hibbard hadn't done something about this before, if she knew it was a problem.

Two days later I walked into the Life Skills classroom about five minutes into the hour to find Ms. Hibbard sitting in a chair in the back of the room. She greeted me, and I nodded to her but deliberately chose a seat far from her in an attempt to communicate to the teachers in the room that I was not aligning myself with her. What I witnessed that hour of Life Skills was nothing like any other day. Mrs. James and Mary asked the students to make a list of places in the city that they often visited, and, as students responded, wrote their answers on the board. The list included places like the mall, the movie theater, the grocery store, the clinic and the YMCA. After students finished generating the list, Mary asked me to give a short explanation about how to ride the bus. I talked about how you needed a bus pass, tokens or cash and coin to pay for a fare and that the fares depended on whether you were a student, adult, elderly or disabled. I also explained how to use a transfer which allows passengers to switch buses at the transfer center. Finally, Mary and Mrs. James divided students into pairs to work together using maps and the online transit website to map routes to various locations. Mary and Mrs. James even mentioned that perhaps one day we would take a field trip to experience the bus first hand. It was, in many ways, one of the

most valuable lessons that occurred in Life Skills that year. Even Addy and Tara, who usually did not willingly participate in activities, talked eagerly about using the bus to go places independently.

Later that day, Ms. Hibbard called me into her office. I slipped into her room quickly, and she shut the door. I felt like I was participating in some undercover mission that I didn't want others to know about. While I didn't record our conversation, I made jottings directly following our visit and used them to write the following exchange.

"That wasn't a typical lesson, was it?" Ms. Hibbard asked. While she hadn't said it, I knew that she was referring to the morning's Life Skills lesson.

"Not at all. It was . . . surprisingly . . . good!" I responded. "Did you tell them that you were coming?"

"I did," Ms. Hibbard admitted. "While I have the right to come in unannounced, I do try to be respectful of the teachers."

"That's very kind of you," I acknowledged, "but I wish you could have gotten to see what a real day is like in that room. Mrs. James was actually there today, which almost never happens. Sophie didn't miss the entire lesson because she was bathroomed before the lesson started instead of in the middle of the period. Mary was respectful. The lesson was engaging. Those things don't typically happen."

Ms. Hibbard agreed. "I know, and I've asked Mrs. James for lessons. I've reminded her that a licensed teacher needs to be in the room but . . . well, I

guess technically you are the licensed teacher in the room most days. I realize that's not your job but it has enabled Mrs. James to get away with being away from the room."

"It is really too bad though," I sighed. "The parents that I've talked to are not happy. Many of the kids don't like it. It is just a really . . . really . . . broken place."

"Well, maybe, with your help, we can change that. Would you be willing to help me put together a training?"

I felt torn. My allegiance was to the kids, and I so badly wanted things to be better for them, but as a researcher, I needed to be conscious of my access to data. I told her that I'd have to think about it. I was worried that, if I participated in a training, the teachers would assume that I wasn't happy about their current practices. I thought that this would result in restricted access to their classrooms and the students. Eventually I agreed to speak with the teachers. I share that experience later in this chapter.

After comparing this day's Life Skills lesson with all of the lessons that proceeded it, and the ones that followed, there are elements that demand further discussion. First, while Mary and Mrs. James clearly have the ability to plan integrated lessons that address the students' interests and topics that potentially impact their independence later in life, they were choosing not to—that is, until they were being supervised. The students' need to learn in and of itself did not seem to be enough to hold the teachers accountable for providing high quality

instruction to students. If this were a regular education classroom, I wondered if this same scenario could have even taken place. To expand this further, on this particular day, Mrs. James was present physically in the classroom for the duration of the lesson, also something that typically did not take place. On most days she left the instruction in the hands of her aide, a woman who lacked formal training in education and the license that was required for her to even be in a classroom with students alone. Whereas typically Mrs. James would have been tending to Sophie's bathroom needs and fetching Eric's breakfast from the cafeteria, that day, those tasks were delegated to aides, something that could be done every day.

Regular education classrooms expect homework to be turned in, assignments and evaluative measurements assessed, grades assigned and all of these communicated to parents through the school's online portal. Life Skills was exempt from this. There were no assignments, no assessments and, beyond behavioral expectations (showing up, doing what the teacher asked), few other course requirements. What I found most frustrating about this was that all of these things were possible. While observing in this instructional void, I thought repeatedly about my own Life Skills experience. While my Special Education experiences were, by no means, perfect, my Life Skills class was individualized, challenging and valuable. My teacher spent time trying to understand my strengths and weaknesses, the things that I wanted to learn and the things she knew I would need to know to go to college. Each week I had assignments that I

needed to complete and turn in and for which I was given feedback. Lessons were scaffolded and grew increasingly more challenging until I was thrust into some very challenging real-life situations that demanded that I pull together everything I had learned. And my classmates were also doing real work in our class, meaningful, but not always the same, work. Whereas a classmate of mine had been riding city transportation and walking the streets of Milwaukee for most of his life, I grew up on a farm and didn't have to cross a street with a stoplight until I was fourteen. Our needs were different. Our instruction was focused and meaningful. Why, I wondered every day, couldn't this have been happening for these students?

While I feel that I have been fairly critical of Mary and Mrs. James to this point, I cannot release Ms. Hibbard from at least a portion of the responsibility. While she collected lesson plans from all teachers, she admitted that she seldom followed up on any concerns. She didn't enjoy confrontation and seemed to avoid it. Additionally, while she knew that Mrs. James never wrote lesson plans, the only action that she took to remedy this was to encourage her, during her teacher evaluations, to do planning. No further action was ever considered. And while I have focused on Mrs. James here, this was also the case for Mrs Matthews, Ms. Marks and Mrs. Gilbert, the other multi-categorical special educators in the middle school. Lesson plans were never submitted, no structured curriculum was in place in any of their classrooms and Ms. Hibbard did not take action to remedy this. She admitted this openly to me and to herself. When I asked her to explain

why, if she knew this was such a widespread problem within the Special

Education Department, she chose not to address it, her answer was two-fold.

First, she felt she lacked the time to pursue these issues more vigorously. She

was the Special Education Director for the entire district as well as the

Curriculum Development Director, and her duties were truly too big for one

person. Second, she feared resistance. While I would describe Ms. Hibbard as a

woman well versed in inclusion and in the critical work being done by scholars in

Critical Special Education and Disability Studies in Education, her staff did not

share her perspective. After several failed attempts to introduce elements of

inclusion as it was intended to be to her Special Education staff and to highlight

the exemplary work being done by one of the special educators in the elementary

school and another in the high school, she admitted defeat. But, with her decision

to give up on her staff and allow them to continue operating within a deficit-model

of disability, she also gave up on the kids as well.

While I have focused my critique almost exclusively on Life Skills,

problems existed in other Special Education teachers' classrooms as well. During

a second hour self-contained science class that Brinna (grade 5) and Sophie

(grade 8) attended together, the aide assigned to work with the students relied on

worksheets taken from an elementary workbook. During a unit on ecosystems,

the two girls colored pictures of animals, cut out the pictures and glued them on

to the ecosystem of the week. When things came up, as they often did in the

Special Education classroom, the two girls would spend an entire hour without

any instruction at all. This happened on at least half of the days that I observed in this classroom. While Sophie and Brinna worked on science, another aide worked with Eric. His work was related to Life Skills. He was given one of a few tasks. He would be asked to sort silverware into appropriate spaces, forks with forks, spoons with spoons, etc. Other times he would be asked to sort other small objects into groups based on similar characteristics.

In another instance that occurred each day during sixth hour, Sophie and Tara attended a pullout class with another of the special education aides, Gina. For Sophie the time spent in pullout was for English, for Tara it was "possibly" reading. I say possibly because, even after an entire year of observing, this never was clear. Gina spent the first twenty minutes of each class period taking Sophie to the bathroom. Before doing so, she told Tara to get to work. Tara took out whatever work she had and worked independently. Once in awhile, she asked me for help with whatever she happened to be working on, sometimes an English writing assignment, sometimes science. Because Gina was in the bathroom with Sophie, Tara was essentially unsupervised (unless my presence was considered) and some days she wandered around the room or put her head down on her desk to rest. Once Gina and Sophie emerged from the bathroom, Sophie was instructed to go to her workstation and was either asked to retype sentences into a word document or complete worksheets from an elementary workbook that required her to match pictures with their correct beginning letter sound. Both of these expectations were mismatched with Sophie's ability, and

she often tried to voice her frustration with her work, calling it "babyish." She

recognized that this work was too easy and that she was capable of much more.

Below is an image of one of Sophie's assignments.

Figure 3: Sophie's Assignment
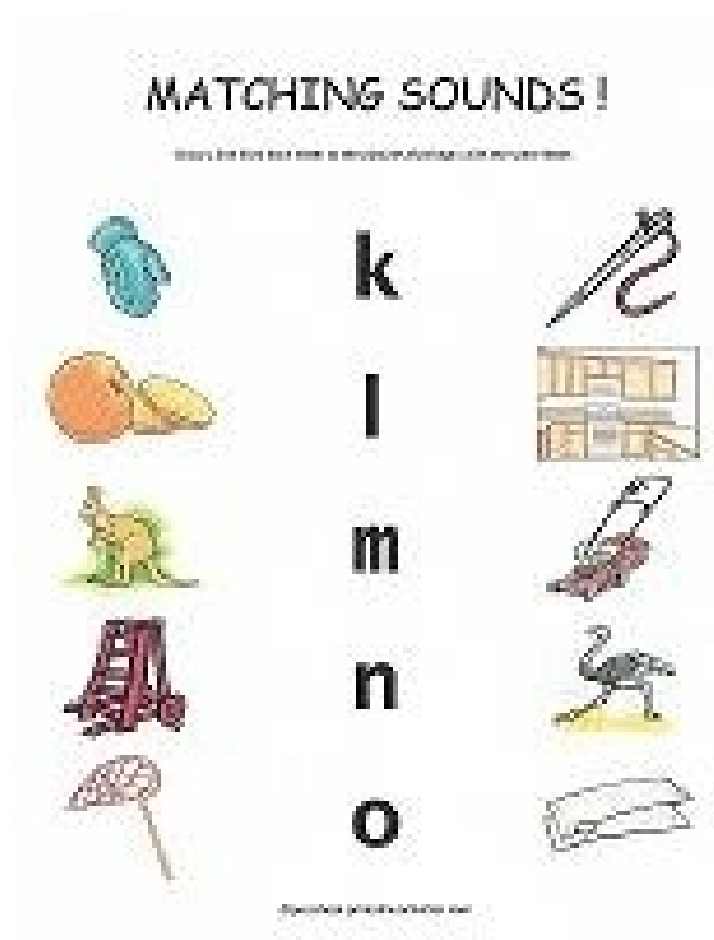
Some similarities existed that cross-cut the Life Skills and pullout

academic classes. First, in both the Life Skills classroom and in the self-

contained pullout classes, aides provided the "instruction." It was commonplace

for the licensed Special Education teachers (who created the schedule for

themselves and their aides) to assign themselves to support inclusion classrooms. For example, while the sixth-hour pullout class was happening with Sophie and Tara, Ms. Marks was in eighth-grade math and Mrs. Matthews was in a fifth-grade classroom. Aides were largely responsible for planning for and finding their own materials for use during pullout sessions with students. Because there was no curriculum available even as a starting point, the aides often resorted to worksheets from elementary workbooks. They were operating under the assumption that, because these students were disabled, they needed simple content, rather than simply a different path to developmentally appropriate content. Additionally, the content that was made available to students in all of these spaces lacked meaningful implications for the futures of students. Counting labels, sorting objects and coloring workbook pictures failed to move students forward in their learning, nor did these activities empower them in ways that prepared them for independent living.

Applying Ladson-Billings's (2009) work related to culturally relevant pedagogy to these classroom environments highlights some of the weaknesses related specifically to academic achievement. Culturally relevant teaching methods communicate to students that they are capable by having high expectations for students. By using materials that were meant for young children and that were far below students' interest levels, teachers were communicating to students that they were not capable of success. When teachers scaffold instruction, this enables students to move from what they know to what they need

to know (Ladson-Billings, 2009). The instructional activities and lessons that were used in these classrooms did not take into account what students knew, nor did they move students onward in developing new understandings. Lessons were repetitive or disconnected from previous learning opportunities.

For students to achieve academically, Ladson-BIllings (2009) stated that the focus of the classroom must be instructional and should continually extend students' thinking and abilities. Instruction and real learning were seldom the case in Life Skills or in the pullout resource room setting. Tasks assigned to students in Life Skills, such as cleaning, making ice packs and counting labels, lacked instructional value. Before these tasks became a regular part of the Life Skills "curriculum," they were activities completed by custodial staff (cleaning) or parents (counting box tops/fluoride). In the case of the sixth-hour pullout class for Sophie and Tara, Tara spent half of each class period without any direct contact with a staff member while Gina tended to Sophie's bathroom needs. In the second-hour science pullout for Sophie and Brinna, when other things came up, their instruction was postponed or abandoned completely. "The message that the classroom is a place where teachers and students engage in serious work" (Ladson-Billings, 2009, p. 135) was certainly not the case. If I were to total the number of minutes students spent waiting for instruction, they literally spent days sitting idly in classrooms. Classrooms were more like places students went to be, but not to learn.

Communicating Expectations Through Words and Actions

Expectations were not only communicated through the curriculum, but also through the things that were said directly to and about students by members of the staff. Early in the year I took note of how many Special Education staff members "talked around" the students. What I mean by this is that teachers, with a great deal of regularity, held personal conversations in front of students, over their heads or in the back of classrooms while students were supposed to be working. Almost daily I observed teachers discussing students' confidential information in the presence of others. On my very first day at CCMS, I listened as two special educators shared with another regular educator that one of their students had just gotten an electronic monitoring bracelet. One afternoon during the spring semester, a seventh grader became so frustrated with Mrs. Matthews, the special educator, that he ran away from school. Not even an hour passed before the teacher was sharing details of the chase with anyone who would listen. Additionally, Special Education staff members regularly humiliated students in public and in private through comments made directly to them about their abilities and behaviors. Several more examples from my fieldnotes illustrate this phenomena.

Sixth hour was about to begin on an afternoon in late October. I returned to the Special Education resource room where Sophie and Tara received their sixth-hour pullout instruction. As I shared earlier in this chapter, on a typical day Sophie would arrive from lunch, Gina would take her to the bathroom and then assign some English work. This week, however, Sophie and Tara were being

allowed to join their classmates for an eighth-grade interdisciplinary career unit taking place in English and reading. Students researched careers, interviewed parents about their professions, completed an interest and skills inventory and, as a culminating activity, prepared a short paper and speech related to the student's chosen future career. As an extra credit option for the unit, students could complete a job shadow. They would be excused from school to spend a day observing someone in a position that interested them. While 20 eighth-grade students took part in the job shadow opportunity, no Special Education students participated. Tara expressed interest in doing the job shadow, but this was not permitted. An aide told me that the logistics of allowing Special Education students to participate would have been too difficult to manage.

The following scene was reconstructed from fieldnotes.

I walked into the resource room, greeted Gina and put my things down on my desk. Gina asked if Sophie was on her way up to the room, and I responded that I was sure she'd be there soon.

Gina sighed, "It hardly pays for Sophie to go to class. By the time she gets there, class is more than half over."

I nodded, acknowledging that Sophie did miss a lot of the class period. The elevator that Sophie needed to take between the cafeteria level and the seventh/eighth grade wing was slow, and Sophie did not travel quickly through the halls in her chair. None of these things, however, were within Sophie's control. Additionally, once Sophie got to the classroom, Gina needed to take her

to the bathroom and get her changed for her afternoon classes. By the time Sophie made it back to the library, where her classmates were doing research, almost twenty minutes would have passed.

"And it is not like she's getting anything out of it, though," Gina responded.

"She does seem to really enjoy it." I tried to defend Sophie, even though I was terrified of Gina's dominating personality.

"Yeah, but it is a waste of time. Researching careers? Really? Let's be realistic. Sophie will be lucky to get a job as a Walmart greeter. . ." Gina trailed off because just as the words left her mouth, Sophie came through the door of the classroom.

"What did you say about me?" Sophie asked with an angry tone in her voice.

"What we talk about when you're not here is none of your business," Gina snapped. "Now get in the bathroom so we can get you to class."

Gina's words, *Sophie will be lucky to get a job as a Walmart greeter,* echoed in my head for weeks. I couldn't shake my disappointment and anger over this belief that Gina harbored about Sophie's future. I came to learn that Gina was not alone in her visions of the future for students with disabilities. While there was an exception in one of the aides, Valerie, many of the teachers openly communicated their belief, or lack of belief, in the kids they were hired to educate. I couldn't help but asking, what did this say about their work as professionals? And, personally, what did this all mean for their perception of me?

After all, I was like the students with whom I was conducting this work. I too, was disabled. Was I not supposed to be successful?

Over the next week, the career unit continued. I encountered more negative attitudes about the abilities and futures of other students with disabilities. While Sophie was allowed to attend reading class, when I asked her if she was preparing the speech, she said that she didn't have to do it. She and the other students were allowed to attend but not held accountable for any of the work. I had assumed that if students were present for the instruction, they would be held accountable for the assignments as well. I came to understand that this lack of accountability and expectation were common. During a recorded conversation with Mrs. Marshall, the English teacher, I asked why she thought this happened. She explained:

> I'm not really surprised. The kids were probably allowed to come, kind of as a "feel good" exercise, but not really because they (the special educators) actually thought the students would ever have real careers. I think these students are capable of doing the work. I do! But sometimes I'm told that I should just lower my expectations, give them a good grade because in the end, it really doesn't matter.

Mrs. Marshall had come to understand over time that while she valued holding students to high expectations, something she frequently communicated to all of her students as part of her teaching routine, the Special Education staff did not expect her to have these same expectations of the Special Education students.

In fact, during the Holocaust unit in mid-March, while a female student was working diligently on her research project, creating depictions that demonstrated a firm grasp of the content, Ms. Marks, the special educator supporting her work, said, "stop taking so much time with this. No one expects you to do so much work." When the student tried to argue, saying that she was following the guidelines provided to the entire class, the special educator replied, "Well, Mrs. Marshall is not expecting that kind of work from someone like you."

While the special educators and some of the aides may have made up their minds about these students and their future prospects, the students tried to hang on to their own visions. Tara hoped to earn an associate's degree so she'd be able to work as an educational aide in a Special Education classroom or in an early childhood setting. Sarah planned to go on to college and eventually law school in hopes of becoming a defense attorney. Addy wanted to take up a career in the medical field as a pediatric nurse or someone who provided child life therapies for sick children. While Sophie wasn't sure about a job after graduating high school, she hoped that one day she could live independently. Other Special Education students who participated in the career unit had future career objectives that included video game programmer, author, teacher and professional singer.

During the career unit, I tried to encourage students to pursue these dreams. As I helped them prepare their research papers and speeches, I answered a lot of questions about what it was really like to go to college. *Was*

the work hard? How did I find a job? Did I still get Special Education help in college? I talked with them about resources that existed for supporting students with disabilities in college, but I also shared some of the challenges. I wanted them to realize that their dreams could be a reality, but that, at least in my experience, managing a disability in higher education and in the workplace did take some additional thought. I shared with some students that I was told more than once that I could never be a teacher because blind people couldn't teach sighted children, but that I didn't listen to what people said. I wanted them to know that I defied other people's expectations of me and that they could do the same. Just because someone told them that they couldn't be something, or do something, didn't mean that it was true. I worried that if students continued to hear messages about what others thought they could or couldn't do, they'd begin to believe it. This was my small way of offering a different perspective.

