

Ableism in Education: A Case Study of a Student with Multiple Disabilities

Ellen Therese Reilly

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Kami M. Patrizio, Chair

Walter D. Mallory

William J. Glenn

Carlyn E. Floyd

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ABSTRACT

This phenomenological case study examines the journey of one female with multiple disabilities and how she achieved success in school against difficult odds. It relies on an overview of the disability movement, related legislation from the 1960s to present, and compares the theoretical models of disability. This framework of historical, political, medical, social, and ableist approaches to disability sets the stage for the study which relies on extensive open-ended interviews, a document review, audio recording of an Individual Education Program (IEP) meeting, and a researcher journal to elucidate the role of ableism in education. Data sources for the research included interviews with the student, her family, and her teacher/tutor, as well as a review of her individualized education plans and medical notes. A research journal that draws on the author's 15 years of experience as her interpreter and as a family friend was also used.

The research begins with an examination of the disability rights movement which has led to disabled people moving into mainstream society. An explanation of how the effect of ableism in schools impacts students with disabilities is provided. The relevant legislative acts and policies in education are reviewed to explain how they were established to assist students with disabilities to become financially and socially independent after graduation from high school. Finally, this dissertation will introduce ways educators can effectively end an ableist attitude toward students with disabilities in order to assist students with disabilities obtain greater opportunities after graduation from high school.

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When I started this journey, I continually heard that it could prove to be quite challenging. Little did I know back then that my personal and professional life would undergo so many changes that impacted this journey. Fortunately for me, I had so many people there to support me along the way so I could finally reach the end of this journey.

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TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
LIST OF TABLES.....	x
CHAPTER 1 INTRODUCTION.....	1
Historical Context: The Disability Rights Movement in America	2
The Early Ages	3
1920s–1950s.....	4
1960s–1970	5
1970s to the Present	5
Disability Versus Impairment.....	7
Language and Identity	8
Lingering Effects of the Medical Model	8
Social Model.....	10
Educational Implications	11
Research Questions.....	11
Significance of the Study	12
Overview of the Study.....	12
Definition of Terms	12
Overview of the Study.....	15
CHAPTER 2 REVIEW OF THE LITERATURE.....	16
Research Questions.....	17
The Disability Rights Movement in America: The Fight for Civil Rights	17

Societal Values: Devalued and Diminished Expectations.....	19
Ableism and People with Disabilities	19
Devaluation and Diminished Expectations of People with Disabilities.....	20
Legislation for Equal Educational Opportunity and Outcomes	23
From Section 504 to the ADAAA	28
Section 504 of the Rehabilitation Act: Background and Purpose.....	35
Advances of Section 504 of the Rehabilitation Act.....	36
Shortcomings of Section 504 of the Rehabilitation Act	37
The Americans with Disabilities Act: Background and Purpose.....	37
Educational Advances of ADA.....	38
Educational Shortcomings of the ADA	39
The Path from the ESEA and the EAHCA to IDEA and NCLB.....	41
EAHCA/IDEA: Background and Purpose	46
Educational Advances of Individuals with Disabilities Education Act (IDEA).....	48
Educational Shortcomings of IDEA.....	48
NCLB: History and Purpose	49
Educational Advances of No Child Left Behind (NCLB).....	50
Educational Shortcomings of NCLB.....	51
Closing the Achievement Gap for Students with Disabilities.....	52
The Reality of Policy in U.S. Education	54
Impact of IDEA and NCLB.....	56
Impact of IDEA and NCLB on Students with Disabilities.....	57
Impact of IDEA and NCLB on Teachers.....	59
Impact of IDEA and NCLB on Accountability and Testing	60
Devalued and Diminished Expectations of Students with Disabilities	61
Ending the Ableist Attitude in Schools	63
Educating Students about Disabilities.....	64
Summary	65

CHAPTER 3 METHODOLOGY	68
Purpose of the Study.....	68
Design.....	69
Narrative Inquiry.....	70
Life History.....	71
Participant Selection.....	71
Confidentiality.....	72
The Role and Background of the Researcher	72
Gaining Access and Entry to the Setting	75
Accessing the Cultural Context.....	75
Data Collection	76
Data Source 1	77
Data Source 2	79
Data Source 3	79
Data Source 3	87
Data Source 5	89
Data Analysis	89
Data Transcription	90
Data Compilation	91
Translation of ASL Interviews	91
Reliability and Validity	92
Peer Review	94
Summary	95
CHAPTER 4 FINDINGS.....	96
Overview of the Problem	98
Finding A: Ableism Exists in the School Setting.....	99
Karen’s Isolation	99
Ableism and School and Family Relations	106

Finding B: Resources Needed for Success.....	123
An Effective School Leader	123
Supportive Adults.....	130
Strong Personal Qualities	135
Summary of Findings.....	140
CHAPTER 5 DISCUSSION, IMPLICATIONS, AND CONCLUSIONS	141
Summary of the Study.....	141
Overview of the Problem	141
Statement of Purpose and Research Questions	142
Review of the Methodology	143
Major Findings Supported by the Literature	144
Discussion Regarding Federal Legislation.....	145
Discussion Regarding Devalued and Diminished Expectations	150
Major Findings Not Supported by the Literature	150
Impact of Ableism on the Family.....	151
Responsibility for Her Own Education.....	152
Unexpected Findings	153
Conclusion Regarding the Findings	154
Implications	154
Disability-oriented Education for Teachers.....	154
Disability-oriented Education for Students.....	156
Recommendations for Further Research	158
Concluding Remarks.....	159
The Tutor's Concluding Remarks.....	159
The Mother's Concluding Remarks.....	159
The Researcher's Concluding Remarks.....	160
The Student's Concluding Remarks.....	160

REFERENCES	162
APPENDICES	170
Appendix A Karen’s Consent Form	171
Appendix B Mary’s Consent Form.....	174
Appendix C Claire’s Consent Form.....	177
Appendix D List of Interviews and Meetings	180
Appendix E Reflexive Journal Protocol.....	181
Appendix F Calendar of Data Collection Activities with Analytic Tool Notations	182

LIST OF TABLES

No.		Page
1.	Educational Attainment in the Year 2011–Ages 21-64 Years	2
2.	Disability Employment Statistics – August 2014 – U.S. Department of Labor	22
3.	Policy Passed with the Intent of Equality of Opportunity	25
4.	Comparison of ADA 2001 and ADAAA 2008	34
5.	Comparison of IDEA and NCLB	57
6.	Documents Analyzed	78
7.	Interview Schedule with Karen	87
8.	Incidents in First Grade of Broken Trust Between Family and School	113
9.	School Personnel’s Descriptions of Karen’s Attitude	127
10.	Standards of Learning	140

CHAPTER 1 INTRODUCTION

In the 1960s, the Disability Rights Movement (DRM) began to work toward the civil rights for people with disabilities, to end isolation, and to bring awareness about disability issues to the general public (Baird, Rosenbaum, & Toombs, 2009; Longmore, 2009). The goal of the DRM was to end the medicalized view of disability; which views people with disabilities as marginalized citizens (Longmore, 2009). To this end, the DRM fought for people with disabilities' rights in schools and in the work place. They sought to have American citizens recognize that people with disabilities cannot change or, in most situations, alter their disability (Longmore, 2009). Further, they tried to raise awareness about how American society can accept people with disabilities as they are (Longmore, 2009) and end ableist attitudes towards people with disabilities.

The goal for people with disabilities is to be able to live independently, be economically self sufficient, and participate fully in society (IDEA, 1990). Many people with disabilities are doing so. There are approximately 54 million people with disabilities in the United States (Baird et al., 2009). In 2012, of people with disabilities between the ages of 21 through 64, 22.2% have less than a high school diploma, 34.4% have attained a high school diploma or the equivalent, 31.0% attended college or received an associate degree, and 12.4% earned a college degree or higher. Of people with disabilities in the year 2012, there were 10.2% with less than a high school diploma, 25.5% who attained a high school diploma or the equivalent, 32.6% who attended college or received an associate degree, and 31.7% who earned a college degree or higher (Erickson, Lee, & Von Schrader, 2012). Table 1 displays the educational attainment of individuals with and without disabilities. Currently, the unemployment rate for the adults with

disability is double that of the non-disabled adult (U.S. Department of Labor, Bureau of Labor Statistics, 2013).