The hopelessness communicated by staff and lack of expectations for students extended far beyond the eighth-grade career unit. Earlier in this chapter I highlighted the experiences of students in the first-hour Life Skills class. Low expectations were communicated to students in that classroom in ways other than through a lack of curriculum.

As highlighted earlier, Mary and Addy had a tenuous relationship from the start of the school year. Addy was a willful student. Unlike many of the other students in first-hour Life Skills who sat passively by while teachers talked about them, Addy did not hesitate to share her feelings of irritation with her instructors.

When Mary assigned a task that Addy found futile, she told Mary that the task was useless. She resisted in other ways as well. Instead of doing an activity that Addy found pointless, she would lose herself in reading. As Addy put it, "at least when I'm reading, I am learning something." While as a former classroom teacher I could empathize with Mary's frustration with a student who defied repeated requests to complete an activity, as an observer I could see why Addy did what she did. She was a capable, smart young woman, and she wanted to spend her time doing activities that mattered, things that taught her something.

In mid-December, Mary and Addy were having another of their bad mornings. Mary asked Addy to complete a Christmas ornament for her parents. Addy refused, arguing that she had social studies homework she needed to finish for second hour. Mary responded that this should have been done already and if she hadn't finished it by now, that was too bad. The following conversation was taken directly from my audio recording.

Addy crossed her arms at her chest. "I'm not doing the ornament. It is just another one of your stupid projects."

"You are going to do the project," Mary ordered.

"It isn't even mine!" She said this because Mary had done a lot of the work on the project for the students already.

Mary grabbed Addy's social studies textbook. "I'm keeping this until you do what I tell you to do. Now, get into the kitchen!" Addy didn't move.

Mary came over to Addy's desk and hovered over her. "That's it. I've had

it. You are not going to get ANY points for today."

"Oh well," Addy responded. "Can I have my social studies book back?"

"No!"

Just then the bell rang.

"I have to go to class. Can you please give me my book back?" Addy pleaded.

"No! You can go to class, but I'm going to call Mr. Larson and tell him you won't have your work done because I took it when you wouldn't do what you were supposed to in my class."

"I need my book!" Addy protested.

"Go to class!" Mary said again. She stormed over to the phone and dialed Mr. Larson's number. He didn't answer, but Mary left the following message on his voicemail.

Hi Mr. Larson, this is Mary. I have Addy here. She tried to do her homework during Life Skills today so I took it from her. She won't have it today. Feel free to discipline her accordingly (just then the final bell rang, and Mary continued) *and now she's refusing to come to class and will be late. Please be sure to mark her tardy.*

"There!" she hung up the phone. "Now go to class!"

"This is so stupid!" Addy half yelled, half cried. "I just want my book. I just wanted to do my homework!"

"You know, young lady, you need to learn who is in charge. You do not get

to decide how the world works. If you act like this, you will never have a job, you will never be anything!"

Addy must have had enough because she grabbed her backpack and stormed out of the classroom. I closed my computer and began packing up my things to move on to my next class.

"Can you believe that girl??" Mary asked. "The things I have to put up with!"

"I'm going to take a walk up to the eighth grade hallway to be sure she made it to class," I responded. I quickly left the room and ran down the hallway. Addy was slowly walking toward her class. I came up behind her and put my hand on her shoulder. "Are you okay?"

She shrugged, "Yeah."

"I'm sorry that happened. I will get your book back and bring it to English class."

"I hate that class, and I hate her! We never do anything and she makes me feel so stupid!"

"You're not stupid, Addy. Please believe me when I say that."

"Yeah, okay." We reached the door to her social studies class. "I'll see you later," she said.

During lunch, Addy ate uncharacteristically fast. She was always the last one done eating. When she'd finished eating, she asked if she could be excused to go to the Life Skills classroom. I agreed but was intrigued by why she would be

going there, so I followed at a distance. I watched Addy storm into the classroom.
I remained in the hallway outside the classroom and while I didn't hear
everything, I heard bits and pieces of the actual conversation and versions of the
story the next day from both Addy and Mary confirmed what I'd heard. Mary had
been eating lunch alone in the Life Skills kitchen when Addy burst in and said:

> I have something to tell you. You Are Nothing! You always tell me
>
> that I have to be more respectful, but you never show me any
>
> respect. You tell me that I will never be anything. I will be
>
> something some day, and when I am it won't be because of any
>
> help I got from people like you.

When Addy shared with me that when she said this to Mary, she did so
with a sense of pride. She felt good about finally telling Mary how she really felt.
Addy recognized that the things that Mary was saying about her didn't have to be
true. Mary, on the other hand, couldn't understand why Addy would say these
things to her, "after ALL that I've done for her!" Mary went on to share that she
immediately went to Mr. Williams, the principal, and filled out a disciplinary
referral. Mary proudly stated that now Addy faced possible suspension because
of the disrespect she demonstrated toward a staff member.

What is most unfortunate about the exchanges that occurred between
Addy and Mary over a period of months was that, while Addy was demonstrating
defiance, she was doing so to preserve her identity. This was her way of resisting
Mary's messages of hopelessness. And, truly, Addy was able to see the situation

in Life Skills for what it was: a place in which real learning was not occurring. Mary did not seem to feel it necessary to act with respect toward Addy or any of the other students in the class. While she expected respect to be shown toward her, she did not give it in return. She used her power as an abled adult to further oppress these students and to, as she said, "put them in their places," which seemed to mean as submissive, powerless beings.

Nearly two years after leaving this school, this situation and the sights and sounds of the many instances of public shaming that happened there have stayed with me. Mrs. Matthews and Ms. Marks almost daily, and some days, multiple times per day, pulled students from their regular education classrooms, escorting them out into the hall only to yell at them about various things while the classroom door remained open. All of the students in the classroom were able to hear these conversations as could anyone in the hall walking by.

Over the course of the year, I gathered recordings from several public shaming events. Ms. Marks, to a female eighth grader who didn't turn in an assignment: "What the hell were you thinking by not turning that in? What are you, stupid? Thinking I wouldn't find out?" Another day, to Matt, an eighth-grade male, "So you screwed up again. Can't you do anything right?" Or, "Can't I trust you to do anything right or do I need to hold your hand for everything?" The contexts in which these statements were shared varied but were often tied to missing assignments or disciplinary infractions

While one might argue that students need to be held responsible for their

mistakes, my point in sharing these examples is to note how it was done. First, students were reprimanded in public places. Anyone walking by or sitting in the nearby classroom could hear. Second, students were rarely, if ever, given the opportunity to tell their own side of the story. Teachers dictated the conversation using information they'd received from an adult source. Students were not given an opportunity to speak for themselves; they were silenced. Third, the public way in which these shaming sessions were handled seemed to suggest that students were not worthy of being treated with respect and weren't dignified enough to deserve private conversations. And finally, students without disabilities were able to witness the ways teachers spoke to and about students with disabilities. To hear their classmates being called stupid and watch them being yelled at by teachers may reaffirm that these students were, indeed, incapable. Students without disabilities would never be disciplined in this manner, so this must mean that these disabled students were less than human.

I know that these public disciplinary measures taken by special educators did not go unnoticed by non-disabled students. During an eighth grade journaling activity, Mrs. Marshall asked students to reflect on ways they had seen or not seen students and adults acting with respect to others throughout the school. I've included two journal entries here. The first is from an eighth-grade boy who wrote:

I'm really glad that I'm not in special ed because I think it would be really embarrassing to be one of those kids when their teachers

take them out in the hall and yell at them. I've never had that

happen to me and I'm glad. I feel bad for those kids when it

happens.

An eighth-grade girl shared the following:

I think it is totally ironic that as part of PBIS we are always

supposed to be respectful and if we don't do it we can get a

consequence but teachers don't seem to have consequences. I

have friends who are in special ed and I can't believe the way that

these teachers can talk to those kids. I feel sorry for them. As if

having a disability wasn't bad enough, but then you get yelled at

too. How come teachers can do that?

These two excerpts highlight that not only are students recognizing these

instances of shaming, but that they evoke emotional responses. As the second

student shared, it is bad enough to be disabled, but then to be disrespected as

well is even worse.

While I have been fairly critical of the Special Education staff for the ways

in which they publicly spoke to students in demeaning ways, this was,

unfortunately, a fairly common practice of two of the general education teachers,

Mr. Gee and Mr. Janke, as well. Mr. Gee, a seventh-grade teacher, almost daily

made comments directed at the students with disabilities in his third-hour

inclusion math class. There were six Special Education students in this class as

well as a female student who recently arrived in the United States from Vietnam.

Mr. Gee operated under the assumption that it was not "his" job to educate "those" kinds of kids. That is why we (the Special Educators, aides and myself) were present in class. Alaina, one of the Special Education students in the class, often struggled with the content. Repeatedly, Mr. Gee called on her, saying things like, "Let me guess, Alaina, you don't get it, right?" "Probably didn't do your homework again, did you, Alaina?" Another day, "If you don't start trying harder in my class, Alaina, you're going to end up pregnant and alone like your teenage sister."

Other students were not immune from Mr. Gee's biting remarks. Mitch, another of the students with disabilities in the class and who had a particular strength for math, tried to participate. While sometimes he offered comments that only served to produce a laugh from his classmates, more often than not he had the correct answer. Even then, comments reserved for Mitch included, "Really Mitch, if I call on you, are you just going to waste our time again with another of your stupid comments?" "You don't mean to tell me that you actually understand this material? Who did you copy from?" Another day when Mr. Gee was particularly verbal, he walked past Mitch's desk and blurted, "God, Mitch, really?" He waved his hand in front of his nose. "If you're going to fart, go do it somewhere else. We're trying to learn here." When Mitch tried to argue that he didn't do it, Mr. Gee sent him next door to the Special Education room for disrupting class.

While Mr. Gee did tease other students without disabilities in his classes,

these comments were more likely to be something like, "Come on Devin, if you make us wait much longer, I'm going to retire." He frequently joked with the athletes in the room or students interested in music (because he both played basketball and played in a band). He never spoke to Than, the female student from Vietnam, directly. Any communication he had for her would always go through me. In fact, one day, I was spending third hour in another classroom assisting with a holiday project, and he sent a student to fetch me because he needed me to help Than with something. When I arrived in his room, he angrily handed me two pieces of paper and told me that next time I needed to be there because he didn't have time to help students like Than. It seemed as though if students didn't fit the English-speaking, able-bodied image of the ideal student, Mr. Gee had little time for them. In his classroom, he not only dehumanized students with disabilities, but by doing this publicly, he was demonstrating that this was an acceptable way for an adult to treat students.

This was not the only classroom in which this happened. During the first week of school, I was approached by a Special Education teacher and asked if I could spend some time in Mr. Janke's tech ed class. I agreed but asked why it was an important place to be. Mrs. Matthews explained that it was rumored that Mr. Janke made extremely disrespectful comments about the students with disabilities in his classroom. She reasoned that if I was present, perhaps he would keep his comments in check. It seemed as though she was sending me in hopes that my presence would protect the students. No such luck. While I was

not able to record any of the classroom discussions because I was not granted permission from the instructor, my role as observer enabled me to take very detailed fieldnotes that in turn allowed me to provide the following examples.

One afternoon I arrived to class before Sophie. It took her an extra five to ten minutes to make it to this classroom because it took place in the high school and required three separate elevator rides. I sat in the back of the classroom as the teacher introduced a project. At the end of his explanation, he clapped his hands together and said, "Well let's get started. The retards aren't here so we should be able to get lots done." His use of the "r-word" was met with some gasps by some of the students, who had all been through the sixth-grade disability unit where they signed the pledge to end the use of the r-word. Mr. Janke seemed unfazed. To him, "retard" must have been equated with those students with visible disabilities because as I looked around the room I noticed three students whom I knew received services in Special Education for learning disabilities. What did that statement do to them?

Unfortunately, Mr. Janke's comments did not end there. During a group project to build a contraption that involved five steps to move a marble from point A to point B, I witnessed him blaming students with disabilities for mistakes. One day he turned to Sam, an eighth grader who was on the Autism spectrum, and said, "Did you screw this thing up?" Sam hadn't even been there the day that the other two males in his group had measured and assembled a piece of their project. Another day when Mr. Janke was assessing a group's final project, as he

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made marks on the rubric, he asked, "did everyone in the group participate?" The girls, which included Sophie, all indicated that everyone helped. Mr. Janke paused and nodded toward Sophie. "Even her?" When the group indicated unanimously that she'd participated, he went on: "No, I doubt it." He deducted two points from their grade simply because he didn't believe that Sophie had helped. It is important to note that, while he was not well liked by many students, he reserved most of his insulting remarks specifically for the students with disabilities. Many of the students in Special Education begged for schedule changes so they could be removed from this "required elective"

Earlier in this chapter I shared that teachers not only said things directly to students, but often spoke about them in front of them. I would like to explain this further. In Life Skills, during the first semester when both Mary and Ms. A, the student teacher, were present in the room, there were days when they proceeded through lessons as if students were not there. Ms. A loved to talk about herself, and she shared intimate details about her relationship with her ex-husband or her current boyfriend and his irresponsible step-daughter. Mary would talk to Ms. A about her elderly mother, her invalid, disabled daughter, her frustration with the administration and her desire to retire so she could "get out of this place." While these conversations were going on, students worked quietly.

Another aide, Diane, frequently talked about her irritation with some of the Special Education students. She complained about how Brinna didn't ever want to try new things and how Eric really drained her nerves with his constant yelling.

On the day that we had arranged to do our interview, she showed up with Eric and Brinna in tow. I told her that I was happy to reschedule for a time during which we could talk privately and she declined. Her response to me was, "it is okay. I can speak openly and honestly. They won't understand anything we say anyways."

In the seventh- and eighth-grade Special Education resource room, sixth hour was often a time during which Ms. Marks and Mrs. Matthews would "debrief," which was their translation for "talking about students," even though Sophie and Tara were in the room. One day I listened while Mrs. Matthews described an IEP meeting from the day before during which a mother cried when she found out that her son would qualify for Special Education. At one point she stated, "If I was that mom and had that kid, I would cry too to know that he'd finally get some help." Another day Mrs. Matthews talked about another mother's relief after her son was released from Special Education. Frequently, the two would talk about the legal issues that certain families were facing. It was during these sixth-hour "sessions" between the two female teachers that I learned about one of the dads who spent every night at the strip club and brought home a new woman almost every night. Another time I learned that Sophie, Sarah and Stephanie's mother was having Stephanie trained as a PCA so that essentially Stephanie could make money for taking care of her disabled sisters and that this would be an additional source of income for the family. All of this was discussed in front of two other students. One afternoon Mrs. Matthews wanted to explain a

particular situation in which I was involved related to one of the students. I asked if we should discuss it in her office, and she waved away my request saying, "Ehh, it's okay. They probably don't really get it anyways."

There seem to exist several assumptions about students at work in these situations. First, teachers seemed to assume that if students had a physical or learning disability, they also weren't able to understand and take in information from conversations taking place around them. I don't believe this is true because on multiple occasions Sophie and Tara wanted to discuss information they overheard Mrs. Matthews and Ms. Marks discussing during sixth hour. Second, teachers also seemed to find it acceptable to carry on adult conversations rather than delivering instruction to students and engaging students in conversations that were student-focused. The time that Mary and Ms. A spent discussing their families could have been better spent interacting directly with the students. Finally, teachers failed to act with discretion in relation to students' personal information. Their justification was couched in a belief that it didn't matter because students didn't understand anyway. It also seemed as though, because they were the "experts," the professionals who supported these students, they were entitled to discussing students publicly at will.

My concerns related to the beliefs that teachers at CCMS harbored about their students were confirmed in a very formal way during the beginning of May. After several conversations with Ms. Hibbard, Director of Special Education, I agreed to stay after school one Thursday afternoon to sit in on an all-Special-

Education-staff meeting She offhandedly mentioned that she'd love it if I'd say a few words about my own experiences as a student with a disability going through the public school system. Ms. Hibbard rationalized this request by telling me that she hoped this would help the teachers see that, with the appropriate educational support and opportunities, students could be successful. I was nervous. I shared my apprehension with Tim, my adviser, and, while he warned me that I could be putting myself in a volatile position, I agreed to speak regardless. I should have listened to him.

On the afternoon of the meeting I walked into Ms. Marks's classroom to see that the students' desks, normally in rows, had been arranged in a circle. I took an empty seat between Valerie and Mrs. Matthews. She did not know that I would be speaking that day. As we waited for the meeting to start, we exchanged stories about what mischief our children were getting into these days. My nerves were getting the best of me ,and I was shaking enough that she asked if I was cold.

As Ms. Hibbard opened the meeting, I began to record our conversations. What follows is taken directly from my transcription.

After thanking everyone for coming, Ms. Hibbard introduced me. "I've brought us all together today so that we can consider our work with students and our perceptions of their abilities. We have a great group of kids, wouldn't you agree?" Heads around the room nodded. She went on, "But sometimes I think it is easy to lose sight of what students are capable of doing and that's why I've

asked Lisa to share with us her own journey through the K-12 setting. I think we would all agree that Lisa is a remarkable woman, devoting her year to us while teaching, raising a family and completing her Ph.D." Again, heads nodded. "So, Lisa, with that, I'll offer you the floor."

I swallowed hard before launching into a story that I'd been crafting all day. I'd been trying to figure out how to restory my life in a way that would be palatable to these people whom I feared would not be receptive. I shared that, upon entering school at age three, I spent just short of three years in a self-contained classroom for, using the language of the early 1980s, the mentally retarded. I never mixed with "normal" students. I recalled how, just before turning six, I earned my way into the regular classroom by surprising everyone with my understanding of kindergarten concepts. From there, I was serviced one to two times a week by a teacher of the visually impaired. I learned to type at age seven and learned to rely on audio texts for reading and typed my assignments. By fifth grade I was writing simple computer programs, was typing 75 words per minute and was excelling academically in my classes. In eighth grade, after moving to a new school, I encountered teachers who did not know how to work with me. I was allowed to sit in my eighth-grade classes, turn in nothing and still receive As because I was "a good kid." During a career unit when I expressed interest in being a teacher, someone commented that I must mean that I wanted to work with other blind people because I couldn't possibly think that I could work with the sighted. That year, I was physically assaulted, plagued with death threats on our

answering machine and dismissed by school officials who said that I must be making up these stories because I wasn't able to identify the culprits (because I couldn't see them). My mother was a wreck.

During my freshman year, I began attending a school an hour away from my home and was thrust into a strong Special Education program. I was taught how to read Braille, how to travel with a cane and how to live independently. I shared that in my Life Skills class I not only had to cook but had to visit colleges, have conversations with career counselors and had to learn to use public transportation. I discussed the access I had to AP classes and the inclusivity with which most of my teachers approached my presence in their classes in high school.

Mrs. James was the first to speak. "While I think your story is inspiring, it isn't realistic. I mean, really, growing up in the 80s, you are lucky your parents even sent you to a real school and didn't just institutionalize you or send you to the School for the Blind."

I stuttered, "Yes, I guess you are right. I was lucky. But I don't know that my story is unrealistic."

She continued, "But it is. I mean, a few of our kids *might* be able to go to college but most of them. . ."

Ms. Hibbard interrupted, "I think Lisa shared her story to offer a personal perspective. I think it should remind us to be aware of how we communicate our expectations to students. We should believe that all of our kids can be

successful."

Ms. Marks jumped in, "But I think we do that. I mean, we have a career unit. We have Life Skills."

Mrs. Matthews added, "Yeah, but even so, let's be realistic. Some of our kids aren't going to be independent, ever."

Mrs. James snapped, "So was this just some way of telling us that we're not doing our jobs here?"

"That is not the case at all," Ms. Hibbard responded.

I worried that eight months of dissertation data was on the line and in that instant, I decided to lie. "I think you are doing some really amazing things here. I hoped that my story would remind you of the influence you have in students' lives. Without some of my teachers, I would not be the person I am today. You could all be that same inspiration to these students, but you may not know it for years to come. It might not look like me, an almost Ph.D., but success will look different for each student," I offered weakly. I didn't really know what else to say. Clearly this had been a bad idea.

I looked around the circle of teachers. Mrs. James slumped in her seat. Ms. Marks excused herself, saying she needed to get to daycare to pick up her kids. Valerie smiled at me sympathetically before she, too, stood up, saying that she needed to get down to Study Club to help some students with a project. Ms. Hibbard just let them go. And I sat there, hurt.

I went home after the meeting and cried most of the night. To say I felt

broken would be an understatement. I felt disempowered and alone. I realized that while I had been operating within this illusion that I could be an "insider" in the lives of these teachers, when I spoke out from a student's perspective, my outsider status became central. To most of these teachers I couldn't be both disabled and successful.

Success was an exception, not a reality.

An Exception with Expectations

With an extensive focus on the low expectations and lack of curricular focus that permeated much of the Special Education Department at this school, I would be misleading if I didn't pay some much deserved respect to those within the system who worked for and with students in powerfully positive ways. Earlier in this chapter I introduced you to Valerie. I first met Valerie in Mr. Janke's tech ed class. We hadn't been formally introduced, and she asked if I was a student teacher. I shared that I was at the school gathering data for my dissertation study. She asked what it was about, and our friendship grew from there. She shared her own experiences as a mother of two twin daughters with Cerebral Palsy, how she felt so frustrated by the challenges that her daughters faced in the public school system and how now this was the inspiration that kept her coming back day after day to Cinder City Middle School.

As Sophie and Sarah had aged through the school system, Valerie had trailed up through the grades with them from kindergarten to what was now eighth grade. She shared many warm and happy memories of the girls from their

younger years. The special educators in the elementary school often took the girls out of their chairs so they could be close to their peers. Valerie took them out to recess and was an active participant in advocating for an accessible playground equipped with ramps and swings that the girls could use. Valerie shared that, through fourth grade, the girls were almost fully included in the regular classroom with the exception of therapies and personal care needs. When they entered middle school in fifth grade, this changed, particularly for Sophie. Scheduling aides to be with Sophie became "a hassle" for special educators, and it was decided that Sophie wasn't really getting anything out of her classes anyway, so she was pulled from all regular education classes at sixth grade. Sarah was able to remain in her classes because, by this time, she'd learned to use a walker and was more independent.

Valerie was furious. She believed firmly that Sophie's teachers were underestimating her abilities and were severely limiting her opportunities to build and maintain relationships with peers. "What is she really getting out of sitting in those self-contained classes. . . Nothing!" Valerie shared during one of our many talks. Valerie was not afraid to tell the special educators how she felt, though she had a way of doing it in the most gentle, but strong, way. Her attempts to advocate for the girls, and for many other Special Education students in the eighth-grade class, however, were dismissed. Once I witnessed a teacher offering an "out" (an easier assignment) to one of the Special Education students. Valerie intervened, saying, "Sam, I know you can do this. You can, can't you?" In

the end, the student completed the same assignment as the other students. In an art class, while all of the students were assigned to make a portfolio to hold their work, the instructor suggested that Sophie could just use a blank piece of paper to hold her work. Valerie said, "Sophie will be doing the work." And Sophie did.

It was truly remarkable to watch Valerie in action. In the classroom where many special educators and aides would "get in the middle of" students' social time, Valerie stood back and let students be with other students. She not once said a negative thing to any student or about any student to me or to a student. When supporting students in classes, she often could be found in the back, not disengaged, but completely aware of what all students were doing. She seemed to have this keen sense of knowing when students needed her, or she would wait for students to ask. She could also be found working alongside any student, not just those with disabilities. As I shared earlier in her introduction, she was of the mindset that all of the students were hers. She was there for everyone. As students left for the day, Valerie stood in the main hallway and had departure messages for many of the students. She checked in with students who had difficult days and commended those students who had great days.

Valerie knew the kids and used what she knew about their personal lives to connect with them, to understand them. When something important was happening in the life of a student, Valerie remembered and would somehow recognize it. When Alex, a shy student in Mrs. Marshall's fourth-hour English class, was celebrating his birthday, Valerie made his favorite treat for the class.

When a student did well in an extracurricular activity, she was sure to compliment him or her.

She could also be heard prompting students who needed extra encouragement to complete work. "I better see that English story tomorrow," or, "just a little more work on that math and you'll have it done." I believe that she epitomized what Ladson-Billings would consider a culturally relevant pedagogue.

Valerie distanced herself from the other special educators and aides. Whereas most aides had work spaces in the various Special Education rooms, her workspace was in the community room. While this space offered little privacy and was shared by many entities in the school, Valerie said it was worth it. She refused to participate in any negative conversations related to students, and, as a result, she seldom joined other staff members for lunch or other celebrations. She aligned herself with the students, and the students knew it and loved her for it.

The other Special Education staff realized that Valerie was "for" the students, as well. I'm not sure they liked it much. One afternoon in seventh/eighth grade study hall, an eighth-grade male student was celebrating a good grade on a math test. He asked Ms. Marks if he could go tell Valerie about the grade. She agreed reluctantly, but under her breath I heard her mumble, "probably just so he can get a treat." The prevailing feeling held by the special educators and some of the aides was that Valerie "babied" the kids. Valerie, on the other hand, saw it as loving the kids. In her decision to be "for" the students, she became part of the

"Other."

And there were others, too, who worked "for" students. Ms. Ana, whom you met in Chapter 4 as the educator who established a comprehensive Disability Unit, aligns herself as one who works for and with students. While her Disability Unit may have reaffirmed some negative thinking associated with the medical model of disability, she is trying and learning along the way. It is, admittedly, difficult to change one's thinking when Ms. Ana and other educators like her were trained in teacher education programs that supported a deficit model of special education. That aside, her classroom was a positive place for students. She provided opportunities for all students to be successful but maintained high expectations for everyone. In conversations with both sixth and eighth graders who had Ms. Ana as an English teacher, I heard comments like this: "Ms. Ana was so hard. Her assignments took SO much time but I learned a lot." "I loved sixth grade English and kind of hated it at the same time because it was hard!" "Even though I didn't like all of the work in sixth grade English, I loved being in Ms. Ana's class. She was funny but tough and I always knew she cared." Not one student whom I interviewed indicated anything other than feeling loved but challenged by Ms. Ana.

Ms. Ana also resisted the actions of special educators who were assigned to her classroom and, as a result, faced isolation. During what was supposed to be an anonymous school-wide survey, Ms. Ana submitted a critical commentary related to the actions of many of the special educators with whom she had been

working over the years. It read:

> I do not have faith that the special educators in this building are
> really invested in the students and of embracing inclusion. There is
> still a dichotomy of ours vs theirs. I would prefer to do the work of
> inclusion myself because when they are in my classroom, they
> make it worse.

The Special Education staff members were so outraged that one teacher went from person to person in the school confronting individuals until it was found out that Ms. Ana was the author. The special educator and aide who supported her students would barely look at her for days. Ms. Ana didn't care. She deliberately skipped the end of the year staff gathering to spend time talking with me. She explained, "someone had to put it out there and I don't care that they know it is me. They need to hear the truth, and the thing is, I'm not the only one that feels this way. I'm just the one that was bold enough to say it."

Mrs. Marshall, another of the eighth-grade teachers who has been featured in this chapter and throughout this piece, was another teacher who faced isolation because of her decision to resist the normative practices of special educators. After watching special educators disrupt her classroom day after day by calling out students in dehumanizing ways, she put in a request with Ms. Hibbard to have the special educator assigned to her removed. While the request couldn't be fulfilled because several of the students' IEPs read that they needed to have support in their academic classes, it was promised that she

would have a "good aide" (i.e., one who supported students in a more positive way—Valerie) the following school year.

Mrs. Marshall often took the time to talk with students after class or during her lunch periods. In late March, after watching the morale in her fourth-hour inclusion English class diminish because of the special educator's presence, Mrs. Marshall asked me to accompany her to a meeting with the principal. She provided extensive evidence to support the abuse of students' humanity that was occurring in her classroom. She recounted several instances in which students were shamed. She shared how the special educators had "loaded" her fourth-hour class with fourteen students with disabilities, an additional six who received title services and four others who were known discipline problems because, as the special educator had put it, "no learning is going to happen there anyways." She tried. She tried hard to work for change. Unfortunately, the principal said his hands were tied but that hopefully next year's promised schedule change would lead to improvements. Because Mr. Williams went on to retire at the end of the 2012 school year, no changes actually occurred for Mrs. Marshall's classroom, and while she continued to work to support students and provide a safe space for them in the school, she has given up the fight. She has since submitted her resignation and will be leaving the teaching profession in June, 2014. She gave her reason for leaving as an inability to function in a system that breaks kids instead of builds them up.

Conclusion

This chapter has presented findings related to how the curriculum and the adults who function within this particular school did not support students' development into empowered young adults. In part one of this chapter I provided examples of how the Special Education curriculum to which students had access for pullout classes and Life Skills did not match their needs. While students wished to learn how to live independently and to explore future careers, they were relegated to counting and sorting activities. Instructional activities in pullout classes were planned by aides who lacked formal training in developing and selecting appropriate materials for students. Sophie and others were "learning" from coloring pages pulled from elementary workbooks. Activities like these communicate a belief that students do not need to be equipped with "real" life skills because most will not ever live independently or participate in gainful employment.

Whereas inclusive classrooms should provide high quality instruction to support students as they grow into high achieving, empowered adults, students at Cinder City Middle School faced a different situation. The instruction provided in pullout classes did not provide them with access to the same content as their non-disabled peers. Instead of offering different paths of learning the same material, they were exposed to "dumbed down" material that failed to move students forward in their learning. While students in eighth-grade science were identifying rocks and writing simple chemical equations, Sophie was coloring animal pictures. In some cases, instruction wasn't even being provided during

pullout classes. For Sophie, Tara, Brinna, Eric and others, this translated into hours and days of missed learning opportunities.

In part two of this chapter I shared several examples of how expectations of individuals with disabilities were embedded in the things that teachers did in the presence of students. I shared the example of the teacher who brought two students with disabilities to an interview and was willing to talk freely about her job and her feelings regarding students and parents in their presence, justifying this as acceptable. She didn't believe they had the cognitive ability to understand anyway. In other instances, teachers carried on their own private conversations as if the students weren't even in the same room. I also shared other examples. Other teachers found it within their right to openly discuss students' confidential information from IEP meetings as well as personal information about their families and academic performance in front of other students. Again, teachers felt comfortable doing this because they operated under the assumption that students didn't understand what was being said.

Other times, expectations about individuals with disabilities were communicated in very direct ways. Mary felt comfortable telling an eighth-grade student that she would "be nothing" and could not understand why Addy repeatedly resisted her demands. Other special educators reprimanded students in public places, essentially shaming the students in front of their general education teachers and non-disabled peers. Not even I was exempt from their hurtful comments, and this became clear when I was told that I was "not like

these students" because I was, in their eyes, successful. For some of these teachers, success and disability were mutually exclusive. You could be one or the other, but not both.

There were, however, pockets of hope at CCMS. Valerie, Ms. Ana and Mrs. Marshall, in their own unique ways were resisting the actions of the Special Education staff. Valerie clearly aligned herself with the students. She pushed them when they needed an extra nudge, supported them when they struggled and congratulated them when they accomplished a goal. Ms. Ana made her classroom a challenging environment, and she pushed her students but loved them at the same time. And for Mrs. Marshall, her story was bittersweet. She worked hard to make her classroom a place in which students felt supported. She communicated high expectations of all students every day, but after years of hiding her own invisible disability from students and staff while witnessing the violence being done to students in her classroom, she felt too broken by the system to continue. And while these teachers and aides were not perfect, they were trying. They seemed to understand that while there is not one way to be a perfect teacher, there are many ways to work for change and to make a difference.

Chapter 6: Detention with Matt: Our Little Barred Room

As students walked through the front doors of Cinder City Middle School, the following message greeted them: "Respect and Dignity within these Walls." The school had embraced various initiatives to promote a sense of safe environment for all students that included both an anti-bullying unit and disability unit in sixth grade, PBIS (Positive Behavior Interventions and Supports) and Second Step, a program that promoted social and academic success through mini-lessons focusing on emotion management, study skills and problem solving. All classrooms were supposed to use the language of PBIS: be safe, be respectful and be responsible.

Each Friday during students' study time, the homeroom teacher was supposed to teach a Second Step lesson from a curriculum binder given to each teacher. While the district provided professional development on these topics, less than half of the teachers regularly taught the lessons or used PBIS language. Some teachers shared in interviews that it "was a waste of time" or that "students weren't invested." Both Mrs. Marshall and Ms. Ana (who were introduced in earlier chapters) communicated their frustration with the program. Ms. Ana shared, "It is hard to ask the kids to be respectful of one another when some of the staff members don't treat students or other staff with respect. It is a situation of 'do what I say, not what I do.'" Unfortunately, this lack of buy-in may have been a contributing factor to students' perceptions that the school wasn't nearly as "safe" and "respectful" as some adults believed. According to the 2011

Youth Risk Behavior Survey administered at the school in the Fall of 2011, 81% of respondents felt that bullying was a problem at CCMS and approximately 75% of females and 53% of males actually experienced bullying.

Students' sense of belonging and access to safe spaces within the school were topics of conversation in several formal and informal spaces over the course of the school year. In eighth-grade English, for example, the students engaged in a twelve-week Holocaust Unit during which they not only explored the persecution of marginalized groups during the 1930s and 1940s, but expanded that discussion to include reflections on how the fire of the Holocaust was present in their communities, in their school and within themselves. During the final week of the unit, I invited all of the students in Mrs. Marshall's sixth-hour English class to participate in a discussion related to their own observations of bullying and marginalization in the school. The focus group happened during a typical sixth-hour class period, and students were given the option to participate or just listen. I had informed the students that our conversation would be recorded and that they were welcome to write things down on paper instead of speaking aloud if that was more comfortable. The dialogue that follows is taken directly from the audio recording and other details were from my fieldnotes.

I began by asking students if they felt that the claim made by a recent Holocaust speaker at the school was correct: that marginalization and persecution of certain groups continued, even in the year 2011.

"I don't see what the big deal is. I really don't think we have groups here.

I've never been bullied. I don't see it. We all, you know, mix."

Several students signaled that they agreed with head nods and statements of agreement. This student's statement, however, was contrary to what I had been observing in the school all year long. I very seldom witnessed "mixing" of groups, particularly in the lunchroom and on the playground and, in an attempt to push the students on this topic, I decided, in the moment, to make this visual for them.

"It seems like some of you agree that there aren't cliques here. Let's explore that." I went to the board and drew a simple diagram of the cafeteria that included some landmarks like the door and the lunch line and empty tables. Then I turned to the students, "So, who sits where?"

"Ooohh, I got this," blurted Alison, a blonde-haired, thin, outgoing female student whose parents both worked at the middle school. She grabbed the dry erase marker from my hand and wrote "Populars," and "Athletic Boys" at opposite ends of the same table. "What else?" she asked as she turned toward her classmates.

"Well, there's Band. They always sit together."

"That's right, and then there's a small group of 'Smart Girls' too." She asked her classmates exactly where to place those groups on our diagram.

"Let me," said another girl, Stephanie, Sophie and Sarah's triplet sister. She went to the board, "The Sk8rs sit here," she said, indicating another table. "And then there's that group with like Brady and Brady and Sean. . ."

"The Video Gamers!" someone shouted.

"Yeah," a few students agreed.

"But I think there's like a subgroup because there's like, the COD [Call of Duty video game] group with John and Sam and those guys that don't talk about anything but COD 24/7."

"Yeah, they should be their own group, and they sit pretty much next to the other gamers but don't really mix. It is like two gamer groups."

"There's the shy kids," added Alison. "They don't really talk to each other but they sort of sit together. Right, Mikayla?" she asked one of the students who had remained silent during the entire diagramming exercise, a student who never spoke up during sixth-hour English at all.

She shrugged, "I guess."

"They can be the Quiet Table then." Alison added the label to a table.

Mrs. Marshall jumped in, "Mikayla, how do you really feel about that? Are you okay with them labeling you as part of the shy group?"

Mikayla just shrugged again, "Doesn't matter."

The tables had nearly filled up, and by this point students were making finishing touches to the diagram, refining group names, and at times, moving groups to make room for a category that had been forgotten. They added certain students' names to tables as an example of the "kind of people" who sat there. I was keeping my eye on the empty table where the students with disabilities always sat. No one was talking about that table, not even Stephanie, whose two

sisters had Cerebral Palsy. I was having this internal conversation with myself about whether I should say something. I was just about to interrupt when Danielle piped up, "I don't want this to sound mean, but no one is talking about the table where all the disabled kids sit."

"Where's that?" asked Mitch, whose mother was involved in school governance. Earlier that year, she'd used her power within the district to demand that the administration agree to remove her son from the fourth-hour inclusion English class. Her rationale was that his learning would suffer by being in a class with "slow learners." While Mrs. Marshall and Mrs. Matthews, the special educator who supported that fourth-hour class, were upset, the administrator okayed the schedule change, to "keep the peace." I was concerned about this on several levels. The parent clearly held a certain opinion of students with disabilities, and the principal, instead of attempting to trouble her perception, agreed to the switch. Additionally, both the special educator and general educator felt that this action devalued everything they were trying to do in that class period.

Danielle went to the board. "Right here," she pointed to the empty table. "They always sit there. They've been sitting there even since fifth grade, don't you remember?"

Students' responses varied between "I guess," and "I didn't really notice," to "oh yeah, that's right," or "I didn't even know they ate with us."

I cut the students off here. "I want to come back to the original statement

that brought us to this activity. You said that we don't really have groups here, but your work here seems to suggest something else."

"Yeah, I guess we are pretty grouped. I mean there are a few floaters . . . the students who go between tables, but that's like three people in our grade."

"So, Mitch, do you still think that there are no groups?"

"Well, so what if there are? I mean, no one is getting hurt by it."

"Do you think that everyone would agree that no one is getting hurt? Do you think that everyone would like how you labeled them just now?"

Mitch shrugged, "I dunno."

"What do you think it means that all of the students with disabilities sit together at one table?" I asked. "And that it was the last table that you thought to label, and that some of you didn't even realize existed?"

"I think they like to sit together," responded Mitch. "I mean, if they didn't want to sit together they should just sit somewhere else."

Danielle argued, "I don't think so. Remember in sixth grade when they made us all mix up our tables at lunch time and even the kids with disabilities were mixed in?"

"Oh yeah," said Alison, "that was so . . . *awkward*. No one really talked and when that week was over, thankfully everything went back to normal."