Table 1

Educational Attainment in the Year 2011–Ages 21-64 Years

Diploma	People with Disabilities	People without Disabilities
Less than high school	22.2%	10.2%
High school/equivalent	34.4%	25.5%
Attended college/Associates	31.0%	32.6%
College/higher	12.4%	31.7%

Having all students, disabled and non-disabled, attend college benefits not only individuals but also society as a whole (Baum & Payea, 2013). A person who has a higher level of education earns, on average, 73% more than a high school graduate, and the unemployment rate is lower for those who have a higher level of education (Baum & Payea, 2013). Legislation was passed in 1973 to provide equal educational opportunities and outcomes for people with disabilities (National Council on Disability, 2004). Since then, doors have been opened and people with disabilities have entered schools; 40 years has passed, however, and an educational academic achievement gap still remains for students with disabilities (National Council on Disability, 2008).

Historical Context: The Disability Rights Movement in America

Approximately 20% of our population is disabled; making the disabled the largest minority in America (Switzer, 2003). Disability can happen to anyone at any time; it does not discriminate (Shapiro, 1994; Switzer, 2003). Most people have a family member, or know a friend, who has a physical or mental disability. Plus, as medicine improves and people begin to live longer, the number of people with impairments increases (Kudlick, 2003; O'Brien, 2001;

Shapiro, 1994; Switzer, 2003, p. 5; Taylor, 2004). Over 40 years ago, Congress began providing federally funded resources to schools to educate children with disabilities (President's Commission on Excellence in Special Education, 2002). As a result of Congress's actions, "special education has become one of the most important symbols of American compassion, inclusion, and educational opportunity" (2002, p. 3). Due to legislation that has been passed in the last 40 years, our schools serve the needs of millions of students who are disabled with the goal of their becoming productive, independent citizens upon graduation (Taylor, 2004).

Yet historically, children with disabilities have not received an appropriate public education (Yell, 1998). In fact, even though every state instituted compulsory attendance for children by the year 1918, public schools continued to exclude students with disabilities from the classroom. Parents and advocates of children with disabilities have been credited with taking on the fight to have children with disabilities accepted into the public school system. It was not until the 1970s that federal legislation was passed to allow students with disabilities into the public classroom, and it was not until the 1990s that legislation was passed to require equal education for students with disabilities (Yell, 1998). I explore the origins of these struggles in the sections ahead.

The Early Ages

Historically, conflicting societal attitudes about how people with disabilities fit into society have existed. The Greeks believed people who had a deformity, mental or physical, were morally bad (Goffman, 1963). However, into the Middle Ages people with disabilities were cared for financially by their families or by the townspeople (Braddock & Parrish, 2001). It was not until the 1890s that medical professionals began to understand that many disabilities were not caused by lack of moral integrity, but rather due to the spread of infectious diseases resulting

from unsanitary living quarters, inappropriate hygiene, and the unsafe working conditions in factories (Hickel, 2001). Through education, people began to learn it was not immorality that caused illness or disability. Wartime solidified this idea because people did not fault soldiers for their misfortune when they were injured during combat (Hickel, p. 241).

1920s–1950s

The 1920s ushered in the concept of eugenics, that is, a belief that by getting rid of people with disabilities society might be “improving the quality of the stock” (Switzer, 2003, p.36). Any person who had any kind of mental or physical disability was considered feeble-minded (Switzer, 2003). People of the time period believed that the feeble-minded should not marry nor should they produce children, because “Certain families should become extinct” (Switzer, 2003, p. 37). In the 1927 court case *Buck v Bell*, the Supreme Court allowed the sterilization of feeble-minded people until the law was repealed in 1968 (National Council on Disability, 1997, 2010; Switzer, 2003).

Through this period of eugenics, people who were mentally or physically disabled were being institutionalized (O’Brien, 2001). The Rehabilitation Movement began in the 1950s, its goal being was that people with disabilities could improve themselves (O’Brien, 2001). The experts of the time believed if people with disabilities maintained a better attitude, they could be mainstreamed into the American society. However, it was still up to people with disabilities to adjust to the norms established by society (O’Brien, 2001). The belief of the rehabilitation experts was “disabled people should accommodate society rather than expecting society to build accommodations that would include them” (2001, p. 9). Ultimately, the Rehabilitation Movement created the idea that anyone who had an impairment could be normalized if the person tried to conform to the norms of the society; hence, the concept of ableism emerged.

Bogdan and Biklen (1977) defined ableism (originally known as handicapism) as “a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences” (p.14).

1960s–1970

The 1960s ushered in the idea of independent living. People with disabilities believed in self-help, and they believed it was the attitudes of the abled that impeded people with disabilities from reaching their goals (O’Brien, 2001). People with disabilities began to self-advocate for independent living and did not want the medical professionals making decisions for them. Instead, they wanted “consumer control, self-reliance, and economic rights” (Baird et al., 2009, p. 138). Ed Roberts, a paraplegic student, led the way for change when he was accepted into the University of California at Berkeley. Against the odds, he was accepted into the university while living at the campus hospital. After his acceptance into the university, other people with disabilities began applying to universities thus beginning the independent living movement (Baird et al., 2009). Just as African-Americans, women, and the transgendered began to push for their civil rights, people with disabilities joined the fight for their own civil rights as citizens who wanted to end discrimination against them (Switzer, 2003). It was the 1960s when the DRM began to show that it was “sociopolitical obstructions, not physical or mental impairments, that restrict people with disabilities” (O’Brien, 2001, p.2). It became increasingly apparent that the attitudes of the abled held people with disabilities back from independence (O’Brien, 2001).

1970s to the Present

By the 1970s, people with disabilities came together to fight for civil rights and to gain access to public schools (Baird et al., 2009). In 1973 the first piece of legislation, the Rehabilitation Act, prohibited discrimination against any qualified individual with a disability

(Baird et al., 2009). Shortly thereafter, the Education for All Handicapped Children Act (EAHCA) was passed to ensure students with disabilities had equal access to public schools (Baird et al., 2009). In 1990, EAHCA was renamed the Individuals with Disabilities Education Act (IDEA) and called for a free, appropriate public education (FAPE) for all students with disabilities in the least restrictive environment (Baird et al., 2009). Finally, in 1990 the Americans with Disabilities Act (ADA), modeled after the Civil Rights Act of 1964, was signed into legislation to provide people with disabilities a broader range of civil rights (Baird et al., 2009). While these laws were passed to provide people with disabilities equal access in society, many barriers impeded people with disabilities from fully participating in society remained (Baird et al., 2009). The obstacles people with disabilities faced were due to “ongoing ignorance and lack of public awareness” (Baird et al., 2009, p. 139). Statutory mandates did not end discrimination, stereotypes, or social exclusion of any race, gender, or disability (Scotch, 2009). This remains true, even today.

A possible solution to end ableist attitudes is through educating people about the abilities people with disabilities do have (Scotch, 2009). Presently, people with disabilities are seeking their own culture and identity in society (Baird et al., 2009; Longmore, 2009). They are defining their own identity, taking pride in their disability, and promoting a positive image of themselves while working toward having society accept them as they are - disabled (Baird et al., 2009).

There is a long history of misconceptions and stereotypes about people with disabilities. U.S. history shows an increasing awareness of the causes, needs, abilities, and rights of those with disabilities. Federal legislation, activist associations, and the emergence of disability studies reflect this increasing awareness. However, history illuminates the apprehension of putting policy into practice for people with disabilities.

Disability Versus Impairment

Labeling a person as an individual with a disability is an ongoing dispute. Initially, a disability was identified by a person's lack of "mobility, vision, or hearing—defects or organic conditions" (Switzer, 2003, p. 13). Each disability was categorized by identifying the illness and a solution was provided to improve the functionality of the person with the disability. For example, a deaf person was fitted for a hearing aid, a blind person received a service dog, and a paralyzed person was provided a wheelchair (Switzer, 2003). This categorization of disabilities led to a separation and isolation of the disabled community. Instead of banding together to face the common obstacles they faced daily, they were categorized by their different illnesses; which separated people with disabilities (Switzer, 2003).

Currently under the American with Disabilities Act (ADA), persons are considered disabled if they fall into one of the three primary terms used to categorize a person as disabled: functional activities, activities of daily life, and instrumental activities (Switzer, 2003). Functional activities are such things like "walking, seeing, hearing" (2003, p. 5). Examples of daily activities include cooking, getting out of bed, and toileting. Examples of instrumental daily activities are paying bills, shopping for oneself, and taking on daily household chores. When a person cannot perform these types of activities, they are considered to be an individual with a disability (2003). The difference between a disability and an impairment is that a disability in a person is a social construction while impairment is a physical factor (Braddock & Parrish, 2001). To be more specific, impairment is the actual medical condition that limits the body from full participation into society (World Health Organization). The use of the term disability is the limitation society places on the individual with an impairment. In other words, disability is not a defect, "but a cultural and minority identity" (Siebers, 2008, p. 4).

Language and Identity

Currently, the term “disabled” is commonly being embraced and used in a positive fashion by people with disabilities (Rauscher & McClintock, 1997). Historically this has not always been the case. In the 19th and early 20th centuries words such as crippled, deaf and dumb, and deformed were used to describe people with disabilities (Rauscher & McClintock, 1997). In the late 20th century, words that were used, such as retarded and handicapped, were deemed unacceptable as a result of the actions of the DRM (Rauscher & McClintock, 1997). Currently, there has been a push to view the person first and the disability second (Yell, Rogers, & Rogers, 1998). It is acceptable to use the term “person with a disability” or “disabled person.” Throughout this dissertation, person/individual/people/ student/ children with disabilities will be used.

There are people with disabilities who view themselves as being disabled by society due to the social structures and the environmental structures that have been built (Rauscher & McClintock, 1997). If society was built with people with disabilities in mind, people with disabilities hold the belief that they could contribute to society both socially and economically. People with disabilities view themselves equal to other oppressed groups who have suffered from discrimination (Rauscher & McClintock, 1997). The roots of this oppression run deep in the U.S. psyche.

Lingering Effects of the Medical Model

Two models of disability can be used to understand the discrimination people with disabilities experience. Before the 1960s, the medical model was the predominant view of how people with disabilities should be regarded by society. The medical model states that people with disabilities should be cured of their impairment and made to be more normal like other

people in society (Switzer, 2003). When these illnesses are eradicated, then the “societal problem” people with disabilities bring will also be eradicated (Switzer, 2003, p.7). Due to this medical viewpoint, “historians may have neglected disability history because they view the experience of disability from a medical perspective” (Longmore & Umansky, 2001, p. 7). According to the medical model viewpoint, the only way for persons with a disability to be accepted into society or to adapt to society is to cure the disability or correct the way they function in society (Longmore, 2009).

From a medical standpoint, the “medical model defines disability as an individual defect lodged in the person, a defect that can be cured or eliminated if the person is to achieve full capacity as a human being” (Siebers, 2011, p. 3). Disability theorists have a different perspective on disabilities, purporting that the physical and social environment needs to be fixed, not the person with a disability (Siebers, 2008). Disability, to them, “is not a physical or mental defect but a cultural and minority identity” (Siebers, 2008, p. 4). Disability theorists do not want to eradicate the disease, instead they want to understand and name how people who have a disability are treated differently in society (Siebers, 2008). Disability studies seek to demonstrate that people who do not have full control of their mind or body still have a right to a full life and should not be looked down upon as less than human (Siebers, 2008, pp. 3-4).

The medical model isolates people with disabilities by labeling them as a “defective person, duplicating the history of discrimination and shame connected to disability in the social world, and it affects the ability of people with disabilities to organize politically” (Siebers, 2008, p.72). It has not kept up with the changing times, new legislation, the changing population, or the identities people with disabilities have formed with people of like disabilities. In essence, the medical model has led to the continued institutional discrimination of people with disabilities in

“healthcare, social services, education, private charity, and public policies” (Longmore, 2009, pp. 143-144). The DRM fought against the medical model through legislation that provided necessary accommodations and prohibited discrimination against people with disabilities (Longmore, 2009). Due to “changes in the economic and social organization of society” (Campbell, 2009, p. 99), the social model has in recent times taken on more predominance among disability theorists. Policies have been passed, laws have been signed, and now the focus of the DRM is on the values of our disabled American citizens (Longmore, 2009). People with disabilities value “not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community” (Longmore, 2009, p.148).

Social Model

The fight against the medical model has led to the realization that people with disabilities are American citizens who deserve and can demand their equal rights and acceptance into society (Longmore, 2009). Since the 1970s disability theorists have been “pushing with increasing strength for disability to be seen as a form of social oppression, and the appropriate response is one of civil rights rather than medical or social care” (Williams, 2001, p. 125). To people with disabilities, it is the discrimination they face that is the most debilitating, not their impairment (Longmore, 2009). The social model rose from the politics of disability research, seeking to unearth and challenge “the structural exclusion of disabled people” (Goodley, 2011, p.23). Unlike the medical model, the “social model looks at how society has built social and physical barriers for people with impairments” (Albrecht, Seelman, & Bury; 2001, p. 11). It has fundamentally altered how society views those with disabilities (Albrecht, Seelman, & Bury; 2001).

Educational Implications

Schools advocate for the acceptance of diversity of students due to race and gender, but schools do not acknowledge disability issues as they pertain to ableism (Johnson, 2003; Storey, 2007). Still, educators continue to maintain practices that do not allow students with disabilities equal access to the curriculum and to hold back students with disabilities from reaching their academic potential (Ashby, 2010; Hehir, 2002). Ableist assumptions can occur in the school setting because of the negative stereotypes of students with disabilities (Hehir, 2002). In addition, educators need to develop an understanding of how students with disabilities complete tasks efficiently and how they learn differently (Storey, 2007). As a result of ableist assumptions, there is often a lack of appropriate educational supports for students with disabilities, leaving students with disabilities less than fully included in the classroom (Ashby, 2010; Hehir, 2002). From the viewpoint of the ableist, the “hidden curriculum of education” (Ashby, 2010, p. 350) is to make the student with a disability as comparable to an abled-bodied student as possible (Ashby, 2010; Hehir, 2002). Due to this ableist belief/mentality, Hehir (2002) contends this “pervasiveness of ableist assumptions in the education of these children not only reinforces prevailing prejudices against disability but may very well contribute to the low levels of educational attainment and employment” (p. 4).

Research Questions

This case study will answer the overarching question: *What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education?*

The study will also answer the following question:

What do the participants' experiences suggest about the need for disability-oriented education in schools today?

Significance of the Study

This case study of a student with multiple disabilities is intended to inform educators and the general public that students with disabilities are capable of being successful in school and in the workforce. It is also intended to diminish the ableist attitude towards people with disabilities in schools and in day-to-day interactions by raising awareness of the lived experiences of those with multiple disabilities. It is through education that this devaluing attitude can cease to exist in our country.

Overview of the Study

In this study, I conducted a case study while employing the methods of narrative inquiry and elements of life history to explore the experiences of the elementary school years of one student with multiple disabilities. A case study was used to add to our knowledge so educators may better understand an individual or group of individuals (Yin, 2014). I interviewed a female, who was born with a degenerative disease to share her story as it unfolded throughout her elementary school years. I also interviewed two other individuals who were involved in her life during this time. I followed the life history method and “restoried” the interviews to share her life with educators in order for them to learn from her experiences (Creswell, 2007).