"So, when you say normal you mean," I pointed at the board, "like this?"

"Yeah, you know, normal, comfortable."

What may have been "normal" and "comfortable" for some of the students

in this focus group was anything but for other students. In Tatum's book (1997) she wrote:

> The parts of our identity that do capture our attention are those that other people notice, and that reflect back on us. The aspect of identity that is the target of others' attention, and subsequently of our own, is often what sets us apart as exceptional or "other" in their eyes. (p. 21)

The lunchroom experience at Cinder City Middle School was notable in many ways. I began observing there daily on the first day of school. My observation began with fifth-grade lunch followed by sixth, seventh and finally eighth. Each grade had about 22 minutes to arrive in the cafeteria, get their food, find a seat and eat. The lunchroom space was monitored by school personnel who included several of the Special Education aides and teachers, the middle school principal and the athletic director/incoming middle school principal. They circulated through the tables, at times stopping to socialize or to remind students to quiet down. Near the end of the period, they were responsible for dismissing students, by table, for recess.

When students arrived in the lunch room they either immediately took a seat if they brought lunch from home or stood in a line that snaked around one quarter of the cafeteria. Once they reached the line, they had a choice between hot food or salad bar. Students slid their trays along a metal shelf, making selections, and when they reached the end of the line, entered a lunch code

before heading to a table. Students then *self-selected* one of the nine long tables with attached benches at which they would eat. This routine held true for every grade, every day.

I chose to italicize "self-selected" in the paragraph above for an important reason. While the ability to choose where to sit was made available to most students in the room, this was not the case for most of the students with disabilities. Each day I would join Diane, a paraprofessional who worked primarily to support three fifth-grade students during meal time. She assisted the students in getting their trays, selecting their food and entering their lunch codes before escorting them to a table in the corner of the lunch room, very near the end of the lunch line. These students were expected to sit together with Diane at their side, every day. The three disabled students were joined at the table by a group of fifth-grade girls whom the aide had confided that she "took under her wing," being like their mother at school because they were all marginalized for various reasons. Two of the girls were new to the school, another's parents had recently divorced, one was uncomfortable with her body because she was overweight and two others were painfully shy. Almost all conversation that took place was between the aide and the non-disabled students, while the three students with disabilities often sat silent.

As fifth-grade lunch transitioned to sixth grade, the girls departed but the three fifth-grade students with disabilities remained at the table because the aide determined that they needed extra time to eat. The table then filled with sixth-

grade students with disabilities. They didn't all necessarily get along, yet they all sat together, often not talking, but just sharing this common space. Sometimes Diane, the aide, engaged the boys in talk about their morning classes or their weekend plans. They were never more than casual greetings exchanged between the fifth-grade students with disabilities and the sixth-grade students with disabilities.

Sixth-grade lunch gave way to seventh-grade lunch, and the table would completely empty. As seventh-grade students filed into the room, the empty spaces were filled by another group of students with disabilities, two female students from the morning Life Skills class, several male students who received support primarily for learning disabilities and two males who received special education services under an EBD (emotional and behavior disorders) label. While these students inhabited the table together, they did not often speak to one another nor did they necessarily sit next to one another. In some cases, there was at least two feet or more between the students, and so while the table was large enough to seat at least 20 students, the eight or ten students who shared this space during this lunch period used the entire table. When I was able, I joined the table and engaged students in conversations. It was often during these lunch times that students opened up about their frustrations with friends, teachers and school.

The seventh graders were joined by two other students each day, Sophie and Tara. While they were eighth graders, because Sophie needed so much

extra time to eat her lunch, she was not allowed to go to recess so that she could use that extra time to eat. Gina, a special education aide, brought her through the lunch line, put her food on her tray and, after entering Sophie's lunch code, deposited her at the end of the "disabled table." Tara followed behind and ate lunch early with Sophie so that the two girls could be one another's company. Again, the two eighth graders would rarely communicate with the seventh graders, even though some of the girls shared the common experience of Life Skills. Sophie talked to Tara. Anna talked to Amanda, and the seventh-grade boys didn't really talk to anyone.

As the eighth-grade lunch period began, the seventh graders left and the disabled table filled with other female students with disabilities and two other students who experienced marginalization for reasons beyond disability. One student moved to the United States from the Philippines two years prior and while she spoke English quite fluently, she didn't feel as though she "fit" well in the United States. The other student had, in elementary school, befriended two of the students with disabilities and was also self-conscious about her weight and her family situation (one of her parents was incarcerated) and so she, too, joined the table. In total, depending on the day, between eight and 15 girls came to the table. Again, while they shared the space, they did not always interact with one another. There were pockets within the larger group of conversation. For example, Sophie spoke to Tara and Emma, Sarah and Cara talked, but the other students just came to eat and often read a book or worked on homework. Two

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students shared with me that they did this so they could "look busy" and avoid talking. One male student, Matt, on occasion, would share the table. He sat as far away from the female students as he could. He ate alone and never talked to anyone. He was frequently not there, because, as you will learn a bit later, he was often excluded by school personnel from social spaces.

Besides Matt, about half a dozen eighth-grade males with disabilities were present in the cafeteria who did not join the "disabled table." Again, they were often found together. They sat at the end of the table directly next to the table where the female students with disabilities sat, and they made up one-half of the "video gamer" table that the focus group students had identified. They often talked about the online games they were currently playing. While my observations of this table occurred less often, I note that they talked with one another but did not converse with the non-disabled gamers. Conversations between non-disabled students happened "around" the students with disabilities frequently, meaning that non-disabled students would talk with one another over the heads off, or across the table from, students with disabilities, making it seem like the disabled students weren't there.

I found the culture of the cafeteria intensely interesting and troubling at the same time. As the school year unfolded, I learned through talking to students and teachers that some students had developed strategies for how to avoid the lunchroom all together. Natalia, whom you will meet later, would hide in the bathroom for the entire lunch and recess period so she wouldn't have to go to the

cafeteria. Another student shared with me that she made up stories that she really needed to work on homework and sometimes would ask teachers whom she'd identified as "nice" if she could stay in their classrooms to work. Some students would go to the library to read. This was a common practice until so many students were utilizing this space that the librarian closed the media center during the seventh- and eighth-grade lunch periods. Several Special Education students would go to the Special Education resource room in hopes of staying there for lunch, but eventually this option also was taken from them when the teachers began to lock students out of the classrooms so they were forced to go to the cafeteria and recess. Which brings me back to my initial concern with the culture of the cafeteria. If this space was as "normal" and "comfortable," as eighth- grade students in the focus group wanted to believe that it was, then why were some students going to such lengths to avoid it?

After nearly six months of observation in the lunchroom during which time I developed several close relationships with students in grades five, seven and eight, my opportunity to observe and participate in the cafeteria culture came to an end. I was approached by the middle school principal and asked to take on lunch detention. I was paid to spend one hour daily with one student. When I was assigned to this duty, all I could think of was how much I would miss. I was angry. I was sad. The principal's request of my time seemed like the end of an opportunity to be with and learn from "my kids." I would have never imagined that what would come of this task was something so powerful and so beautiful that I

am still in awe of it today.

Meet Matt

I'd first met Matthew in September. Mrs. Matthews's resource room was empty, or so I thought, and I sat down at my table to Braille some alphabet cards for a fifth-grade student. As I typed, I suddenly got the feeling that I was not alone and, upon turning around, found a male student sitting quietly in one of the empty student desks watching me with great intensity. Embarrassed that I hadn't realized he was there, I apologized for disturbing him, saying that I hadn't realized anyone was in the room. What follows is a conversation that I reconstructed from fieldnotes directly following our conversation.

"What are you doing?" he asked, unconcerned with my apologies. "That's pretty cool."

"I'm Brailling some cards for a student in fifth grade."

"Do you know how to read Braille, too?" he questioned.

"Yep, I learned to read it when I was in high school," I responded. "But I will stop. I know it is really loud, and I didn't mean to disturb you."

"That's okay. I was bored anyways and that was cool."

"Why are you in here? I don't think I've seen you before."

"Matthew!" Gina boomed as she entered the room and noticed us talking. "Get back in the quiet room. You aren't supposed to be out here."

"I was just watching her." He pointed his finger at me.

Gina glared at me, and I felt small. "Doesn't matter, get back to work."

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I turned away from Matt, feeling guilty that I somehow contributed to his admonishment and quickly put my project away, grabbed my things and stood up. I mumbled a quick, "I'm sorry." Before walking down the hallway, I stood just outside the door for a minute, listening to Gina discipline Matt for his apparent misbehavior. All along I couldn't shake my confusion as to why Matt was all alone in Mrs. Matthews's room. Why hadn't I seen him before, and why wasn't he in class?

A few days later, after questioning Ms. A, the Special Education student teacher, I learned more about the mystery of Matt. This eighth-grade student, son of a single, teacher-labeled "dead beat dad," received services through Special Education because of an emotional/behavioral disability, which no one ever defined more specifically. Several Special Education and general education teachers viewed him as a disruption. As one Special Education teacher described him in an interview, "He lacks respect for adults and is basically a jerk in class. He likes to act up in front of his peers by defying teachers, irritating other students and making inappropriate comments." Because his behavior deviated so greatly from what was expected in the classroom, Matt was pulled from all academic classes early in the school year and spent his days in one of two Special Education classrooms under the constant supervision of an adult. Most of the time, he could be found in the "timeout" room in Mrs. Matthews's room, a cinderblock, windowless space measuring about seven feet by seven feet that contained two bean bag chairs and a single student desk. His core teachers

brought work to him, and he was expected, with some assistance from Special Education teachers and aides, to complete his work independently. He was assigned points for each class period and, if several days passed without any altercations with adults, Matt would earn his way back into one academic class. If, after returning to class, he acted out, he was pulled from the class and the process began again. If, even while in the Special Education classroom, he was unable to comply with expectations, he could be assigned to an in-school suspension, in which case he would spend his day in the suspension room in the District Office.

After our chance meeting, I began to focus on Matt and his experiences in school. I found him easy to talk to; he frequently engaged me in conversations when I was at my desk in Mrs. Matthews's room. As other teachers reported to me during interviews, in one-on-one settings, Matt was great. He seemed to have a particular affinity for conversing with adults. That said, two of the Special Education teachers warned me that I should be wary of Matt and his ability to spin stories. He had a "knack for manipulating people's trust." I kept an open mind when talking to him and often cross-referenced things he told me in my notes to check for accuracy, seldom finding contradictions. Within days, I had learned of his interest in video games and the respect he had for his sister. He worked in a paid position as a moderator for an online gaming website. He often did this late into the evenings and reported not sleeping much. He would sometimes go fishing with his father before the school day, so his days often

began at 4 AM. Just as I grew to know him, he took an interest in me. He was fascinated with my four children, particularly my infant son, and asked a lot of questions about my vision and my iPad.

At the end of February I was approached by the middle school principal who expressed interest in hiring me as a one-to-one supervisor for Matt during his lunch and recess. Mr. Williams explained that he thought Matt needed to be away from his peers because this was when he got in the most trouble. I agreed to the position because I felt obligated to give back to the school. The teachers and administrators had given me relatively unrestricted access to the students, so I felt like this was a fair exchange.

By this time in the year, Matt had earned his way into all of his academic classes but, as Mr. Williams explained, he was still displaying inappropriate behaviors during less structured periods of the day. Mr. Williams, the special educators and Matt's dad had together determined that removing him from the social settings within which he misbehaved would be the best option. I found their reasons unsettling. First, I wasn't sure how I felt about Matt being removed from his only time to socialize with peers without direct adult supervision. Second, this assignment would put an end to the time I had invested in building relationships with so many seventh- and eighth-grade students in the lunchroom. Weighing my options though, I hoped that taking the position would give me the opportunity to connect further with Matt. Mr. Williams was excited that I agreed, saying that he trusted that I would make the detention experience a positive one.

I began supervising Matt during the first week of March. I was told to report to Mrs. Matthews's room and Matt would come there. I was to escort him to the lunchroom and wait while he got his lunch before walking him back to the Special Education room where he would then eat and do homework. When Matt arrived in Mrs. Matthews's room to begin our time together, he dropped into a desk and put his head down. Despite attempts to start a conversation, he refused. I really couldn't blame him. I wondered if he thought I was somehow involved in putting him in this position, and I vowed to clear that up as soon as I felt Matt was ready to listen.

When it was time to walk Matt to the cafeteria for lunch, I walked behind him down the hall. I didn't want him to feel worse by having me walk right beside him. As he went through the lunch line, Natalia, an eighth-grade student with whom I had been eating lunch, ran over to me to ask why I wasn't at our usual table. I turned to her to explain that I'd been assigned to a new duty and in that instant I lost sight of Matt. I told Natalie to go back to her seat and that hopefully we could still eat together once in awhile and then walked through the entire cafeteria, pausing at each table to search for Matt. I couldn't find him anywhere. Panic washed over me. I had one responsibility, to watch Matt, and I had failed.

I left the cafeteria and returned to Mrs. Matthews's room, hoping I would find Matt there; the room was empty. I returned to the hallway and retraced my steps to the cafeteria and then back again to the Special Education room. The hallways were empty. After several minutes of searching in vain, I walked to the

middle school office; asking to speak with the principal, I was told he was in with a student. I took a seat outside of his office to wait. In that moment I felt like a naughty student waiting to receive my punishment.

Just a moment later the door opened and, to my surprise, out walked Matt, followed closely by Mr. Williams. "Look who I found!" Mr. Williams said.

"Hey Matt, I was looking for you!" I tried to sound like it was by chance that we were meeting under these circumstances.

"Matt decided to take a detour from the lunchroom. But we had a talk, didn't we, Matt?" Mr. Williams asked.

"Yeah," Matt mumbled. His shoulders slumped under the watchful eyes of the principal and his office staff.

"This won't happen again," Mr. Williams promised. "Matt will have an after-school detention with me for running away from you. Matt, you can go get rid of your lunch tray. Lisa, can we talk?"

I felt sick. Matt had another detention just for running away from me? Mr. Williams asked me to step just inside his office for a moment.

"I'm really sorry about today. I'm sure Matt didn't intend to do this."

"You didn't do anything wrong. Matt just needs to learn what is expected. If you have any more trouble with him, let me know."

I nodded, thanked Mr. Williams for his time and left his office feeling defeated. I saw Matt ahead of me and I quickened my pace to catch up with him. "Hey!"

"Hey."

"Listen, I'm sorry that you got another detention."

"Whatever. Everyone expects me to be in trouble all the time anyways. I'll see you tomorrow."

I watched as he walked up the stairs to his sixth-hour math class.

Several things went through my mind as I watched him walk away. First, I couldn't help but wonder if another student roaming the hall during a lunch period would have received the same consequence. Second, Matt's comment, "everyone expects me to be in trouble all the time," was very powerful. It communicated that Matt had internalized messages conveyed to him by staff members that they expected him to get in trouble. During an interview when I questioned him on this, he shared that he felt as though, when something bad happened in class, he was targeted. He shared:

> I've done some stupid things and made some bad choices at my
>
> other schools. I've been expelled for doing some dumb stuff, but I'm
>
> trying to be better at this school but sometimes that doesn't seem to
>
> matter anyways. It is like they expect me to be bad, so I may as well
>
> just be bad.

Matt's comment seems to suggest that he felt defeated by the system. In a school in which the teachers have readily embraced PBIS, students like Matt were feeling the consequences of their negative behaviors and were seldom recognized for what they were doing well. I believe that Matt really did have the

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intention of making this year better. In an English assignment dated September

25, students were asked to write a letter to their "End of Eighth Grade Selves."

Matt's letter outlined his intentions:

> *Dear Future Eighth Grade Self,*
> *Things so far have been going well for me. I did get a lot of referrals but I am planning to step it up and actually get good grades. The things that are really going well are Science which I first thought was going to be hard but it turned out to be easy. The notes give me headaches. English class is also going well because I find the career unit interesting because it gives me a chance to find out what I want to do for the rest of my life. At home things are getting better because my dad isn't getting on me as much about homework. It is nice to not have him yelling at me all the time.*
> *One thing that is bad so far is that I still have to earn my classes back for my bad behavior. I now have earned about 4 classes and I am hoping to get them all back. Something that I am struggling with right now is keeping up with assignments. I think I am doing better this year. As the year progresses I hope that I will be caught up and not have to worry about late assignments.*
> *Overall, I am looking forward to developing better note-taking skills so I have more information to study with. I am also looking forward to making good grades and this is my goal for the end of the year. I hope I get what I want because it would help for high school and my whole life in general. I have high expectations for myself. I hope I can meet them.*

He clearly had goals set for himself related to academics and behavior,

expectations that Matt felt most of his teachers weren't aware of or would even

believe. He also recognized his past mistakes and communicated his intent to

move past these and make better choices.

I was worried about how Matt's permanent lunch detention with me would

impact his image with classmates. To respect him and his space, I tried to give

him as much space as possible when we walked the hallways and lunch line

together. Nevertheless, other students found out about his punishment. I was

approached by three students with whom I previously had spent my lunch hours. One of the girls asked if I would ever be back, to which Sophie announced, "She has to be with Matthew; he's been bad." While I tried to diffuse comments like these by saying that Matt was not bad and that we were spending lunch and recess together to work on some things, the kids seemed to have already made their minds up that he must have done something horrible. I heard two male students harassing Matt, saying that he must have "messed up bad" to be stuck in detention for so many days with "that researcher person."

While students were busy forming their opinions of Matt's mandatory detention, our time together was evolving into something interesting. After the first day's disaster, two things changed immediately. First, I sought a change in the physical space in which we met. In that room I felt like we would always be under the watchful gaze of the Special Education teachers and aides. After observing the ways in which they interacted with Matt, I didn't feel that this additional contact time with them would be beneficial. I approached Mrs. Marshall, the eighth-grade English teacher, to see if we could have detention in her classroom. She was more than agreeable. It was a practical decision not only because I was in her room for the two hours proceeding lunch as well as the one after but because, in my absence, she would fill in for me. So, when we met on the second day in Mrs. Marshall's room for detention, Matt seemed more relaxed. I took the opportunity to explain that it was never my intent to get him in trouble. He seemed to understand, dismissing my comment with an, "Ah, no big deal."

I was distressed with how easily Matt seemed to dismiss the violent things happening to him at school. As genuinely and gently as possible, I started asking Matt to share more about himself. Matt seemed eager to open up about his past school experiences, his present peer relationships and his home life. By the end of our first week together, I had learned that he'd been in three schools over the past three years, that he'd been expelled for making some bad choices (at one school he climbed up onto the roof), that he lived with his unemployed father and that he missed his older sister, who lived in Minneapolis with Matt's newborn niece.

I was feeling good about the relationship we were forming, and I arrived at school on Monday morning of the second week of detention duty looking forward to seeing Matt during lunch. I had done a little reading on online gaming and was eager to learn more about this special hobby of his. I was met, however, with a note on my desk from the principal letting me know that he had assigned two new "customers" to detention for the next two days. He relayed their names to me and shared that they'd gotten in trouble for being repeatedly disrespectful to a teacher and that, since I was already supervising Matt, he thought a few more kids wouldn't be a bother. I assured him that it would be fine. The following vignette is a direct transcription from a recording of the detention period.

Recess arrived. Matt was seated at a computer typing an English assignment when the two eighth-grade boys assigned to detention arrived. The minute that Kevin and Jacob, two peers of Matt's, walked into the room, the Matt

who had so openly shared things about his personal life with me disappeared.