Definition of Terms

Ableism—“a pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities” (Rauscher & McClintock, 1997, p. 198).

American with Disabilities Act of 1990—the purpose of the ADA is “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities; to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities” (42 U.S.C.A. § 12101 et seq.).

American Sign Language (ASL)—The National Institute on Deafness and Other Communication Disorders (NIDCD) defines ASL as “a complete, complex language that employs signs made by moving the hands combined with facial expressions and postures of the body. It is the primary language of many North Americans who are deaf and is one of several communication options used by people who are deaf or hard-of-hearing” (<http://www.nidcd.nih.gov/health/hearing/pages/asl.aspx>).

Cued Speech—The National Cued Speech Foundations states that cued speech is a visual mode of communication in which mouth movements of speech combine with “cues” to make the sounds (phonemes) of traditional spoken languages look different. Cueing allows users who are deaf, hard of hearing or who have language / communication disorders to access the basic, fundamental properties of spoken languages through the use of vision” (<http://www.cuedspeech.org/>).

Free, appropriate public education (FAPE)—According to Section 504, ADA, and IDEA, schools must meet the needs of students with disabilities while educating them along-side their non-disabled peers as much as possible during the school day. If a student with a disability is not

educated along-side his/her non-disabled peer, schools must show that the general education program cannot meet the student's needs satisfactorily (Smith, 2001).

Individuals with Disabilities Education Act of 1990 (IDEA)—successful in ensuring children with disabilities and the families of such children access to a free appropriate public education and in improving results for children with disabilities (20 U.S.C. §1400 *et seq.*).

Individual Education Program (IEP)—the courts call the IEP “the decision making document” (National Council on Disability, 2005, p. 13). It is an educational tool that allows teachers, parents, and the student to participate in the student's educational plan. It is a plan that protects the well-being of the student (National Council on Disability, 2005).

Reasonable Accommodation—“Purposes of Title I of the ADA as including ‘making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities’” [42 U.S.C. § 12111(9); National Council on Disability, 2008, p. 46].

Rehabilitation Act of 1973—“The purposes of this Act are to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society, through statewide workforce investment systems implemented in accordance with title I of the Workforce Investment Act of 1998 that include, as integral components, comprehensive and coordinated state-of-the-art programs of vocational rehabilitation; independent living centers and services; research; training; demonstration projects; and the guarantee of equal opportunity; and to ensure that the Federal Government

plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living” (Pub.L. 93-112, 87 § 35 *et seq*).

Section 504 of the Rehabilitation Act—“No otherwise qualified individual with a disability in the United States...shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...” (Section 504 of the *Rehabilitation Act of 1973*, as amended, 29 U.S.C. 794).

Overview of the Study

Chapter 1 introduced the problem, provided a historical context to the problem, presented the purpose and the significance of the study, gave an overview of the methodology, and provided a definition of terms that will be used in this study. Chapter 2 provides the significance the disability rights movement had on people with disabilities and legislation and describes the legislation that has been passed over the past 40 years to ensure equal outcomes and opportunities for people with disabilities. Chapter 2 concludes with literature describing how to end the ableist attitude in schools today. Chapter 3 outlines the research design, methodology, and data analysis to be used in this study. Chapter 4 and 5 presents the findings and makes recommendations based on those findings.

CHAPTER 2 REVIEW OF THE LITERATURE

The Disability Rights Movement (DRM) has brought about improvements in the quality of life for people with disabilities since its inception in the 1960s (National Council on Disability, 2010), and has had three particularly noteworthy outcomes. First, the DRM made disability a civil rights issue, prompting the creation of a public policy to benefit people with disabilities (National Council on Disability, 2010). Second, it helped end the isolation of disabled people and allowed them to join society as citizens who are able to obtain employment, procure a public education, and access public places (National Council on Disability, 2010). Third, it has brought public awareness about people and issues related to those who live with disabilities (Kimberlin, 2009; Longmore & Umansky, 2001; National Council on Disability, 2010).

However, even with the passing of legislation and heightened public awareness, people with disabilities still faced discrimination in their everyday life at work and in school (Baird et al., 2009; Scotch, 2009). In schools around the country, students with disabilities have twice the dropout rate of their abled peers, and the matriculation rate of students with disabilities entering college is 50% lower than their abled peers (President's Commission on Excellence in Special Education, 2002). For people with severe or visible disabilities, it is still a trying experience to obtain employment (Rosen, 2014). Even with the implementation of public policy that is beneficial to people with disabilities, the elimination of disability discrimination has not taken place (Ramey, 2007; Hehir, 2005; Scotch, 2009). Many Americans with disabilities reported the barriers they face have been attitudinal barriers such as pity for being disabled, fear of becoming disabled, admiration for the hardships people with disabilities face every day, and stereotyping of people with disabilities (National Council on Disability, 2007; Shapiro, 1994).

This literature review will provide a brief social history of the DRM in the US and an explanation of the two main conceptual models that inform public perceptions of people with disabilities. It then will present an analysis of disability related legislation, drawing on the social and medical models to illustrate how gaps between legislative intent and reality play out in the field of education today for people with disabilities. The review relies on this legislative analysis to show the major issues facing people with disabilities in the field of education. It then turns to contemporary research in the field of disability studies in education to frame the main research questions for this study.

Research Questions

The main research question is: *What can the experiences of a multi-handicapped, medically fragile student and her family reveal about the role of ableism in education?*

The second question is: *What do the participants' experiences suggest about the need for disability-oriented education in schools today?*

The Disability Rights Movement in America: The Fight for Civil Rights

In the decision *Brown v. Board of Education*, 347 U.S. 483 (1954), the Supreme Court ruled “that separate but equal was inherently unequal” (*Brown v. Board of Education*, 1954, p. 7). The decision declared students could not succeed in life without the opportunity to receive an education “on equal terms” (Weber, Mawsdley, & Redfield, 2010). Prior to this decision, students who were disabled, physically and mentally, were excluded from education. However, the Supreme Court’s ruling in *Brown v. Board of Education* motivated families of children with disabilities to advocate for their children to attend school and receive an equal education (Weber et al., 2010). Along with the civil rights movement of the 1960s, the return of disabled young soldiers from the Vietnam War, and the independent living movement of the disabled of the

1970s gave rise to the Disability Rights Movement (DRM) (O'Brien, 2001; National Council on Disability, 1997, 2010). In the early days of the movement, the activists focused on alleviating problems, particularly the everyday struggles society created for people with disabilities and their families. However, disability advocates began to recognize the need to discuss, listen to, and understand the struggles of the disabled and their families (Ferguson & Nusbaum, 2012). Disability theorists recognized the role of social oppression and advocated for an agenda that demanded civil rights instead of medical or social care for the disabled (Williams, 2001).

The DRM represented a shift from traditional ways of thinking about people with disabilities. Prior to the civil rights movement of the 1960s, disability was generally medicalized. People with disabilities were perceived as impaired with illnesses that needed to be cured (Siebers, 2008; Switzer, 2003). This medical model isolated, and in some cases still isolates, people with disabilities (Siebers, 2008). It labeled them “defective,” thereby “duplicating the history of discrimination and shame connected to disability in the social world,” and affecting “the ability of people with disabilities to organize politically” (Siebers, 2008, p. 72).

Medicalization creates problems in the lives of people with disabilities and the disability of the person. In his book, Shapiro (1994) stated the DRM is “the new thinking by disabled people that there is no pity or tragedy in disability, and that it is society’s myths, fears, and stereotypes that most make being disabled difficult” (p. 5).

Members of the DRM, however, focused on sociopolitical issues surrounding disabilities instead of individuals’ impairments (Gabel, 2009). In the social model disabled people are minorities who experience “marginalization, disenfranchisement, discrimination, stigmatization, and stereotyping” (Gabel, 2009, p. 3). In other words, the social model frames disability as a civil rights issue, likening the disabled to other marginalized groups who have fought for civil

rights because of their race, gender, or sexual orientation (Shapiro, 1994). In the US, proponents of the social model advocated for using the collective voices of the disabled to make political and social change instead of curing the disability of the person (Johnson, 2003). In this way, the social model contradicts the medical model; problematizing society instead of the individual with the disability (Johnson, 2003).

As a result of the DRM, disabled Americans and their families were given a voice in the public arena and started to fight for their rights in the work place, and in schools, buoyed by the belief it was able-bodied people holding them back (O'Brien, 2001). Given the DRMs social orientation to disabilities and the political context of the civil rights movement, it is hardly surprising the DRM coincided with the creation of disability-related policy. Disability-related policy began to address discrimination against people with disabilities. However, people with disabilities still faced discrimination in the world around them (Scotch, 2009).

Societal Values: Devalued and Diminished Expectations

Ableism, a foundational theoretical construct in the field of disability studies, provides a holistic lens through which to examine assumptions, beliefs, and values about people with disabilities. In so doing, ableism brings into clear relief the culture of devaluation and diminished expectations that plague persons with disabilities and their families. An examination of the gaps in disability studies scholarship, particularly in the field of education, frames research on disability and special education research in school settings. This analysis highlights the need for better understanding of the experiences of students with disabilities and their families.

Ableism and People with Disabilities

American disability theorists ascribed to the social model and sought to focus on society's definition of disability (Taylor, 2004). Notable amongst disability scholarship is

Bogden and Biklen's (1977) work on ableism; which established the foundation "...for thinking about so-called handicapped people as societally created rather than as a natural or objective condition" (p. 14). In so doing, they problematized society instead of problematizing people with disabilities. This paradigm, originally called handicapism, is now commonly referred to as ableism.

Ableism is "a set of assumptions and practices that promotes the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences" (Bogdan & Biklen, 1977, p. 14). Generally speaking, ableism is enacted by the "kinds of policies and practices that discriminate against people with disabilities" (Bogdan & Biklen, 1977, p. 15). From the ableist perspective, these norms maintain the stereotypes that diminish disabled people. Ableism occurs when social biases happen against people with disabilities because their bodies function differently than what is considered to be normal (Albrecht, Selman & Berry, 2001). There are two important outcomes of these stereotypes. First, the lives of people with disabilities are devalued because they function differently than most people in society (Campbell, 2009). Second, because they function differently, people with disabilities are subject to lowered expectations (Campbell, 2009). Both of these outcomes act to prevent people with disabilities from fully experiencing life in mainstream society (Campbell, 2009).

Devaluation and Diminished Expectations of People with Disabilities

Perspectives of disability grounded in the social model add to the ableists' position suggesting viewpoints of stereotyping "do more than discriminate; they oppress" (Gabel, 2009, p. 4). When people see disability as located inside the individual, they assume a dominant attitude over disabled people (Siebers, 2008). In other words, the abled person feels superior to the person with disability. Often, stereotyping occurs at great cost. As Siebers (2008) suggests,

“people perceive when someone is different from them but rarely acknowledge the violence of their perception” (p. 55). The abled person’s perception of the disabled person has damaged and hurt the worth of the disabled person’s being, further isolating the person with the disability.

Beliefs about people with disabilities have deep roots in the human psyche. As Freud suggests, violence is perpetrated because of the belief that people who suffer are narcissistic and incapable of loving anything other than themselves (Seibers, 2011). Hence, by Freud’s reasoning, when someone who is able first meets someone who is disabled, s/he is inclined to believe that person is self-centered and unloving (Seibers, 2011). This diminishes, stigmatizes, and devalues the person with disabilities, justifying the position of the abled and their inclination to “lessen and label this person as a cripple, bastard, [and] moron” (Goffman, 1963, p. 5).

Goffman (1963) summarizes this phenomenon as taking “...one piece of the person we find undesirable” and creating “more undesirable characteristics” (p. 5). In more modern times:

the devaluation of disability results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use spell check, and hang out with nondisabled kids as opposed to other disabled kids. (Hehir, 2002, p. 3)

Here, it becomes easy to see how Goffman’s phenomenon contributes to a climate of diminished expectations for people with disabilities. Disability theorists want everyone to understand that ableism “actually involves practices and attitudes that induce other forms of impairment and injury” (Campbell, 2009, p. 17). Due to this ableist belief/mentality, Hehir (2002) contends that ableist assumptions are pervasive in the education of children with disabilities. The ableist assumption “not only reinforces prevailing prejudices against disability

but may very well contribute to the low levels of educational attainment and employment” (Heir, 2002, p. 4).

This is evidenced in the fact that 17.2% of disabled adults who are in the working-age range are employed and 12.8% are unemployed (U.S. Department of Labor, Bureau of Labor Statistics, 2014). An unemployed person is one who is actively seeking work but at the time is not employed. The labor force participation rate is the ratio of the labor force and the national population of the same age range (U.S. Department of Labor, Bureau of Labor Statistics, 2014). To provide a concrete example, in 2012 there was 1,353,800 people with disabilities out of 12,562,000 people with disabilities between the ages of 21 to 64 who were not institutionalized who were actively seeking employment. In the year 2012, a person with disabilities average median earning was \$36,400 while a person without a disability averaged \$42,400 (Disability Statistics, 2014). Table 2 shows that the unemployment rate for people with disabilities is double the rate of people without disabilities. According to the Bureau of Labor Statistics, in the year 2012 “persons with higher levels of education were more likely to be hired than those with less education” (U.S. Department of Labor, 2013). However, a person without a disability is more likely to be hired than a person with a disability, no matter their level of education.

Table 2

Disability Employment Statistics – August 2014 – U.S. Department of Labor

Labor Force	Labor Force Participation	Unemployment Rate
People with Disabilities	19.8%	12.8%
People without Disabilities	68.8%	6.0%

Diminished expectations for people with disabilities are relevant when it comes to U.S. schools. While there here have been positive steps towards an equal education for all students, the “ableist assumptions of performance can limit access to needed support and meaningful

engagement with academic content” (Ashby, 2010, p. 346). The goal of legislation since the 1970s has been “to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society” (p. 395 Id. at § 702(b)(1)). However, without a right to an education, a person’s chances of leading an independent life, earning a livelihood, supporting a family, or contributing positively to society can prove to be complicated (National Council on Disability, 2005).

Policy and legislative mandates allowed people with disabilities to enter mainstream society and the school system (National Council on Disability, 2010). But, in many ways, these acts fell short of meeting the needs of people with disabilities because policy did not change public perceptions (Longmore, 2009; Scotch, 2009). Laws alone cannot change the attitudes of people who devalue and diminish the expectations of other people who are not like them (Campbell, 2009; Scotch, 2009). The review of disability-related legislation in the sections ahead explains how the gap between legislative intent and practical enactment has evolved in the field of disabilities, particularly when it comes to education.

Legislation for Equal Educational Opportunity and Outcomes

People with disabilities still struggle with many facets of life in contemporary society. The history of the disability rights movement illustrates societal values can cause problems for people with disabilities. Ableism, in particular, contributes to a climate of devaluation and diminished expectations for people with disabilities. The civil rights movement, the ruling in *Brown v. Board of Education*, and the return of Vietnam veterans in the late 1960s and the early 1970s ushered in the idea of independent living for the disabled; this encouraged people with disabilities to advocate for self-help which allows them a voice in their own life choices

(O'Brien, 2001). Between 1968 and 1990, more than 50 acts were passed into law pertaining to people with disabilities (Longmore & Umansky, 2001).