"Whasup?!?" Matt got up from his chair and high-fived Kevin first, and then Jacob.

"You're here?" Kevin asked. "What'd you do?"

Matt ignored his question and instead made a pretend farting noise as Jacob sat in one of the desks. "God, Jake, you sicko!"

"Whatever," Jake dismissed him. "God, this sucks."

"Yeah, tell me about it," Matt agreed, looking at me out of the corner of his eye. I said nothing. I knew what he was trying to do and was not about to interrupt it. I let the three exchange comments for another minute before interjecting.

"Hey guys. While it has been fun listening to you all joke around, it is time to get some work out."

"I ain't got none," Matt yelled, and the other two boys snickered.

"There's always books to read," I responded.

"I don't read," Jake responded, and Kevin smacked him on the back approvingly, as if to say, *way to go*.

"Well, since I know that's not the case, you can either pick a book or I'd be happy to get one for you." I refused to play along with their game.

"All right, all right," Kevin conceded. He got up and took a book from Mrs. Marshall's rack and sat down to read. The other two didn't move.

"Come on, guys," I prodded. "I don't want this to be a big deal. Let's just

get a book to read."

"Let's just get a book to read," Matt repeated in a mocking tone. Again, the other two boys erupted in laughter. I so badly wanted to say something to Matt, to ask him why he suddenly had become this way, but I didn't.

When it was time to go for lunch, I told the three boys that I'd walk them down to get their food and that we'd come right back, that they were not to talk with friends or stop anywhere along the way.

"God, and you're stuck here for how long?" Jacob asked.

"Tell me about it. I can't wait to get out of this place!" Matt pushed back his chair roughly, which tipped over and crashed to the floor.

"Come on, Matt, pick it up," I ordered.

"You do it. You're getting paid to take care of me, right?" he shot back.

"Pick it up, Matt," I repeated, trying to keep the edge out of my voice, but I could feel the anger rising.

""Pick it up, Matt!" Kevin mimicked. "This is your babysitter talking."

"All right, that's enough, guys. Let's get our lunch." I opened the door and waited until they all filed out of the room.

"Well, if this isn't like prison, I don't know what is!" Kevin snarled at me.

When we returned to the classroom with trays, things did not improve. Matt exploded a bag of Doritos all over the floor, and Jacob decided that it would be fun to poke a hole in the side of his milk carton with a pen and drink from a stream of chocolate milk that shot out of the side, instead of drinking from the

top. No amount of prompting from me made any difference. Jacob summed it up when he finally looked at me after my fourth request to settle down and said, "Why should I listen to you? You aren't even a real teacher."

The following day's detention was mildly better. I attribute this to the presence of Mrs. Marshall, the English teacher. She decided to use her lunch hour for some grading. The boys acted up for only the first three minutes. She warned them once, and then a second time before she threatened to remove Kevin and Jacob to Mr. Williams's office. They quieted down, with the exception of snickers that erupted from each boy from time to time.

On Wednesday when we met for lunch detention Matt was really quiet. After we walked down to the lunchroom to get his food and returned to the room, he flopped in a seat. I asked him how his day was going and what his plans were for after school. He offered only mumbled answers. Finally I asked, "What's wrong?"

"Aren't you mad?" Matt asked.

"About what?" I was pretty sure I knew what he meant.

"About how I acted the other day!" he blurted.

"Well, it wasn't cool but I got what you were doing."

"You do? Wow . . . I thought you'd be like, really mad." He went on, "I didn't mean it but those guys are like. . . I dunno. . ."

"It's okay. It is over, but let's try to not do that again."

As I walked out of Mrs. Marshall's room that same day, I nearly ran right

into Sophie and Tara as they walked down the hall toward the Special Education room for English class. Sophie whined that lunch was not the same without me and couldn't I please, please, please come back. I tried to explain to her that this was my job now and that, while I missed them a lot, I had to do this.

Tara put her finger on the side of her cheek like she was thinking before she asked, "Well, if you can't come back, can we come eat with you there?"

I told the girls that this would take work. I'd have to ask Matt if that would be okay with him, and we'd have to check with Gina (Sophie's lunch aide) to see if she'd allow it. That afternoon Gina and I talked, and she reluctantly agreed, saying that she didn't know why I'd want to take on more responsibility than I needed to, but by all means, to go ahead and take on Sophie. I caught Matt in the hall, and he shrugged and agreed, saying of Sophie and Tara that they were not "that bad."

And so began the lunch detention that students were ASKING to attend. In the pages that follow I introduce readers to each student in the order that they joined the detention space. Each introduction offers important information about the context of the student's lived experiences. Each student narrative is followed by an audio-recorded exchange that occurred sometime after they joined the lunch detention space in which they were a central participant. Student narratives were crafted from information they provided to me during interviews, during our time together in lunch detention and through writing samples completed in English class. Dialogue exchanges were directly transcribed from audio

recordings of each detention. While some of the students have been introduced in Chapter 5, I revisit each of their stories again here in greater detail.

Sophie

Sophie was one of the three triplet sisters introduced in a previous chapter. With her dark head of hair and easy smile, Sophie traveled about the school in her electric wheelchair that she operated through the use of her right hand and a joystick. Unable to sit up for long periods of time independently, Sophie was buckled into her seat and her neck was secured by a brace that she hated wearing. One of her favorite times of the day was lunch because the brace was removed. Sophie's sister Stephanie and Tara often grabbed on to Sophie's body and adjusted it for her if she was slouching. Sophie carried her belongings in a backpack that hung from the back of her chair. Sophie frequently asked me to put things into her backpack, and I noticed that, while she carried a binder that was outfitted with folders and a notebook for all of the traditional academic subjects (English, math, social studies, science, reading), there was never anything in any of her folders, nor was there anything written in her notebook. Her student planner did not have any academic related notes on any pages, but from time to time, one of the Special Education teachers and Sophie's mother communicated with one another through this means. Sophie was seldom seen without a book. Over the course of the school year, *Twilight, New Moon, Harry Potter and the Sorcerer's Stone,* and *Uglies* were on Sophie's wheelchair tray or in her lap. I watched Sophie's bookmark make its way gradually through the first

30 pages or so of a book before it would be time to return it to the library. While she told me she liked to read, she said she was slow. One of the Special Education aides offered a contrasting insight, saying, "Sophie only carries a book to look normal. She doesn't really read."

Sophie had little time to socialize outside of school. Her time with friends was restricted to lunch, recess and unstructured class time, which for Sophie, because of her need for a personal care attendant for bathroom needs twice daily and for extra travel time from class to class, was very little. She often talked about wanting to do things with friends, but her mom not letting this happen because it was either too much work, another family not being able to take care of her or a friend not having a house that was accessible (even though Sophie's own house wasn't accessible). Usually Sophie spent time at home just hanging out and being with her annoying brother. Her family, however, was heavily involved in a local chapter of United Cerebral Palsy/Easter Seals, and they participated in large fundraiser held in the spring. Sophie was very proud of her participation in this event and talked about it for weeks before and after it happened.

* * *

I walked through the lunch line, adding the fixings that Sophie liked best to her salad—lettuce, broccoli, egg, croutons and ranch dressing—and punched in her lunch code before making my way back to Mrs. Marshall's room where she was waiting. Unlike most days, she asked if I would just get her food for her

because she didn't want to come along.

When I returned to the classroom, her head was down on her tray. "Hey sleepyhead!" I joked, "time to wake up."

"I'm not tired!" she snapped.

"What's going on?" I asked.

"I bet I know," offered Tara, who also seemed to be more irritable than usual.

"What happened?" asked Natalia. "Ms. Lisa, do you have any goldfish today?"

"Just Chex Mix," I reached into my backpack and pulled out an unopened bag of cheddar-flavored Chex Mix.

"Thanks! . . . So, why are you crabby?" she asked Sophie.

"My sister is so stupid!" Sophie snapped. "It's just not fair!" Her voice was unusually forceful and angry-sounding.

"Yeah, her sister is a, pardon my language, but," she whispered the next word, "bitch."

"Whoa!" Matt interjected. "Did you just really say that?? *You??*"

"Yes!" Tara snapped. "I'm mad!"

"Yeah! Me too!" Sophie went on. "My stupid sister told my parents some lie about Tara and now we can't be friends."

"What?" I asked. "What kind of lie was this?"

"Well, Stephanie told Mom that Tara said she wanted to kill my parents for

not letting us hang out."

"And I never said that!" said Tara. "I, like, am really mad that Sophie's mom never let's us be together outside of school but . . . I wouldn't do that, or say that!"

"And so now Stephanie keeps getting in Tara's face and telling her to get away from me. Stephanie always thinks she can be my boss."

"I would just keep being friends," Matt said.

"Yeah, but Stephanie has her phone with her all the time, and she says she'll call Mom, and when my Mom is mad, it is bad for everyone."

"That's ridiculous!" chimed in Danielle. "Your sister needs to leave you alone. You should get to pick your own friends."

"Yeah, but I don't. It is like because Stephanie and even Sarah sometimes are better than me, that they get to be my boss. They treat me like a baby."

I felt like I understood what was happening here. Because Sophie was the least-physically abled of the three sisters, the other two yielded power over her. This was seen in the way they ordered her around at school and felt as though they could take her things, move her body and tell her what to do, positioning her as a child in front of her peers on repeated occasions. "This is hard, Sophie. What do you think you can do about it?"

"Probably nothing," she signed.

"Well, I don't think it is fair but you can be friends in here. We aren't going to tell anyone!" Matt said. "This is just dumb."

"Thanks, I guess," said Sophie.

"Yeah, thanks," agreed Tara. "I just wish we could be friends all the time and not just when no one is looking."

* * *

Sophie was struggling with several things. First, because she didn't possess the physical strength to move her limbs independently, she often expressed frustration with her body and her lack of control over it. She'd say things like, "I wish I could just open my milk myself," or "I'm trying to sit up but I just can't." She became angry when others readjusted her because they almost always did it without asking. While she never said so directly, it seemed like she felt others had more ownership over her body than she did. It seemed also that because Sophie had difficulty with many physical tasks, assumptions were made about her intellectual abilities.

Second, there existed a hierarchy of ability between Sophie and her two sisters. Because the other two sisters were more physically abled than she, they yielded control over Sophie. This was particularly true of her non-disabled sister, Stephanie, who was responsible for providing care for Sophie at home. She could choose when to help, and if she wasn't ready to assist, Sophie (or Sarah) would have to wait. Stephanie's power over Sophie could be seen at school where she made decisions about whom Sophie could spend time with and "reported back" to their parents. Stephanie carried a cell phone and was allowed to use it to make calls to their mother to provide updates about the disabled

sisters. While that did enable the mother to know what was going on at school, it also gave Stephanie the ability to tell the stories she wanted her parents to hear about her sisters. As a result, Stephanie had control over who Sophie could be friends with in and out of school. Sophie lacked decision-making power with regard to her own social group and felt she had to "hide" her friendship with Tara from her sister.

Tara

Tara, also introduced earlier in this study as one of the students in the Life Skills course, identified herself as Sophie's best friend. Tara had an immediate connection with Sophie even during her first days at Cinder City Middle School. She moved to Cinder City in early September from a very small, rural school in Wisconsin. The mother gave the reason that she wasn't able to see well and that the surrounding communities offered public transportation and access to better education for her daughters, who both received services through Special Education for Epilepsy. The family, consisting of the mother, grandfather and two girls, lived in a small rental home. One of the Special Education teachers guessed that Tara's mother provided housing for the grandfather in exchange for transportation for her and the girls.

Tara felt like her family wasn't "normal." During one of our many lunch conversations, Tara shared,

> My family didn't used to be like this. When my dad was around we
> were a normal family. I wasn't even disabled then. My mom wasn't

angry. We were happy. And then the accident happened. My mom

got really sad and mad. My grandpa moved in to help, and then

my sister and I got Epilepsy. I just wish our family could be like it

was before it got all messed up.

I was intrigued by Tara's choice of words in describing her Epilepsy. She "got it"

when she was older. I asked a special educator about this and was told that Tara

and her sister became Epileptic only a few years ago. Prior to that, they were

"normal," so, unlike Sophie, who had been disabled her entire life, Tara recalled

a time when she was "okay" and then a period after which she acquired a

condition.

Tara yearned to talk about her father and used opportunities in English

class to write about him. She carried around a copy of his obituary in her

notebook and brought it out during classes to read many times during the year. In

one English assignment about an important, life-changing event Tara wrote:

> *I love my dad so much. I wish I could tell him how much I love him.*
>
> *On the day he died, I didn't tell him I loved him before he left. I was*
>
> *in fifth grade and I should've said I loved him but I didn't. Now he's*
>
> *gone. I wonder if he knows how much I love him. I know he is in*
>
> *heaven and I hope he can see me writing this so he knows. I love*
>
> *you daddy.*

One day in mid-January, Natalia, Sophie and Tara were in the middle of a

conversation at lunch when Tara unexpectedly laid her head on the table. I asked

her if she was okay, and she failed to respond. I put my hand on her arm and could feel her muscles contracting. Not wanting to startle the students around us, who were starting to stare, I asked Natalia to get the lunch monitor. As she went for him, Tara's shaking became worse. Realizing that she could easily fall from the bench, I grabbed Tara around the waist and pulled her to the floor. By the time I got her situated on the floor, her entire body was convulsing and the cafeteria had become silent. Students were standing up at their tables to get a better look at what was happening. The school nurse, principal and Special Education aide came and, after the convulsions subsided, lifted Tara into a wheelchair and pushed her from the room. This was the first of many seizure episodes to come.

Just two weeks later in English class, nearly the same events unfolded. The bell rang, signaling the end of the hour but Tara didn't move. I went to her and touched her arm. I could immediately feel the tensing of muscles. I turned to Mrs. Marshall and mouthed to call the office. Students were still in the classroom, and I wanted to protect Tara's privacy. The student teacher and I pulled her from her desk and laid her on the floor, loosened her clothing and began watching the clock. The minutes ticked by, and we were joined by the school nurse, Special Education teacher and assistant principal. Tara's rescue medication was not at school. The parent, we were told, refused to provide a dose for Tara at school. As the seizure extended to 15 minutes, and then 20, the nurse made the executive decision to call the ambulance. She sent someone to the elementary

office to fetch Tara's little sister's rescue medication. She decided that, though this could be a career-ending move for her, using another student's medication to treat another child, she worried that if we did nothing, Tara could have permanent physical damage. Twenty five minutes. . . The mother arrived, frantic, yet angry that the school had decided to call the ambulance, and, while Tara lay seizing on the ground, she admonished us for overreacting. The ambulance came and strapped Tara, who was still unresponsive, to the stretcher and carried her away. After she left, I sat in Teri's empty classroom and cried.

Following these seizures, the mother demanded a meeting with Tara's Special Education teacher, the administrator and the school superintendent. She asked a lawyer to draw up a document that prevented the school from calling the ambulance if Tara had a seizure. While school personnel were uncomfortable with this decision, they were then legally obligated to comply. The Special Education teacher who handled Tara's case questioned the mother during parent-teacher conferences that took place in early February, following the legal meeting. She asked if it would be okay for the school to contact Tara's pediatrician and neurologist to be sure that they were doing the right things for Tara at school. The mother refused. She blamed the school for serving food high in preservatives and told her that if she continued to ask questions, Tara would be removed from the school. Feeling helpless, the special educator agreed to not pursue the issue as long as Tara would remain enrolled. The teacher did, however, make a phone call to Tara's previous school and learned that a similar

pattern developed there. When that school began asking questions, Tara and her sister were pulled from the district. Behind closed doors, several teachers and aides whispered about the possibility that Tara's mother was a "Münchausen Mom." This term referenced a psychological disorder formerly referred to as Münchausen by Proxy, but according to the DSM-5, is now known as "factitious disorder," categorized by a parent or another caregiver falsifying medical or psychological signs and symptoms to deceive others, including falsify medical information shared, tampering with medication, surreptitious attempts to mislead, simulate or deliberately cause symptoms to happen but for no external reward (DSM-5, 2013). While the teachers were never able to prove that the mother was purposely making Tara sick, they continued to worry about her and considered her situation a borderline case of abuse.

<center>* * *</center>

"So what are you wearing for Farewell?" Sophie asked everyone as she took a bite of salad on this last day of May. The room was stuffy and the lights were off. We ate by sun that streamed through the windows that overlooked the parking lot. "My mom took us shopping this weekend and I got a black outfit with sparkles."

Farewell was an important rite of passage for eighth graders at CCMS. I'd watched over the past three weeks as students prepared artifacts that would be placed in a time capsule that would be sealed on the day following Farewell and presented to the students again on the day of their high school graduation.

Students prepared speeches and reflections that would be read aloud at a gathering, one that closely resembled a graduation ceremony. Parents were invited to attend, and more than half of all students in the eighth grade had indicated that their families would be there, many parents taking off work so they wouldn't miss this big event. While the dress code was not specific, students were encouraged to "look their best" for this special day.

"I'm wearing a tie!" Matt announced proudly. "I never wear ties, but this is a big deal!"

"I got this really pretty dark blue dress at the mall on Saturday," responded Addy.

"My mom is making SUCH a big deal out of this," Natalia remarked. "She made me get this really fancy black dress. She says that this will be a day I will want to remember after we go back home."

"I got a really pretty dress at DEB and my mom is going to drive me over to a friend's house early tomorrow morning so she can do my hair." Danielle added.

Noticing that Tara hadn't said a word, I asked, "What about you?"

She shrugged and then, without warning, got up and walked across the room and crawled under a large table in the opposite corner of the room. Students often used this space during silent reading. Once in awhile, Danielle had crawled under there during lunch hour to catch a quick nap after spending hours of her nights and weekends preparing for her most recent play production.

But Tara had never before gone under the table. It was like she was trying to escape.

I put down my notebook and walked across the room and crouched down to peak underneath. "Do you want to talk?"

"No," she responded. "It won't make any difference anyways."

"Are you sure?" I asked. She nodded. "Okay, but if you change your mind, we are all here to listen." She stayed there for the rest of the hour. When Sophie called her name and asked if she was ready to go, Tara did not respond but stood up, approached her desk, grabbed her pile of books and, leaving her half uneaten tray on the teacher's desk, walked out of the room.

"That was weird. She must have her period or something," shrugged Sophie.

The following day our lunch bunch was again gathered together for what would be our second-to-last time together. It wasn't a typical lunch bunch gathering, however. Natalia said that she was "too nervous to eat," and instead went to the bathroom to get changed into her dress for the afternoon's ceremony. The phone in the classroom rang, and the secretary asked if I could send Addy down because her mom had just dropped off her dress clothes. Matt sat in his seat, ignoring his lunch tray, all dressed up in a dress shirt and, of course, his tie. Everyone else was already ready and lunch was the furthest from anyone's minds. Tara sat alone at the teacher's desk, picking at her lunch. Like the day before, she was unusually quiet.

"Do you need to change?" I asked.

"I don't have anything," she mumbled.

"That's okay, you don't have to dress up," I tried to shrug off what was clearly disappointment.

"I want to, but my mom wouldn't let me. I don't have a dress."

"Why wouldn't she let you?"

"She said it wasn't a big deal. Graduating from middle school isn't important."

"Is she coming today?" I asked.

"No. And so no one will be there for me. Everyone else here will have someone there, everyone but me."

I wasn't sure if it was me being emotional having four, almost five children of my own, but I could not bear to listen to this child go on thinking that no one would be there for her.

"Tara, I will be there for you. In fact, I am going to be there for all of you today. And, Tara, I have an idea. Just give me a little time."

I looked at my watch: 40 minutes until Farewell was slotted to begin. We lived 15 minutes from the school. This was possible. I picked up the phone in the classroom and called home. I had a quick, whispered exchange with my husband during which I explained my plan. Grumbling only a little bit, he agreed. I ended the conversation by telling him to hurry and that I'd meet him in the back parking lot. Tara stared at me with curiosity. "I have a surprise but you'll have to wait just

a little bit to find out what it is."

Twenty minutes later I stood in the parking lot waiting for my husband. He pulled up and thrust a plastic bag through the open window and wished me good luck. I ran back into the school and to the Special Education room. Tara wasn't there. I had clued Melinda and Gina in to my plan, and they said that she'd went to the gym for practice.

I ran to the gym and found Tara sitting on a folding chair in the last row. The gym was abuzz with parents who were filling the bleacher seating that extended the full length of the back of the gym. "Come with me!"

Tara followed me with a confused look on her face. We ran to the Special Education room, and I told her to follow me into the bathroom. She did, and once we were in there I pulled out a dress and necklace out of the bag. "Now you have a dress, but you need to hurry!" I stepped out of the bathroom to give her privacy while she dressed. Two minutes later she emerged, ran to me and threw her arms around me. "Thank you!!" The sun dress, bright pink with tropical flowers, fit her perfectly.

"You look beautiful!" I exclaimed. "And you deserve this. This is a special day for you!" As I stepped and grabbed my phone to take a picture I noticed her shoes, tennis shoes that looked like they were about to fall apart.

"What size shoes do you wear?" I asked.

"Eight or eight and a half," she responded.

"Perfect," I said. I kicked off my own black dress shoes and leaned over,

picked them up and handed them to her. "Put these on. This will be the finishing touch."

"But what about you?"

"Don't worry about me," I said. "This is your day." She slid her feet into my shoes. "There, now you are ready for Farewell."

She hugged me again. "I can't believe this dress! I feel like a princess."

I put my hand on her back and gently pushed her out of the room. "Now, you don't want to be late for your graduation!" I followed her in my bare feet and took a seat on the bottom row of the bleachers and joined the other parents in cheering and wiping tears from my eyes, feeling so proud of all of "my kids."

* * *

Tara "felt" the isolation that she felt her disability caused and talked about it a lot. Nearly all of her English assignments featured reflections of her dad or her disability. And while other students with disabilities were talked about and bullied behind their backs, Tara experienced bullying directly. I witnessed instances in which Tara was called a "weirdo" and a "spaz" by some male eighth-grade students. These same students made faces at her and mocked her in class. One male in particular,refused to work with Tara in class and very directly told the teacher that he wouldn't work with her because she was stupid. When the teacher demanded that he "fix" the situation by apologizing, he refused. What ensued was like a standoff. The teacher, Tara and the offending student stood in a triangle, their arms crossed. This lasted for almost ten minutes, during which

time Tara tried to dismiss the situation saying, "just forget it," but the teacher wouldn't back down. In the end, the boy offered a mumbled, "I'm sorry." The teacher's intentions here only made things worse for Tara because the male student was mad that he'd been required to apologize for something he wasn't sorry for. Tara felt uncomfortable that the entire situation was handled in a public way (during class, in the back of the classroom), and she too, realized, that the boy, Chris, wasn't even sorry.

Tara was also angry. She yearned to be "normal." She envisioned a life in which she could go to the mall, hang out with friends and do after school activities. She blamed her disability and the disability of her mother (visual impairment). I heard many times, "If I was cooler. . ." or "if I didn't have Epilepsy. . ." or "if my mom wasn't blind . . .", then "I could have friends," "I would be cooler," "I could go places on my own," "I could have friends over."

The thing that seemed to bring her the most joy was the 50 minutes each day she spent volunteering in the elementary Special Education room. I went with her three times to observe her work there. Unlike the withdrawn, sad Tara that I saw in her middle school classes, Tara was energetic and enthusiastic. She smiled and laughed often. She worked most closely with a kindergarten boy who was blind. They read together, played games and sometimes just snuggled. She told me that she felt "happy" in that classroom because she was doing something for others. She felt valuable and important. I often wondered if other middle school students made her feel so devalued that this experience helped her

realize that she was a capable young woman. She shared once that, unlike her classes and in her home, she didn't feel like anyone cared if she was there or not, but that "when I'm not here, the kids miss me."

Addy

Addy was another of the students introduced in Chapter 5. She lived at home with her twin sister and sixth-grade brother. Whenever she had a moment of free time at school, she could be found with a book. As an avid reader, she was happy to read almost anything but found historical fiction or science fiction favorites. She was included in all academic classes with the exception of reading, which, I was told, she "tested out of" because of her astounding reading scores.

Addy, unlike some of the other students with disabilities, did participate in some extracurricular activities. She joined the middle school chorus and, even though she found the instructor strict, she loved the class. She hoped to continue singing once she went on to high school. Outside of school, she attended karate classes two days a week and was working toward a black belt. She said she was very focused when she was there and really liked doing it. She wished that school was more like karate because even though karate was challenging, she reported feeling like she was "not as judged" there. She felt like she could "just be herself."

* * *

"Can you help me with this social studies homework?" Addy mumbled, as she rifled through her stuffed binder and pulled out a map of the original 13

colonies and a second sheet on which were listed 50 landmarks that needed to be labeled. "I can't do this. It is so dumb!"

"Why don't you just leave your stuff here for now, go get your lunch and then come here and we'll work on it," I said. "Just bring your social studies book because I don't know where most of these places are." Even though I offered, I doubted that I'd be much help. Geography and labeling things on maps had always been difficult for me because it was so hard for me to read maps. For Addy, though, I was willing to try. She was clearly distressed and I knew, from sitting in on a recent team meeting, that if Addy didn't complete this assignment, she wouldn't pass history this quarter.

When Addy returned with her lunch tray, she plopped it down and opened her textbook to a political map of the colonies. I pulled the book close to me and tried to read the print. "Yikes, I can't even read the print!"

"Yeah, it is really hard to see," Addy agreed.

I took a second look at the worksheet that she needed to complete. It was such a small map, and I knew that Addy would have a difficult time fitting many labels on the map with her large, sprawling print. I thought that she was supposed to have modified assignments, including enlarged maps, so I asked, "Did you ask Mr. Larson for a larger map?"

"He said no. He said that I should've done my work when it was due and I wouldn't be on remediation and so now I just have to deal with it."

"Maybe I can take this and make a bigger copy so you have more room to

write. Would that help?"

"Yeah, that might help."

I took the map and went next door to the copyroom and enlarged the map as much as I could and transferred it to a legal-sized sheet of paper. When I brought it back to her, Addy seemed relieved. I sat down next to her again, and together we looked at the map. "Okay, the first one is Lexington. Do you know where that is?" I asked.

""I already did that assignment," Matt offered. "Can I help you?"

"I guess," Addy shrugged. I got up and Matt took my seat. I returned to my usual chair and watched as the two, heads together, examined the map. I listened as Matt gave Addy clues like what state a location was in or if a location was near something they had already labeled. By the end of the hour they'd found 15 of the 50 items.

"Hey, thanks," Addy said to Matt as he got up and pushed the desk he'd been sitting in back into its place.

"Yeah, no big deal."

* * *

Addy was often angry. As explored in Chapter 5, she resisted teachers who acted in ways that she found disrespectful. When she felt respected and validated by adults, she always responded positively, but when she felt that adults weren't treating her fairly and failed to recognize her abilities, she acted out. Her situation with her social studies teacher was frustrating to me because

the teacher was choosing to withhold accommodations (modifying her maps) because he didn't like the way she behaved. After I took less than two minutes of my time to enlarge Addy's map, thus giving her more space with which to work, she was able to complete the homework with some assistance from another classmate. Had Mr. Larson, her social studies teacher, done the same and modified Addy's assignments immediately, she might have never been behind. Instead, he interpreted her resistance in his class as an unwillingness to work. He retaliated by withholding support.

As we saw in Life Skills, Addy didn't feel compelled to work for an aide who told her she was going to be nothing. She refused to do work that she didn't feel was valuable. Addy was an extremely intelligent teen who yearned to be treated as such. While her eighth-grade English teacher and I were able to recognize this, many other teachers were not. They only saw Addy as a sullen, defiant student who couldn't learn, rather than a determined young woman who wanted to learn, wanted to be challenged and wanted to be treated with the dignity she deserved.

Natalia

I first met Natalia in mid-September while observing in the lunchroom. Natalia was sitting at the disabled table, not with the students with disabilities, but near them. She ate alone. As I took a seat at the staff table across from the disabled table, I watched her pick at her food. She alternated between watching the students with disabilities, looking at me and staring down at her food. I seized

one of the moments when she looked my way and smiled at her. She smiled and gave me a small wave. The seat across from her was empty so I asked if I could join her.

"Are you a teacher?" she asked. I said that I wasn't and that I was just doing some research at the school this year, so mostly it was my job to just hang out with kids. "That's cool!" she responded, her words revealing a heavy accent. "I've seen you hanging out with Than before, too."

"Yes, I help out in Than's math class."

"Do you know my sister, Mary Catherine?"" Natalia asked. "She's a seventh grader too." I shared that I didn't realize the two girls were related. "We're very different," she shared. "She's much more outgoing than me. She's trying to help Than right now. We know what it is like to be new and to not know the language."

"When were you new here?" I asked, surprised that this student had opened up to me so quickly when I had watched her, day after day, silent and alone at lunch and in her English class.

""We came when I was in sixth grade." She explained that her family moved from the Philippines in early 2009. She moved with her mother, step-father and sister so that her step-dad could take a high-paying job in the pharmaceutical field. Her mother didn't have to work because her step-dad made lots of money. This was a good move for her family, she explained, because in the Philippines they didn't have the same opportunities they did here.

Our conversation ended that day when the bell rang. Over the coming weeks, I spoke with Natalia nearly every day and learned that she did not love school, nor did she love America. In an interview she shared,

American kids are so . . . loud and some are very mean. There are some nice ones, but they don't seem to appreciate the things they have. And they think that school is so hard, but actually it is much easier here than it is in the Philippines. Bad behavior is not tolerated there.

She also was discontented with the food, frequently complaining that the school lunches were so unhealthy, with not enough rice and vegetables. "And everything is sweeter here." She shared that at her house they tried to maintain traditions from their home country and that her mom found a store that sold food that reminded her of home.

School and home were isolating spaces for Natalia. She shared that she often was frustrated with Mary Catherine because she "acted American." She hung out with friends, went to the mall and loved it here. Unlike Natalia, Mary Catherine hoped to stay in America forever while Natalia was hoping that one day she would return to her home country and all the family they left behind there.

* * *

One day Natalia asked, "Whose parents are divorced?"

Sophie and Matt indicated that their parents were not together.

"Why do you ask?" I questioned.

"My step-dad and mom are getting a divorce. I do not understand it. I wonder what will happen to us."

I watched as Matt got up from his place next to me and pulled up an extra desk next to Natalia. He angled his body toward hers. "I know what that's like, well sort of. My mom left me and my dad and sister. They didn't exactly get divorced. She just left."

Tara looked down at her plate. "My parents would be together but . . . my dad is dead. But I know what it is like to only live with a mom."

"We have a step-dad too," replied Sophie, whose father was in prison before her parents divorced and the mother remarried.

"I am worried. My mom does not work. We will not have enough money to stay here."

"Where will you go?" I asked.

"Back to the Philippines."

"Well, that would suck!" blurted Matt. "You're too cool to leave." The others nodded in agreement.

"It is okay. Actually, it might be good. I want to go back. I mean, I don't want to leave all of you, but I miss my family. I just don't know where we will live or what will happen when we get back. My step-dad was in control of everything, and now we will have nothing."

"That is a lot to worry about, Natalia," I responded. "What do your mom and sister think?"

"Mary Catherine is really upset. She does not want to go back. I think my mother is worried. She wanted us to stay here because she wants me to become a dentist and go to a good school and get a high paying job so I can have a good life. If we go back, that might not happen. But because she doesn't have a good job and doesn't speak good English, my mom says we probably can't stay here."

"When would you go?" asked Addy, as she took another bite of her pizza.

"In the summer, probably in July."

"Well, at least we still have the rest of the school year to be together." Addy patted her arm.

Sam

Sam, a seventh-grade student, stopped me in the hall one afternoon in early April as I carried Sophie's tray toward the English room for detention. "Mrs. Johnson, I miss you at lunch."

I began working with Sam early in September. This was Sam's first year at CCMS. He and his mother lived with his grandmother, and they moved to Cinder City so that Sam could have access to a better school, one that they had heard offered strong Special education services. Sam was in Special Ed for a learning disability, but he also had been diagnosed with depression and anxiety. At his previous school, Sam was teased by the sixth-grade students because of his disability and his bright red head of hair. For his twelfth birthday his mother allowed him to invite as many friends as he wanted to his party, and no one showed up. When Sam's mother called some of the parents to find out why they

didn't come, she was told that their children didn't feel comfortable being around him because he was "different." His social status hadn't improved much at CCMS. He spent most of his time alone, and kids teased him because he cried easily and read slowly. His math teacher shamed him in front of classmates for mispronouncing a word, and one day I found him in the quiet room in Mrs. Marshall's classroom crying because he felt "too stupid for this school."

"I miss you too, Sam! How are things?" I asked him on this day in April.

"Can I come to your lunch detention, too?"

"I don't see why not. Why don't you get your lunch and come join us."

"Thanks, Mrs. Johnson!" he grinned and practically skipped down the hall toward the lunchroom.

I entered the English classroom and informed everyone that Sam wanted to join us. Everyone nodded their approval. Matt added, "He's okay for a seventh grader." We settled into our usual circle and began to eat our lunch. Only three minutes or so passed before I noticed Sam timidly standing in the open door.

"Hey guys!" his voice squeaked.

"Hi Sam!" everyone greeted him.

"Pull up a desk!" I stood and held his tray, and he oriented a desk toward our circle. I put his tray down, and he slid into the seat.

We returned to a conversation we'd been having about who had seen the *Hunger Games* movie and whether they thought it was as good as the book. Matt made a joke about Katniss being hot when Ms. Marks barged into the room.

"What IS this???" she shouted. "And who is in charge?"

"I am," I stood up timidly, though I didn't feel like I had to be "in charge" in the way that I thought she meant.

"This is supposed to be detention, not some social hour. You guys don't belong in here!" she continued to shout, pushing into the center of our circle and getting in the face of each and every student there.

"I'm sorry," I stammered, "but I gave them permission to be here. They aren't doing anything wrong."

"This cannot continue. I will be speaking to Mr. Williams about this. This is a punishment!" She turned to me. "If you can't manage this space, then we will have to get somebody else to do it." She then turned to Sam. "And you, why are you here? You're not even in eighth grade. GET OUT!"

She stormed out of the door. The students sat in complete silence. "I'm so sorry, guys. You didn't do anything wrong."

Sam got up from his seat and picked up his tray. "I better go," he replied weakly, tears in his eyes.

"I told you you were welcome here, Sam," I protested. "You should stay."

"No way, Mrs. Johnson. I have Ms. Marks for two classes a day. I do not want her mad at me. She scares me."

I walked him to the door and watched him walk slowly down the hall, his gait drastically different than just ten minutes earlier when he was about to join our space. After he was out of my sight, I turned around to the sad faces of my

students and made a decision.

"No one else needs to leave. You are not doing anything wrong by being here. From now on, I think we'll just close the door."

* * *

The Barring Room

In that moment, when I chose to close the door on that teacher, and on others like her who threatened our lunch detention space, I was living out something that Collins (1990) referenced in her work. She quoted the notable Black civil rights activist Bernice Johnson Reagon and her thoughts on the "barred room." She imagined such a space as:

> That space while it lasts should be a nurturing space where you
>
> sift out what people are saying about you and decide who you
>
> really are . . . in that little barred room where you check everybody
>
> at the door, you act out community. You pretend that your room is
>
> a world. (p. 145)

The dialogue that happened in our own little barred room allowed students to explore those things that they wondered about, with others who perhaps were wondering the same. The conversations we had were powerful and sometimes painful. That is not to say that every dialogue was about difficult things. Some days our talk simply focused on the low quality of the school food or what we planned to do on our weekends. We could be serious or silly. And thankfully, the principal, Mr. Williams, agreed that this space was important. Ms. Marks did

speak with him and argued that my detention space had become something fun. Mr. Williams and I talked, and I explained what was happening in that room. He agreed that what was happening there was too important to interrupt and that it should continue in its present form. I was so relieved. I can't quite put into words what that space meant to me and to the kids. While marginalizing experiences had so often made these students feel alone, in this situation, marginalization seemed to have brought individuals together.

While the students whose stories I have already highlighted were the most central contributors to our space, other students found a safe space in detention. I will share just a paragraph about a few of the students that came with the most regularity to acknowledge the value of their presence and to recognize the many struggles that united this little group. It is important to note, however, that while these students did join our space, they did not do so until May. They joined conversations from time to time and shared the classroom space but did not join in the circle that our core group formed daily. Danielle was the only exception to this. She was invited to join the circle. The others sat outside the circle or joined in conversations with other students in small groups. By the end of May, more than 20 students regularly attended lunch detention by choice.

Danielle lived with her mother, Debbie, and step-father, James, and while they lived in the city adjacent to Cinder City, Danielle's mom open-enrolled her in the Cinder City School District because she worried about her daughter getting lost in a larger school. Danielle's father, Kevin, and mother, Debbie, divorced

when Danielle was very young because her father came out as gay and didn't feel it was right to continue a marriage to which he was not committed. After the divorce, Danielle and her mother were quite poor. Debbie worked part-time and went to school to earn first her bachelors and then a masters degree in social work in order to provide a better life for her daughter. Debbie remarried several years prior, and Danielle spent most her time with her mother and step-father. She and her step-father did not get along at all. James, according to Danielle, was always crabby and depressed. She wished she could spend more time with her real dad but at the same time, she worried about him a lot. He was unemployed after a recent heart attack and was in danger of being evicted from his apartment. When I asked her why she started coming to lunch detention, she shared:

> Middle school kids an be so immature. They think their problems
> are so big but really most of the time they are not. I could care less
> about going to the mall and buying new clothes when I'm worried
> that pretty soon my dad might be homeless. And they say things
> about certain groups of people in our school that are really
> offensive. Like when they throw around the word homo and gay
> and use it to tease people, I keep thinking about my dad. And when
> they say they are all accepting of everyone, really they aren't.