The sections ahead provide an overview of major legislation passed between 1973 to present, define the legal purpose of each act, and consider advances and shortcomings of the acts as they pertain to the education of students with disabilities. The focus is on how Section 504, the ADA, IDEA, and NCLB have provided students with disabilities the opportunity to receive accommodations under the law and to achieve an education that is equal to their abled peers. In summary, implications of these legislative acts for closing the achievement gap between students with disabilities and students who are able-bodied are included in Table 3

Table 3

Policy Passed with the Intent of Equality of Opportunity

Year	Act	Legal Purpose	Educational Impact
1965	Elementary and Secondary Education Act of 1965 (ESEA)	Federal legislation passed to provide states and districts money to serve economically disadvantaged students. (Weber, et al., 2010)	<ul style="list-style-type: none"> • Improved the education for low socioeconomic students (Smith, 2001) • Led to NCLB legislation for all
1973	Section 504 of the Rehabilitation Act	“No otherwise qualified individual with a disability... be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...” (Weber, et al., 2010, p. 18; 29 U.S.C.A § 794)	<ul style="list-style-type: none"> • Prohibited discrimination on the basis of disability (Longmore, 2003) • Involved students with disabilities in school and in extra-curricular activities • Paved the way for the ADA (Longmore, 2003) • Provided no funding to schools (Smith, 2001)
1975	Education for All Handicapped Children Act (EAHCA)	<p>“successful in ensuring children with disabilities and the families of such children access to a free appropriate public education and in improving results for children with disabilities” (§1400 (a)(3); Weber, et al., 2010, p. 1, statutes)</p> <ul style="list-style-type: none"> • Provide FAPE for children with disabilities • Protect the rights of students with disabilities and their parents by providing due process • Implement an Individualized Education Program • Instruct students with disabilities in the Least Restrictive Environment • Provide Federal funding to states to educate students with disabilities (§ 1400 (a)(3)) 	<ul style="list-style-type: none"> • Mandated school districts to educate students with disabilities with their peers (Longmore & Umansky, 2001) • Did not guarantee any kind of educational benefit or requirement for eligibility for handicapped children (Weber et al., 2010, p. 44)
1990	Americans with Disabilities Act (ADA)	Civil rights legislation offered disabled people the ability to access employment, transportation, and businesses - all entities must follow except churches and private clubs (Rauscher & McClintock, 1997;	<ul style="list-style-type: none"> • Provided no funding to schools (Smith, 2001) • Increased access to grade-level curriculum (NCD, 2004) • Educated students with a vast number of varying disabilities by providing students who were found

Year	Act	Legal Purpose	Educational Impact
1990	Individuals with Disabilities Act (IDEA)	<p>Smith, 2001). Goal is to end discrimination of people with disabilities because of their impairments (O'Brien, 2001)</p> <p>“Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.” (§1400 (a)(1); Weber, et al., 2010, p. 1)</p>	<p>disabled a 504 plan (Smith & Bales, 2010)</p> <ul style="list-style-type: none"> • Allowed children with disabilities attain higher education, be self-employed, and lead to an independent life (Smith & Bales, 2010) • Changed name of EAHCA • Added Traumatic Brain Injury and Autism to a distinct disability category • Added transition service requirement to students with IEPs when they turned 16 years old (Yell, et.al., 2006)
1997	Individuals with Disabilities Act (IDEA)	<p>“increased emphasis on student outcomes data reduction of paperwork and procedural complexity, and a reduction or consolidation of separately funded research, training, and support programs” (NCD, 2004, “IDEA, para. 2)</p>	<ul style="list-style-type: none"> • Strengthened parents’ role • Emphasized student progress • Added mediation services • Added disciplinary procedures • Changed IEP requirements regarding • Added transition from high school to post-secondary plan • Added students older than 14 must participate in plan • Required “participation and progress in general education curriculum • Required “participation state- or district-wide assessments” • Expected “involvement of general education teachers” (Yell, et al., 2006, p. 2; NCD, 2004)
2001	No Child Left Behind (NCLB)	<p>“Increase the academic performance of all public school students, and improve the performance of low-performing schools” Require state-wide assessments (Yell, et al., 2006)</p>	<ul style="list-style-type: none"> • Expected all students proficient in reading and math— Adequate Yearly Progress • Required highly qualified teachers • Expected safe, drug-free schools, conducive to learning • Expected every student graduate from high school • Implemented evidence based practices

Year	Act	Legal Purpose	Educational Impact
			<ul style="list-style-type: none"> • Enacted rigorous accountability system for all states and schools (Yell, et al., 2006, p. 2)
2004	Individuals with Disabilities Act Improvement Act (IDEIA)	To improve the educational outcomes for students with disabilities and to have meaningful educational benefits. (Yell, et al., 2006)	<ul style="list-style-type: none"> • Aligned NCLB and IDEIA • Changed disciplinary process • Changed dispute-resolution system • (Yell, et al., 2006, p. 4)
2008	Americans with Disabilities Act Amendment Act (ADAAA)	<p>Provide ‘a clear and comprehensive national mandate for the elimination of discrimination’</p> <p>Broadened the definition of disability by expanding the list of major life activities covered by ADA (Weber et al., 2010; Zirkel, 2009a)</p>	<ul style="list-style-type: none"> • Allowed students who do not meet the IDEA definition of disability but meet the ADA definition of disability are eligible to qualify for special services under Section 504 (Smith & Bales, 2010; Zirkel, 2009a) • Adopted Section 504 of the Rehabilitation Act and now more and more students have a 504 plan • Increased academic achievement (NCD, 2008) • Appropriated funding not provided under Section 504 and the ADA • Increased qualification of students for services under the expanded definition of disability (Zirkel, 2009a) • Opened schools to more liability because students now have more protection (Smith & Bales, 2010) • Addressed the needs of the general education population (Zirkel, 2009a)
2008	No Child Left Behind (NCLB)	Close the achievement gap and for every student to “meet academic proficiency” (NCD, 2008)	<ul style="list-style-type: none"> • Improved accountability and transparency, graduation rates reporting disaggregated, improved parental notification • Increased number of “proficient” in end of the year exams for students with disabilities (NCD, 2008)

From Section 504 to the ADA

Due to federal legislation, Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), Americans with disabilities were given equality of opportunity to access and obtain a public education (Smith & Bales, 2010). Years later, IDEA and NCLB were passed to ensure students with disabilities equity in education by improving the educational achievement and performance of students. They required states and schools to test all students with state academic standards (National Council on Disability, 2008). These two laws hold teachers and schools accountable for students' academic progress and results on end of the year assessments (National Council on Disability, 2004, 2008; Yell, Rogers, & Rogers, 1998). Table 3 on the previous pages provides an overview of the laws passed, and reauthorized, for students with disabilities to receive an equal opportunity to access schooling. It also provides an explanation of the laws passed and reauthorized for students with disabilities to receive an education with equal outcomes. Generally speaking, these laws made educational advances for students with disabilities, but the enactment of these laws often fell short of meeting real, human needs (Johnson, 2003).

The Rehabilitation Act of 1973 was the first civil rights statute that offered protection to people with disabilities through Section 504 of the Act (Longmore & Umansky, 2001). For the first time in history, people with disabilities were recognized as a minority group (Ramey, 2007) and Section 504 "implemented a fundamental redefinition of 'disability' as a social more than a medical problem" (Longmore, 2009, p. 142). The purpose of the Rehabilitation Act was to provide opportunities, primarily, through vocational rehabilitation services to people who were physically or mentally disabled (Ramey, 2007). Congress's intent for passing the Rehabilitation Act was "to empower individuals with disabilities to maximize employment, economic self-

sufficiency, independence, and inclusion and integration into society” (p. 395 Id. at § 702(b)(1)). Section 504 prohibited any federally funded program from discriminating against any person with a disability, and, as such, was the first civil rights statute to protect people with disabilities (Longmore, 2003; Longmore & Umansky, 2001; National Council on Disability, 2005; Smith, 2001). It was a “one sentence paragraph prohibiting any program or activity receiving U.S. governmental financial assistance from discriminating against qualified individuals with disabilities” (Baird et al., 2009, p. 139). This Act was modeled after the 1972 Title IX Educational Act and the 1964 Civil Rights Act, and congressional staff members silently added Section 504 after the original draft (National Council on Disability, 2010; Yell et al., 1998). The section mandates: “No otherwise qualified handicapped individual ...shall...be excluded for participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance” (Public law, 93-112, The Rehabilitation Act of 1973). The reason congressional staffers added this phrase was due to concerns that people with disabilities who received vocational rehabilitation would not be hired for employment (National Council on Disability, 2010). Even though President Nixon signed the Rehabilitation Act into law, his administration failed to develop the regulations associated with Section 504 (National Council on Disability, 2010). They were not developed and signed until five years later under President Carter’s administration (National Council on Disability, 2010). Section 504 was added without a debate or questions from either Congress or the President; however, there was no mechanism to fund the law and it lacked a congressional statement of purpose (National Council on Disability, 2010).