Sarah, another of the triplets, and her best friend Emma joined detention together. Since they met in fifth grade when Emma left her Catholic elementary

school to enroll in the public middle school, they had been nearly inseparable. It was nearly impossible to find one without the other. Their class schedules were identical and were arranged so deliberately by special educators at the school so that Emma could assist Sarah when she needed it. This eliminated the need for Sarah to have an aide present in all of her classes. While Emma also received Special Education services for a learning disability, she kept this hidden from others as much as she could. When given the opportunity to work in groups, Emma and Sarah were usually a group of their own. In English class, when assigned to write a short story, they co-authored a story about a girl with a disability who found friendship at a new school. The two girls relied on one another, and while Sarah preferred Emma's help to that of an adult aide, she shared a piece of writing with me in which she expressed concerns about trust. She wrote:

> *Sometimes I wonder about what is a true friend and who in my life*
> *I can really trust. Sometimes I wonder if people help me because*
> *they feel sorry for me or because they feel like they have to help*
> *me or that they do it because they want to because we are*
> *actually friends. Sometimes I feel like I am a project that someone*
> *helps with to get praise. Other times I feel like I am a burden. I*
> *hate it. And then, there are some people who won't leave me*
> *alone. Like, they try to do too much and that is almost worse.*

Kayla also joined our space in mid-May. Kayla gravitated toward students

with disabilities or other students who needed help. Her tendencies toward taking on the role of caregiver, other teachers predicted, was most likely a carryover from all of the responsibilities she had at home. Her mother worked a lot, and Kayla had to spend most of her time taking care of her younger sibling. Her father was incarcerated after being found guilty of abuse of his family. Kayla did have to participate in some mediation (a mandatory after-school study time) for missing work at the end of third quarter because her grades in two classes suffered because she didn't have time to do her homework at night. She didn't socialize well with classmates and told me that she found it easier to talk to adults or the students who "understand that life is hard."

* * *

"So when will you have your baby, Mrs. Johnson?" asked Matt as he pointed at my belly. It had recently become apparent to some of the students that I was expecting my fifth child.

"It will be awhile, not until October," I answered.

"My sister just had a baby a few months ago. My niece, she's so cute!" Matt said.

"Will you let me babysit once you've had the baby? I love little babies!" Addy begged.

"Well, you know where I live; you can call me too!" Danielle offered.

"We'll have to see what you're all up to once the baby is here."

"Can I ask you something?" Matt asked.

"Sure."

"I don't want you to be offended or anything but do any of your other kids . . . like . . . do they have the same eye thing as you? "

"Nope. All of my kids are able to see just fine." I paused before going on. "Why do you ask?"

"I was just wondering. I didn't know if something like that passed on to others. Do you ever worry it could happen?"

"That's a hard question. I think the question is yes and no. No, because I know that if one of my kids had a disability, which one of them does have Epilepsy and another has a speech delay, it doesn't change how much I love them. But yes, I do worry because I think the world can be a harder place for people with disabilities because they can be judged unfairly and may not have as many opportunities made available to them."

"Yeah, I get that," said Matt, "especially the judged unfairly part. Like coming here. I was kicked out of my other school for a dumb thing that I did and when I got here, it was like everyone just figured I would screw up again and so they were always watching me and waiting for me to mess up. And when I did, I got in trouble right away but like someone else could do the same thing that I did and not even get a detention."

"Me too," said Addy. "Sometimes it is like I just walk into Life Skills and I'm in trouble."

"I think it is unfair at my house that Stephanie gets to hang out with friends

and do things after school and on weekends but I never get to. Then she makes me stay home with my stupid brother," Sophie added.

"Yeah, like that whole thing with me wanting to kill her parents. Whatever. Stephanie, Sophie's sister, just thinks I'm not good enough because I'm disabled."

"So I think you all get what I mean," I added. "It sounds like you've all had unfair things happen to you, and that's what I would worry about for my own kids."

"Did this kind of stuff happen to you, too, Mrs. Johnson?" asked Sarah.

"Yeah, it did. I was teased a lot, especially in middle school. Once, when I was in college, I applied for a job at the daycare center on our campus and was given the job, until the director found out I couldn't see well, and then she started making all sorts of comments like that she wasn't sure I could do the job."

"Did you get the job?" Danielle asked.

"Well, she said she would still hire me, but after all of the comments she made, I had a feeling that I wasn't really welcome and that she didn't really think I could do it, and so I turned the job down."

"Why? You should have fought for it!" Danielle demanded.

"I would've been so mad!" Kayla added.

"Sometimes I just was tired of fighting, if that makes sense."

"I think it is cool that you at least tried. In the Philippines I don't think I ever saw people with disabilities like, umm . . . you know in like, working jobs."

"Really?" Matt asked.

"Yeah. No offense, Sophie, but like, I don't think I ever had a kid in a wheelchair at my school. I don't know where people like that were."

"People with disabilities are treated differently in different countries," I stated.

"Yeah, like what we learned about the Holocaust. People with disabilities were, like, killed."

"Yeah," Natalia said. "That was so sad."

"If we lived back then, probably none of us would be alive." Matt pointed out.

No one said anything for awhile. The only thing I could hear was the sound of Sophie chomping on her lettuce leaves and Matt as he grabbed for my bag of goldfish crackers and poured a few into his hand.

Finally Matt broke the silence, "Wasn't that storm last night like SO awesome?"

"Yeah," agreed Danielle. "I was at play practice and like, we were standing in pitch dark on the stage, it was crazy." Our conversation continued as we all recounted our own storm stories from a spring storm that left nearly half of the city without power and branches and tree limbs blocking streets for miles.

* * *

In our little barred room, bonds formed, questioned were asked, tears shed and laughter shared, yet I worried. I knew this space was temporary, that as

the days until summer vacation and the end of my time at CCMS fell away, that

this space, itself, was not enough. While we were, in our own small way, resisting

the norms of the school by creating a space in which the students could speak

freely, in which the adults with power who repeatedly had oppressed these

students were literally locked outside and where students struggled together to

find meaning in their experiences, this would not last.

Again, Reagon, the Black civil rights activist provided insight. She agreed

that while our space may have been one of comfort and a starting point in which

students felt safe to engage in critically valuable conversations, this in itself

would not be sufficient for larger social change because

> the problem with an experiment (the barred room) is that there
>
> ain't nobody in there but folk like you . . . Now that's nationalism. . .
>
> it's nurturing, but it is also nationalism. At a certain stage
>
> nationalism is crucial to people if you are going to ever impact as a
>
> group in your own interest. Nationalism at another point becomes
>
> reactionary because it is totally inadequate for surviving in the
>
> world with many peoples. (cited in Collins, 1990, p.145)

Our little barred room was a "sphere of influence" in the "struggle for group

survival" (Collins, 1990, p. 141). In private, we engaged in work that didn't really

seem like work at the time to figure things out together; as that happened, I saw

students change. Particularly as the year drew to a close, I saw students grow

more willing to question the low expectations of authority and to share their

stories in very public ways with their teachers and peers. They seemed to be making this movement from survival to transformation because, as they began to open up to peers, they demonstrated, to students and adults alike, their resilience.

The Little Barred Room Goes Public

"What is that box for?" asked Sophie, pointing to a square, unfinished wooden box that sat on a table in the front of the English classroom.

"That's the time capsule," I explained. "Aren't you working on something to put inside?"

Tara interrupted, "She's not doing it. Neither am I. Gina said we didn't have to do it."

"Why not? Don't you want to have something to remember about middle school when you graduate?" I asked.

"Well, I won't be here anyways," said Tara, whose mother had already confirmed with the school district that she would be moving at the end of the year.

"But you can leave something behind that others can remember you by," Danielle offered.

"That would be cool," responded Sophie. "I want to do it. I'm going to tell Gina that this is what I want to work on during English today . . . but I don't know what people are putting in."

"Some are putting in stories; some are putting in pictures or things from

important events that happened this year or during middle school. I am putting in a program from the play I was just in," explained Danielle. "Matt, what are you putting in?"

"I'm working on something, but I'm not saying what." Matt pushed the conversation along: "Natalia, what are you putting in?"

"I don't know," she shrugged. "I might not be here either so, I don't know. I want it to be something good though, something memorable."

"Well, I want to do something!" Sophie announced. "Mrs. Johnson, can you help me write a story?"

"Sure, I can do that."

"Okay, so, like, get your computer out."

I rummaged in my bag and pulled out my computer, lifted the screen and opened a blank Pages document. "What's the story about?"

"It is going to be about this, our lunch time. This was my best part of middle school so I want to write a story about everyone here."

""That's sweet, Sophie," Danielle responded. "That's very cool."

"Okay, so here's how it will start." Sophie began dictating her story to me. After she'd shared about two sentences worth of material, she paused. "I think everyone should help write this. We are all here. We should all add stuff to it."

"Okay," Tara said. She thought for a minute before adding a sentence of her own.

Over the next four days we spent our time together creating the story. I

typed the story for the students because Sophie didn't have access to her accessible computer station. I typed their words verbatim, and the grouped edited the piece together, giving suggestions as we went. I would frequently reread the piece to remind students of our progress. When completed, I emailed it to the students and to the English teacher and printed copies for everyone in the group. The group agreed that Tara and Sophie could submit this project as their contribution to the time capsule but would share with the class that it was a collaborative project and would credit all of the contributors.

When the time came for time capsule presentations in fourth-hour English, "my" students were nervous, but ready. The presentations were spread over two days. Most of the students in fourth-hour English completed their presentations on the first day, some to "get it over with" and others because they were eager to share. During the presentation, each student was required to show their artifact, read a paragraph that explained why this item represented their middle school experience and place the item into the time capsule.

On a typical day, Sophie would not attend English class with her classmates. As mentioned in the previous chapter, she received her English instruction in a self-contained environment. Sophie very much wanted to participate in the presentations, and she asked me to help her seek permission from the Special Education staff to attend the presentations. I told Sophie she would have to do the asking, but that I would go with her to talk with Gina. While her request was met with a sigh and a, "I guess, but I don't see why you need to

go because you haven't been a part of this all year," Sophie was ecstatic. She asked to attend both days of presentations but told me from the start that she didn't want to go on the first day. All of the students from detention felt the same way. They all decided to save their presentations for the second day.

The second day of presentations got underway. Because all of the most outgoing students had already completed their presentations, the students who remained were those who were most nervous about presenting. Mrs. Marshall asked for volunteers to get class started. No one wanted to go first. I whispered quietly to my group, who were all sitting in the row nearest to me. "Come on. . . You all have such great stuff to share."

"Oh, all right, I'll go," Addy stood up. "I wrote two poems for the time capsule. One is about how much I hate school; the other is about how much fun I had on Special Kids Day. I don't like school because most of my teachers don't treat me very well but I loved Special Kids Day because I felt good there. There was a dance party and for the first time ever, I was good at something." She held the two papers in her shaking hands and started to read:

My Best Day
I don't remember the song
We closed our eyes
The audience cheered
We danced and danced
The cheering grew louder
And the winner is...
I felt his hand on my shoulder
"Addy!"

Celebration time, trophy in hand
A long line for a
delicious bratwurst
Wish I could've gotten one to go

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Then a horse drawn wagon ride
Through the countryside
Wish everyday could be for Special Kids

She shuffled her papers and then went on to read her second piece:

School for Me
School is a prison
The desks are the cells
The teachers, the guards
The windows are bars
The grounds is the yard
Classmates, the inmates
The principal is our warden,
To me school is prison,
nothing more.

The class clapped loudly, and Addy hurriedly added her work to the time capsule and sat down in her seat.

Sophie nudged Tara and whispered that she should go next. Tara slowly raised her hand to go next. Mrs. Marshall nodded to her, and Tara walked to the front of the room. She quietly began to read the statement we had written together. "I'm going to read a poem about lunch. I used to eat lunch in the cafeteria but not anymore. My poem is about how much I love my lunch now and the friends I have made there." She began:

Good eats, Bad times

We have fun
Sophie, Natalia, Matt,
Mrs. Johnson and me
We do more than just eat
We talk, we laugh, we relax.

I'd rather be here
Than in the cafeteria
We write stories, take pictures
And Mrs. Johnson listens
Whether we are happy or sad.

It hasn't all been good
Its hard to make friends
Enemies seem to be everywhere
My friends are my choice
But some people get in the way.

Sophie's a good friend
Her dad says I'm no good
Her sister says I'm no good.
But I am. I need her.
She was the best part of my year.

Again, the class applauded as Tara returned to her seat. "I was so nervous!" she whispered to me.

"But you did great!" I reassured her. "You can be so proud of what you did!"

I was about to prompt another of "my group" to go, but Mrs. Matthews, the special educator who supported this hour, loudly prompted two of the other Special Education students to "get it over with!" and so they read their contributions. Then it was Sophie's turn.

"Are you ready?" I asked.

"Can Tara help me?" Sophie pleaded.

"It is up to you and her." Sophie looked at Tara. Tara took the empty chair next to my desk and pulled it over so she could sit next to Sophie.

Sophie began, "I wrote a story about lunch time with Mrs. Johnson and our lunch bunch. We stopped going to the cafeteria and came here to eat instead. It was a lot of fun." Because Sophie's story was more than four pages long in total, we had decided ahead of time which sections she would read:

Lunch Time Memories
We have had lots of lunchtime adventures during our eighth grade year. We have also had a lot of fun. We'd like to share some of our best memories of the year.

We used to eat in the lunch room but since March we have been going to Mrs. Marshall's room as long as Mrs. Johnson is here. I (Sophie) like to go there to talk to Matt and Tara. Natalia comes with us to escape recess and the lunch room because it is more fun to hang out with us. Addy stays some days too and so does Danielle. When we are in Mrs. Marshall's room we steal Mrs. Johnson's snacks like her honey mustard pretzels and Chex Mix. She doesn't seem to mind though.

We talk about a lot of different things. There are times we talk about friend problems or school problems. Sometimes we just talk about fun things. One day Tara broke her glasses and was really worried that her mom was going to be mad about it so she hid under Mrs. Marshall's back table. Mrs. Johnson went under there too and stayed with Tara until she was done crying and felt better. That is what we do here. We help each other out.

We have to talk about Tara and how she always says "Tick" because she knows it makes Mrs. Johnson squirm and shiver because she is NOT a big fan of bugs. Sometimes Tara will go up behind Mrs. Johnson and pretend she's a bug crawling on her neck. We all think it is SO funny. I don't know how Mrs. Johnson feels about it though. We all have to be careful when Tara eats sugar. You never know what's going to happen. When she gets hyper she forgets things and makes us laugh with all of the funny things she does and all of her jokes. One day she drank a Sprite. We won't even talk about what happened then.

And Matt… he says the funniest things. You just never know what he is going to say or do. He can do the best impressions. He makes me laugh sometimes that I spill food all over from laughing so hard.

We are all really sad that the year is ending. Natalia is going back to the Philippines. Tara is moving. Addy and I will be staying here and going on to Cinder City High School. Matt is going to Memorial. Mrs. Johnson will go back to the University of Minnesota and will only be here once in awhile. It was a great year and what comes

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next, we don't know. It is hard to say good bye but we made some good friendships, had lots of laughs. There is hopefully a lot more good things to come.

Natalia went next and shared her story related to a day in her life. She shared with the class that she chose this because it represented the person she was at school and the person she was at home and how she and her family still did many things to honor their culture from the Philippines.

There were less than five minutes left remaining in the hour when Mrs. Marshall turned to Matt and said, "Ready?"

"Ooh, I guess. But you guys can't laugh!" he ordered the class as he lumbered to the front. "Okay, so like, I am putting in this picture of a set of stairs. I chose this picture because . . . well . . . I'm just going to read what I wrote."

The reason I choose to put a picture of the steps in the eighth grade time capsule is that it resembles the steps I have gone up in eighth grade. I started at the bottom but I, myself have overcome many struggles. I have tried to keep my grades up and think I am going to end the year in a good place. I came from having terrible grades the year before to having grades I am okay with this year. I am not at the top of the stairs yet because I still have to keep going up. I want to keep things together in high school so I can graduate with a good grade point average and get my diploma. In a few years I want to look back on this year and know how far I've come. This year has been great for me. I know I had some struggles but Mrs. Marshall and Mrs. Johnson, they have helped me. I know that by them being my teachers this year, I am a better writer and a better person. Thank you for helping me this year.

The students clapped politely. Matt took several goofy bows and said, "thank you, thank you," over and over before returning to his seat. I took off my glasses and quickly dabbed tears from my eyes. I noticed Mrs. Marshall sitting at her computer desk doing the same. The bell rang and the classroom emptied

quickly. Matt rushed for the door before either of us could say anything to him.

Mrs. Marshall came over to me and whispered, "Did you know he wrote that?"

"No, I didn't. He's been very secretive about what he was writing."

"I don't know what to say, I mean. Maybe you were right. All year he's been driving me crazy. I couldn't see it."

"Like I've said before, I don't think he was ready to let people in. He's had to overcome a lot in his life and he hasn't had a dependable female in his life. Maybe he just didn't know how to *be* with you."

To understand the full value of the students' work, it is important to consider the content and the public way in which it was shared. Addy offered two poems. Her first poem was a commentary on her positive experience at Special Kids Day. Special Kids Day is a regional project organized and funded by volunteers. The mission is twofold: first this day offers students with special needs an opportunity to practice social skills and network with other students with disabilities. Children are given the opportunity to try new activities that typically are not accessible to all, like boating and fishing. Second, organizers wish to (in the words of the organization's website) "say THANK YOU to all of the special educators and staff who work so hard to help others accomplish so much."

For Addy, Special Kids Day was "her day." She participated in a dance contest, ate way too much food and met new friends. She went on a pontoon for the first time and returned to school happier than I had seen her all year. She

explained to me that at Special Kids Day, it was "okay to be disabled." She felt proud there. This contrasted greatly with her piece that likened the school to a prison and used several similes to provide the reader with the visual imagery to support her claim. Her Special Kids Day poem ended with the line, "I wish everyday could be for Special Kids." She did not seem to feel that her school experience was "for" kids like her, with its guards (teachers) and cells (classrooms). And she shared this information in front of her classmates. While Addy had been required to give speeches or share pieces of work aloud earlier in the year, she had refused. She chose to have points taken from her grade rather than to speak in front of classmates. So for her to not only share these poems, but to do so publicly was a major accomplishment for Addy.

Tara and Sophie presented pieces related to their unique lunch experience. Both girls wrote about the happy times that happened when we were together in detention but alluded to some of the challenges as well. Tara referred to Stephanie trying to end the friendship that she and Sophie shared. Sophie wrote about the time that Tara broke her glasses and was worried about how her mother would respond. For both students, the lunch time space they developed was recognized as the most positive experience of their eighth-grade year.

Sophie's piece was important for other reasons. First, as noted in the previous chapter, she typically attended a self-contained English class for approximately 20 minutes per day. She hadn't been given the opportunity to participate in "regular" English since sixth grade. In pullout English she spent

time typing sentences that were dictated to her or completing worksheets taken from an early elementary workbook. That is what teachers thought she was capable of doing, yet Sophie's story about her lunch experience was initiated by her. The only assistance she received was my typing her story as she dictated. Not only did she complete the assignment, but she advocated, with my assistance, to attend English class with her classmates and to present her piece to the class. When the aide was initially resistant, Sophie pushed on until Gina agreed. While I think it strange that a student had to beg to participate in a class with her peers and to ask to do an assignment, I believe that this represents an attempt by Sophie to be with her peers and demonstrate to her special educators her ability. Whether they believe it or not is questionable.

Tara's written submission represented more than just her effort to complete an assignment. While Tara did regularly attend fourth-hour English, the expectation that she participate and submit assignments was greatly reduced. If she did not complete assignments, there were no penalties. Her grade was never adversely impacted. She was, from time to time, told that completing assignments was not necessary. Despite these things, Tara chose to write her poem and to read it aloud to a class. She stood in front of a classroom, in front of some of the same students who had mocked and teased her throughout the year. Despite all of this, Tara felt empowered enough to stand before this classroom full of people who had not always been kind to her and shared those things that were very personal to her.

Matt's piece was different in that he chose to use a picture as his time capsule artifact, and it was his written explanation of the image that provided important insight into his year at CCMS. The image of a set of stairs, Matt explained, represented his journey in middle school. He felt as though he started the year at the bottom, when he was pulled out of all of his courses and was in the processes of proving he should be allowed to attend classes with his peers. As he made the improvements in his behavior that the teachers and administrators wanted to see, as he described, he made his way up the stairs. Matt had yet to reach the top because, while he recognized he had made improvements and was making better choices, he still saw improvements he wanted to make in himself. What was also important to note in his reflection was his recognition of the role that Mrs. Marshall played in that journey. While I never had any ongoing trouble with Matt, he and Mrs. Marshall had several altercations. She was convinced that Matt hated her and was deliberately trying to throw off her class. As I observed in her class and listened to what Matt had to say about Mrs. Marshall when she wasn't around, I was certain that this was not the case. Matt had a lot of respect for Mrs. Marshall and enjoyed her class. Mrs. Marshall was like a mother to many of her students and for Matt, this was something he hadn't experienced. His mother had abandoned him when he was young, and I wondered if his initial resistance to Mrs. Marshall's nurturing actions toward him made him uncomfortable. For him to publicly acknowledge her as a contributor to his success was a big step for him and an even bigger surprise for

Mrs. Marshall.

As was the case with Tara, Matt chose to be vulnerable in front of his peers, something that is hard for many people, but I believe was particularly difficult in this situation. Whereas just months earlier, Matt put on an act to impress two of his male classmates when they were assigned to my lunch detention, on this day he stood before them and read aloud this powerful piece. I found his presentation particularly moving and very brave, and I told him at lunch following his presentation. He said, "Now don't go and cry on me but, it was all true. It was time to just be real."

Matt captured the essence of what happened in lunch detention. Throughout the year, I watched these students act one way in classes but then so differently in our little barred room. But when these students stood before their classmates and read their work, they were stepping outside our little room and bringing their stories into a bigger space. They were, as Matt said, ready to just be real.

Where are They Now?

Sophie

Sophie will complete her sophomore year at CCHS in June, 2014. She spends her entire day, with the exception of lunch, in a self-contained Special Education class. She continues to receive assistance during the school day from a personal care attendant. Sophie's sister Stephanie is responsible for most of the personal care responsibilities of both Sophie and Sarah at home. Sophie is

hoping to graduate from high school but is not sure what will happen after that.

Tara

Tara will also finish her sophomore year of high school in June, 2014, though not at Cinder City High School. Following the end of her eighth-grade year, her mother removed both daughters from the school district and relocated to a larger nearby city where Tara now attends a large high school. When we last spoke, Tara was in a relationship with another male student who is "disabled too, but still cool" and she loves all of her classes. She's had fewer seizures and is feeling good. She and Sophie talk on the phone occasionally, but Sophie's mother still tries to prohibit communication between the two girls. Tara is hoping to be able to go on to school after graduation and become a teaching assistant for young children, especially those with disabilities.

Natalia

Natalia, her sister and her mother returned to the Philippines in mid July, 2012. They planned to stay with family until they were able to establish their own housing; however, in late July, Typhoon Saola struck the Philippines. The natural disaster resulted in millions of dollars of damage and displaced hundreds of thousands of people, among them, members of Natalia's immediate family. After living in a shelter for a period of weeks, Natalia's mother and step-dad were able to reconnect. The thought of having lost his family in the typhoon had impacted him so greatly that he begged them to return to the United States and to give the marriage another try. The family returned to the United States in late August,

2012, just before the start of the school year and to this day are still together. Natalia is enjoying high school and remains connected to the lunch bunch friends who are attending Cinder City High School.

Addy

Addy will complete her sophomore year of high school at Cinder City High School in June, 2014. She enjoys high school more than she did middle school. She finds that her teachers respect her more, and she has a bit more independence. She continues to sing in choir and take karate lessons. She still loves reading and one day would love to go into a career working with children either in a childcare or medical setting.

Matt

After graduating from Cinder City Middle School, Matt and his father also moved to a larger nearby city, where he now attends the largest high school in the region. He is doing well academically and checks in with both Mrs. Marshall and me from time to time. He still enjoys fishing and gaming and is looking forward to graduating with good grades so he can go on to establish a good career and lead a more stable life.

Lunch Detention

After the "success" of lunch detention, the middle school administration decided to provide a lunch and recess alternative to all students. Beginning with the 2012-13 school year, students had the option of taking lunch in the cafeteria and then going to recess or participating in what they called "alternate recess."

The alternate recess space was similar to our lunch detention in that it is held in a middle school classroom and is intended to provide an option for those students who do not find the cafeteria or playground comfortable spaces. It is different in that supervision of "alternate recess" is now a duty to which teachers are assigned. The lunch space shifts from week to week, being held in the classroom of whichever teacher has been assigned to supervision duty that week. Alternate recess also differs in that teachers have been using it as a punishment. While it was conceived as a safe space for students, some teachers require students to go there to complete missing work or for behavior infractions. This, I have been told, impacts the dynamics of the space. Whereas at the end of my time at CCMS, lunch detention was a safe space to which students chose to come, it is now more closely resembling a traditional detention space.

Conclusion

This experience was nothing like I had expected it to be. I had been told by teaching colleagues and parents that the atmosphere for students with disabilities at Cinder City Middle School was one of positivity and support. I believed them. I had spoken to parents who moved to the school district to access what they believed was the best possible education for their children with disabilities. On the surface, staff members who worked at the school shared that what was happening at their school was something to be studied and recreated elsewhere. Hearing this, I could hardly wait to see what they were doing. When I first met with the middle school special educators and aides during the summer prior to my study, they bragged about their practices and couldn't wait for me to write about all of the wonderful things that they did for students. I was excited. Reflecting on my own middle school experience with Special Education, one marked by pain, marginalization and bullying, I was eager to see something good. I wanted everything I had heard about this school to be true. What I found, however, was something altogether different, and I am still left wondering how it is that so many people hold CCMS in such high regard.

The teachers and administrators of Cinder City Middle School, with a few exceptions, did believe that they were doing great things for students and that CCMS was a place at which all students felt welcome. They attributed much of the "accepting environment" to a nine-week Disability Unit taught as part of sixth-grade English. Ms. Ana, the sixth-grade English teacher, designed what she

thought was an opportunity to expose students to the "differently abled" in a positive way. As I described in Chapter 4, she used a variety of media that included fiction and non-fiction texts, videos and speakers to explore disability. Students had to create a public service announcement or t-shirt in support of the national "spread the word to end the word" campaign as well as to select and research a disability and present a speech to classmates. The most memorable part of the unit for most students, however, was the opportunities they were given to "put on" disabilities. Mrs. Ana believed that the opportunities she provided students during this unit helped them view disability as just a difference and not a deficit.

I expressed my worry, though, about the degree to which Ms. Ana was successful in achieving this goal. Nearly all of the non-fiction texts that were used for the research portion of the unit were written by doctors and therapists. The texts focused on medical implications, treatments and rehabilitation and failed to provide insight into the societal factors that oppress individuals with impairments. As students prepared their speeches, Ms. Ana's requirement that the majority of the speech content focus on the medical implications and treatment of various conditions left many students believing that a disability was a medical condition and that the "problem" of disability resided within the individual. Nowhere in the unit did the teacher provide students with information regarding the many ways society marginalizes students and adults with disabilities.

I wish there would have been some exploration of the barriers that

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individuals face with regard to the built environment, transportation, communication, technology, education and employment. It would have been particularly enlightening for students to explore the various accessibility features of their own school. An examination of the entrances to the school, for example, would have illustrated that to use the main entrance of the Middle School, students must be able to climb stairs. Students in wheelchairs were required to use the staff entrance found at the back of the building. An assignment like this might push students to consider disability as something other than a medical condition, particularly if they were able to understand things like inaccessible entrances and the extra expense of assistive technology as a problem with society, not the person with a disability.

My worries related to the content of the speech unit extended beyond the required focus on medical information. As I highlighted in Chapter 4, students were required to end their speech with a statement about how this unit changed the way they thought about the "differently abled" in order to receive full credit. While some students were "changed" by this unit, many were not. When interviewing eighth-grade students about their experiences during the sixth-grade unit, many admitted to saying things that weren't true in order to earn the points, but not necessarily because change actually occurred. As one eighth grader explained, "Kids said things in the speech that they knew the teacher wanted to hear, like, 'I'll ask a student with a disability to join our table at lunch' and then walk out the door and never think about that unit again." The requirement also

presented challenges for students with disabilities. Some students with disabilities admitted to using phrases similar to their non-disabled peers, saying things like, "I now feel more accepting of people with disabilities," or, "I won't be afraid to sit by them or be friends with them." In this way, the disabled students' conclusions sounded like those of their non-disabled classmates. It was what they felt like they had to do "for the grade."

Arguably, the most problematic component of the unit was the use of disability simulations. Students sampled a "disability buffet" of sorts. One day they got to "be" hearing impaired, then blind and finally mobility impaired. Students' responses to these exercises ranged from finding the experiences funny to being completely horrified, proclaiming death as preferable to living with a disability. Simulations lacked a realistic quality in that students were thrown into situations without any time to develop ways of "being" disabled. For example, Ms. Ana asked students to walk blindfolded through the hallways of school and outside on the uneven school grounds with only a "walking stick" and a student untrained in appropriate sighted guide protocol. Students were scared, and many of them became so immersed in the bodily experience of blindness that this was what they remembered. Siebers (2008) and others suggest alternative ways of teaching about disability that move beyond exercises that rely on embodiment and that instead encourage students to focus on the social implications of disability.

While Ms. Ana used her English curriculum to teach students about

disability, the curriculum in other spaces, as explored in Chapter 5, failed to provide students with disabilities with challenging, developmentally appropriate learning opportunities. In the Life Skills classroom, students counted Box Tops for Education into groups of 50 and glued Campbell's soup labels to pieces of paper day after day. While students in that class brainstormed a list of things that they believed would help them live more independent lives, their list was immediately disregarded by Mary, the aide, because it was "too much work" and "not realistic" for kids with disabilities. In another of the Special Education classrooms, students colored and cut out pictures of animals. For Sophie, half of her pullout English class was spent being taken to the bathroom while the second half might be spent matching pictures to their beginning letter sounds on a worksheet taken from a first-grade workbook. In other instances, students could sit for entire class periods without any instruction taking place at all, resulting in literally days of lost learning time.

In other instances, students were allowed to attend general education "inclusion" classes with their non-disabled peers. Unfortunately, their access to learning was often restricted in those settings as well. In the case of Tara and Sophie, they were allowed to attend the eighth-grade career unit in English and reading but were not expected to do any of the work. They were allowed to be present as more of a "feel good" exercise and not an educational one. While the classroom teacher believed that the students could be held accountable for some of the work, the Special Education aide told the girls they did not need to

complete the work. In another situation in eighth-grade English, a student who was putting a lot of thought and effort into a Holocaust research paper was told that she was "doing too much." The student wanted to do the work and was engaged in the topic, but the special educator literally told her to stop working.

Students lacked access to a curriculum that challenged them and provided them with the knowledge they would need later in life. Some of the special educators had decided that these students wouldn't ever become anything and therefore provided them with opportunities in their classes that prepared them to do nothing. It didn't seem to matter that some of the students had dreams of pursuing postsecondary education. Instead of providing different pathways to learning the same curriculum as their non-disabled peers through differentiated instructional practices, students experienced "dumbed down" elementary learning. Each year that they remained in Special Education, students fell further and further behind their peers. This, unfortunately, is not a practice unique to Cinder City Middle School. Research by Critical Special Educators and others in Disability Studies in Education have written of the widespread problem of substandard educational practices in Special Education settings.

Teachers not only communicated their beliefs about students through the learning opportunities they provided, but in the things that they said to and about students. In the second half of Chapter 5, I explored the ways special educators, and to a lesser degree, regular educators talked to and behaved around students with disabilities. Mary, the primary instructor for Life Skills, was quick to remind

students of what they couldn't do and how much they didn't understand about "the real world." Gina, another aide, said that Sophie would be "lucky to get a job as a Walmart greeter." Mrs. Matthews and Ms. Marks, two of the other special educators, discussed confidential student information in front of students because they believed that the students didn't possess the cognitive ability to understand anyway. Another of the Special Education aides believed the same and demonstrated this to me when she brought students along to our scheduled formal interview.

But students did understand, and they were beginning to internalize what was being done to them. Mitch, a seventh grader, was constantly targeted by his seventh-grade math teacher and Ms. Marks, his special educator. One afternoon he was sent to the timeout room for arguing. He spent several minutes yelling at the teachers from inside the little room. After being told to quiet down for the third time, Mitch shouted:

> You may all think I'm stupid but I'm not. I know what you think of us.
> You don't help us, you just spend your days reminding us how
> stupid we are. You yell at me in front of my friends and teachers.
> They all start to think I'm stupid too and treat me like I'm stupid
> because of you. And you talk about us behind our backs. And then
> when we try to fight back, you send us to the timeout room or you
> give us a detention or suspend us so you don't have to listen to us.
> I hate you. I hate special ed and I hate this school.

While Mitch was one of the students known to resist the teachers' actions, he was not alone. Eighth-grader Addy also challenged Mary's accusation that she would never "be anything." For both these students, attempts to speak out against the teachers' damaging comments earned them detentions. It seemed as though when students made efforts to resist the oppressive actions of the teachers and to assert themselves, the adults used their power to silence their attempts.

Teachers found other ways to oppress students. This was the case for Matt, an eighth-grade student who spent the first several weeks of the school year earning the right to attend his academic classes. He earned classes by being submissive, sitting quietly in the timeout room, doing his homework. Once Matt was allowed to start attending classes with peers, he was escorted from room to room by a special educator, and if he made even the smallest misstep in class, speaking out of turn, questioning an adult, he would be returned to the timeout room and would have to, again, earn his way back into classes.

While many teachers found Matt to be defiant, I had a completely different experience with him. In Chapter 6 I provided a look inside an important space that developed: lunch detention. After misbehaving one day at lunch, Matt was assigned to a three-month lunch detention, and I was hired to be his supervisor. Over the course of several weeks, our one-on-one detention grew to include other students who were marginalized for various reasons and who wanted to escape the cafeteria. In detention, students ate and talked, and I watched in awe

as this amazing bond formed among the teens. They comforted one another, laughed with each other and helped each other figure out some difficult things.

Our safe space was nearly destroyed by a special educator who, one day, barged in and reprimanded me for providing a "fun" place for students. On that day, we closed the door, something that I didn't consider particularly significant at the time. The work of Patricia Hill Collins, however, helped me to understand it as an important move. In doing that, we had created what black civil rights activist Bernice Johnson Reagon called "the little barred room." In our little barred room, the students figured things out, and some of them emerged from that space at the end of the year ready to share pieces of themselves with their classmates. Addy, Sophie, Tara, Natalia and Matt went on to present artifacts to their classmates as part of an eighth-grade time capsule project, including poems, stories and pictures that I believe represented the growth they'd made, in part, from participating in lunch detention. It was a powerful experience for all of us. We all emerged from that room as different people. I was encouraged by the strength demonstrated by those students. When my own experiences at CCMS became painful and tiresome, it was my time in "our little barred room" that sustained me and my work.

I learned so much from the students, parents and teachers at Cinder City Middle School and the things I learned have implications that reach beyond the boundaries of that small school district. In preparation for this work I immersed myself in works by scholars writing in the fields of Disability Studies and Disability

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Studies in Education. While I was relieved to find others who conceptualized disability as something more than a medical condition, what I did not find was much in the way of research that explored the experiences of students with disabilities in schools from the students' perspectives. While I yearned to read the stories of students with disabilities speaking directly about their school experiences, I found very little. This work attempts to respond to this need. While engaging in this work, I tried to keep the focus on the students. I went to their spaces and listened to their stories. It is their words that I privileged in this work. I often found myself asking students, "why do you think that happened?" and I used their understandings to guide me through this work.

Taylor (2006) called for research that not only explores the social experiences of children and teens with disabilities, but that is undertaken by researchers who are, themselves, disabled. Within this work I included some of my own experiences because, as I quickly learned, my disability identity was fundamental to this work. I do not believe that I would have enjoyed the same relationships with students that I developed had I not been disabled. The students and I were able to share stories and help each other through some things. And while it certainly wasn't always easy to be an "insider" with the students (while being an outsider because I was still an adult and a former teacher) and an "outsider" among the staff because I was disabled (yet an insider because I was, like them, an educator), it made me realize that work like this is possible. I hope that this serves as a form of encouragement for other

researchers with disabilities who are considering the pursuit of work in this field.

This piece also has implications for teacher educators. First, in reading this work, I hope that those considering a future in education would consider carefully the ways we communicate our beliefs about students to students. In this study I provided examples of how, when we provide substandard educational opportunities for students with disabilities, we are communicating a belief that they are unlikely to succeed. Just as Ladson-Billings (2009) supports the creation of a learning environment that is academically challenging and holds African-American students to high expectations, the same should be extended to students with disabilities. Whereas students often receive "dumbed down" content, they should be supported in inclusive spaces that utilize multiple ways of accessing learning.

Additionally, teacher educators need to consider not only the formal ways by which we share information with students, but the informal ways as well. In this work students were publicly shamed in front of their peers. Their confidential personal information became fair game for casual discussions in the resource room and hallways of the middle school. Teachers, instead of using instructional time for instruction, used it for socialization, thus devaluing the students' desires and needs to learn. Some of the things that happened in this school still astound me, and perhaps they astound you too, but I believe that these things make this work all the more powerful. Future teachers need to read this and understand that what they say and do directly impacts students in very powerful ways. Their

impact on students is directly tied to how they decide to "be" with students.

While I was able to learn a great deal in the year I spent at CCMS, this work has revealed just how much there is yet to understand and explore related to the experiences of students with disabilities. This study focused specifically on the experiences and goings-on in a middle school setting and throughout, things that students and parents said left me wondering if the experiences of students in elementary school or high school would be different. Two parents in this study believed that their children had more friends and were more included in elementary school. I am interested to learn if this is true for other parents and students. In talking with older students with disabilities, some have indicated that there came a time in their lives when they became more comfortable with their disabilities. Others have suggested that, even as adults, they feel isolated and restricted by their impairments. Future research endeavors are calling me to explore the experiences of those both younger and older than the population of this study.

Just as my research has uncovered questions that will guide my future research, I also reflect back on my process and recognize some limitations. In reading this work, the reader will notice that I was critical of the practices of several of the special educators at this school. While I included quotations and reflections from students, parents and regular educators, none of the full-time special educators agreed to participate in a formal interview. Two of the teachers refused and the other two initially agreed but kept delaying any scheduled

interviews until they eventually stopped responding altogether to my requests. I do believe that their insights would have added value to this piece in that multiple perspectives can serve to make a piece of work stronger. Were I to do this work over, I would have completed interviews with special educators at the beginning of the year before they developed the perception of me as someone who was against them.

This research was important to me for both professional and personal reasons. Professionally, this represents my first comprehensive attempt at understanding disability as something more than a personal experience. I was able to learn and theorize students' experiences in schools alongside individuals whom I consider to be the "real" experts, the students themselves. Additionally, this work helped me grow in my own understanding of myself. In this case, answers to my questions were not to be found in a book. Instead, they were waiting for me in the hallways and classrooms of Cinder City Middle School. My "research assistants" were the students. Children are capable of teaching us great things. We need only be ready to listen.

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