The passing of the regulations of Section 504 was an arduous grassroots movement led by people with disabilities (National Council on Disability, 2010). People with disabilities came

together to demand their rights as one group because of the delay in developing the regulations associated with the procedural aspects of the law (National Council on Disability, 2010). Even though President Nixon signed the Rehabilitation Act in 1973, the regulations of Section 504 were not developed under the Nixon administration (National Council on Disability, 2010). In their struggle to have the regulations of 504 signed, people with disabilities formed the first cross-disability organization, the American Coalition of Citizens with Disabilities (ACCD) in 1974 (National Council on Disability, 2010). It was not until April 28, 1978, that Secretary Joseph Califano, under President Carter's administration, signed the regulations for Section 504.

The passing of Section 504 was a turning point for the civil rights of people with disabilities for three reasons. First, with the passing of Section 504, American citizens began to understand people with disabilities wanted their civil rights and did not want to be a group of people who relied on government welfare (National Council on Disability, 2010). Second, Section 504 marked the first time people with disabilities came together as one group and they defined the disability rights movement when they protested for their rights as citizens (National Council on Disability, 2010). Third, the Americans with Disabilities Act (ADA) replicated the legal standard for the civil rights of people with disabilities as stated in Section 504 (National Council on Disability, 2010). Overall, people with disabilities created their credibility as a community who demanded their civil rights as American citizens (National Council on Disability, 2010).

In 1978, the same year Section 504 was signed into law, the National Council on Disability (formerly the National Council on the Handicapped) was formed. This small advisory council became part of the U.S. Department of Education and sought to "empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and

integration into all aspects of society” (29 U.S.C.A. 780 *et seq.*). In 1984, the National Council on Disability became an independent federal agency tasked with advising the President, Congress, and various federal agencies about the impact of federally approved disability legislation on the lives of people with disabilities (National Council on Disability, 2008) and how to increase their independence while decreasing their dependence on government programs (National Council on Disability, 2010). The National Council on Disability report, *Toward Independence*, listed more than forty recommendations and was officially presented on February 1, 1986 (National Council on Disability, 2010). The report called on the government to provide people with disabilities their civil rights and demanded officials enact policies in a manner allowing people with disabilities to “achieve maximum life potential, self-reliance, independence, productivity, and equitable mainstream social participation in the most productive and the least restrictive environment” (Switzer, 2003, p. 13). The report, *Toward Independence*, stressed the civil rights for people with disabilities would increase accessibility and assist with finding employment (National Council on Disability, 2010).

In August 1987, a member of National Council on Disability drafted another report entitled *On the Threshold of Independence*, which became the draft of the current ADA (National Council on Disability, 2010). Members of the disability community looked for sponsorship of the law from various members of the Senate and Congress who supported people with disabilities (National Council on Disability, 2005). Senator Weicker introduced the ADA on the Senate floor on April 28, 1988 (National Council on Disability, 2010). There were great rumblings among senators about the ADA due to the financial cost to the public (National Council on Disability, 2010). During this time, George Bush was the Vice President under President Ronald Reagan. Personally, George Bush had members of his family who were

disabled. Later, during his acceptance speech at the Republican convention, President Bush stated, “I am going to do whatever it takes to make sure the disabled are included in the mainstream. For too long, they have been left out, but they are not going to be left out anymore” (National Council on Disability, 2010, p. 69).

President George H. W. Bush signed the ADA into law on July 26, 1990, as public law 101-336 (National Council on Disability, 2008, & National Council on Disability, 2010). The ADA of 1990 stated “census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally” (ADA Sec. 12101 (a) (6), 1990). The ADA took the same wording as Section 504 and expanded the prohibition of discrimination against people with disabilities to the private sector as well (National Council on Disability, 2010). Unique to the ADA was that it was a civil rights law with financial implications, and it applied to the private and public sectors in society (National Council on Disability, 2010).

The definition of disability was worded vaguely in the ADA due to the variations of types of disabilities (Ramey, 2007). The courts further narrowed the definition of disability through their rulings (Zirkel, 2009a). Two Supreme Court cases, *Sutton v. United Airlines, Inc.* (1999) and *Toyota Motor Manufacturing v. Williams* (2002), limited the qualifications of eligibility under Section 504 and ADA “by defining a major life activity as only an activity of central importance to daily living” (Zirkel, 2009a, p. 210); which was not the intent of the ADA (Zirkel, 2009a). The message being sent to the school districts through the courts was “to avoid the loose use of 504 Plans as consolation prizes for individualized education programs” (Zirkel, 2009a, p. 62;).

In September 2008, President George W. Bush passed the American with Disabilities Act Amendment Act (ADAAA) changing the judicial interpretation of the term ‘individual with disability.’ The ADAAA broadened the definition of ‘individual with disability’ under Section 504 and ADA, thus discarding the *Sutton* and *Toyota* court cases (Zirkel, 2009a; Smith & Bales, 2010). Additionally, ADAAA is coded as legislation and not as a regulation, further strengthening Section 504 and the ADA (Zirkel, 2009a). Table 4 provides a comparison of ADA (1990) and ADAAA (2008). The Act did not set out to help the disabled, but rather “reflected and sought to implement a fundamental redefinition of what disability is, of what it means to be disabled in American society” (Longmore & Umansky, 2001, p. 10). As a result of the ADAAA, it became easier to establish someone as disabled (Federal Register, 2011, and ADAAA, 2008).

Language, resources, enforcement, and enactment of the laws mitigated the impact of the legal gains this triumvirate of laws established for those with disabilities. Closer consideration of each act reflects vestiges of the medical model and corresponding values that contribute to “the longstanding history of segregation and isolation” (Ramey, 2007, p. 133) people with disabilities have experienced, particularly as those attitudes manifested in schools.

Table 4

Comparison of ADA 2001 and ADAAA 2008

	Americans with Disabilities Act 2001*	Americans with Disabilities Act Amendment Act 2008**
Criterion 1	<p>“substantially limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working.”</p> <p><u>Example:</u> “An individual with epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, mental retardation, or a specific learning disability”</p>	<p>“a physical or mental impairment that substantially limits one or more major life activities of such individual”</p> <p><u>Example:</u> “major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.”</p>
Criterion 2	<p>“individuals with a record of a disability”</p> <p><u>Example:</u> an individual who recovered from a major illness such as “cancer or a mental illness.”</p>	<p>“a record of such an impairment”</p> <p><u>Example:</u> “a major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions</p>
Criterion 3	<p>“individuals who are regarded as having a substantially limiting impairment, even though they may not have such an impairment.”</p> <p><u>Example:</u> “severe facial disfigurement”</p>	<p>“being regarded as having such an impairment”</p> <p><u>Example:</u> “if the individual establishes that he or she has been subjected to an action prohibited under this chapter because an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity</p>

*<http://www.ada.gov/q%26aeng02.htm>): **(<http://www.ada.gov/pubs/adastatute08.htm#12101note>)

Section 504 of the Rehabilitation Act: Background and Purpose

Section 504 provided the first civil rights protections for people with disabilities by recognizing them as a minority group (Ramey, 2007). As such, the act represented a shift in how the law viewed people with disabilities (Ramey, 2007). Previous to the passing of Section 504, people were diagnosed as disabled according to medical categories and disabilities were lumped into one medical category (Ramey, 2007). The passing of Section 504 allowed disabilities to be labeled individually which acknowledged that people with disabilities had different needs (Ramey, 2007). Indeed, at the time the Act was passed, there were many Americans who still believed that a disability was an individual, not a societal issue (Ramey, 2007).

Students with disabilities were assured through Section 504 that they would not be discriminated in education programs receiving federal financial assistance (34 C.F.R. § 104.4 (a)). Section 504 required ‘reasonable accommodations’ to be made in all public places, so long as the accommodations did not cause ‘undue hardship’ on the entity making the accommodation (Switzer, 2003). While Section 504 applied to employees in the public sector, it also applied to students in the K-12 setting (Zirkel, 2009c).

Section 504 expressly stated that students with disabilities were to be educated ‘as adequately’ as their nondisabled peers (34 C.F.R. § 104.33-36). As a result, students who qualified as disabled under Section 504 were eligible to receive any necessary educational accommodations. Section 504 was, in large part, the reason students with disabilities were admitted into mainstream classes as individuals with recognized civil rights (Smith & Bales, 2010). However, after the inception of Section 504 of the Rehabilitation Act in 1973, school districts did not establish policies to implement Section 504 legislation because of the lack of funding of the legislation (Switzer, 2003). As a result, the policy advances did not create wide-

sweeping changes as intended by Congress and the people with disabilities who fought, as a unified group, for their civil rights.

Advances of Section 504 of the Rehabilitation Act

Section 504 had particular implications for schools. To be eligible to receive Section 504 accommodations in schools, students needed to have a mental or physical disability that substantially limited a major life activity (Smith, 2001). For a school to meet the needs of a student with a 504 plan, the school based their decision using “common sense and treating individuals with disabilities fairly” (Smith, 2001, p. 338). School personnel were given license to determine if the student met the criteria necessary to receive Section 504 services (Smith, 2001). Students who did not qualify as a child with a disability under IDEA were able to find assistance if they had a disability as defined by the Section 504 and the ADA (Smith, 2001). Section 504 focused on the civil rights of individuals with disabilities and “Congress articulated broader protection under these laws, going beyond educational contexts” (Ramey, 2010, p. 395). Students were provided a “504 plan” to accommodate and provide modifications for the student’s educational needs (Smith & Bales, 2010).

These services, called ‘reasonable accommodations’, were provided to people with disabilities under Section 504. Reasonable accommodations gave students with disabilities interpreters, extended time on tests, and assistive learning and communication technologies (National Council on Disability, 2004). The definition of disability under Section 504 and ADA was broader than the definition of disability under IDEA (Smith, 2001; Smith & Bales, 2010). To this day, students who are not found eligible for services under IDEA receive services under Section 504 of the Rehabilitation Act (Ramey, 2007; Smith, 2001).

Shortcomings of Section 504 of the Rehabilitation Act

Section 504 was designed to provide students with disabilities an equal educational opportunity. While Section 504 legislated opportunities for people with disabilities simultaneously paving the way for the creation of the ADA, it did not provide funding (Smith & Bales, 2010). And it was first signed into law, school personnel did not address the underlying issues of equality that plagued students with disabilities at that time (Smith, 2001). Presently, parents and school advocates no longer allow schools to ignore their students' rights under Section 504 (Smith, 2001). That being said, more students have been found eligible for services under Section 504 and schools have been forced to learn about the legal requirements and services required to serve the students (Ramey, 2010; Smith, 2001). However, educators were initially "without the guidance or resources to adequately provide services in compliance with all of these laws" (Smith & Bales, 2010, p. 390).

The Americans with Disabilities Act: Background and Purpose

The purpose of the ADA was to provide Americans with disabilities equal opportunity and access to mainstream society as well as to end discrimination against the disabled (Longmore & Umansky, 2001; EEOC/DOJ, 1992). The ADA strengthened the Rehabilitation Act by requiring private businesses, not just federally funded entities, to make the same physical changes to their buildings to accommodate people with disabilities (Switzer, 2003). The ADA demanded that public and non-religious private schools, businesses, and public places provide environmental modifications such as wheelchair ramps, increased door sizes, elevators in buildings, and telecommunication devices (TTY/TDD) to accommodate individuals with disabilities (Laffe, 2011). Both the ADA and Section 504 of the Rehabilitation Act are civil right statutes, and the ADA defined an individual with a disability exactly the same as Section 504

(Zirkel, 2009b). This definition of an individual with a disability is less restrictive than the definition used in IDEA which has a list of impairments that qualify a student for special education (Zirkel, 2009, March.) On January 1, 2009, the ADAAA was enacted and the new expanded definition changed considerably the interpretative standards for the Section 504 definition of disability for students (Zirkel, 2009b). As a result of this broadened definition, more students became eligible to receive a 504 plan and general education teachers and administrators were now further responsible for serving general education students' accommodations (Zirkel, 2009b). Furthermore, education teams had to decide the most appropriate avenue for meeting students' educational needs: should a student be found eligible under the ADAAA's definition of disability and receive a 504 plan, or should the student be provided an IEP if the student's needs met the IDEA definition of disability (Zirkel, 2009b).

Educational Advances of ADA

Congress overwhelmingly passed the ADA to provide access for disabled people "to ensure the right of Americans with disabilities to move from the margins of society into the mainstream" (Longmore & Umansky, 2001, p. 1). In doing so, Congress recognized that people with disabilities were restricted in societal participation "because of prejudices, antiquated attitudes, or the failure to remove societal and institutional barriers" (U.S. Equal Opportunity Commission, Section 2, (2)). Allowing students with disabilities to physically enter the school building led to social access for all students (Laffe, 2001). Indeed, students with a variety of abilities are sitting side by side in classrooms today (Smith & Bales, 2010). One might speculate that the changes wrought by ADA contributed to students becoming more sensitive and understanding to the needs of people with disabilities as they learned together (Lafee, 2011). However, this was not always the case, necessarily.

The passing of the ADAAA in 2009 “was intended to ‘restore the intent and protections’ of the ADA after the ADA’s reach had been limited by certain Supreme Court decisions” (National Council on Disability, 2013, p. 28). The new standards under the ADAAA expanded the list of “major life activities” to include “concentrating, reading, and thinking” and included “various bodily functions, including those of the digestive, bowel, bladder, and endocrine systems” (Zirkel, 2009a, p. 210). As for the “substantially” limiting criteria, a student’s disability must now be reviewed without mitigating measures (Smith & Bales, 2010). These measures include auxiliary aids, medications, learned behavior, and health devices, such as hearing aids (Zirkel, 2009a, 2009b).

As a result of the new definition under ADAAA the court system currently focuses on the actions of the school (Smith & Bales, 2010). Courts look at the schools and decide if the school has made reasonable accommodations or discriminated against the student due to the student’s diagnosed disability (Smith & Bales, 2010). Additionally, the courts do not compare the student’s achievement to an average student’s level of performance, nor does the court look at the student’s “own mitigating measures” (Smith & Bales, 2010, p. 390). Because of the ADAAA, the focus is now on the school and whether the school made an appropriate accommodation for a student with a disability as defined by ADAAA (Smith & Bales, 2010).

Educational Shortcomings of the ADA

Legislation and policy did not provide funding to make the requisite environmental modifications as set forth by the ADA, nor did they come with fiduciary consequences for organizations failing to comply (National Council on Disability, 2010). Schools have no exceptions to this legislation. When constructing new schools, school districts have been building ADA-compliant schools (Laffe, 2011). However, school districts with older buildings

have found it financially difficult to make classrooms, buses, bathrooms, hallways, and playgrounds ADA-compliant (Laffe, 2011; Ramey, 2007).

The ADA does not provide a clear model of who is disabled and what treatment that person with a disability should receive (Scotch, 2009). To provide accommodations to a person with disabilities the law requires the focus to be on that person's impairment and the needs of that person to function in the environment (Scotch, 2009). People's disabilities vary from person to person as do their individual needs which leads to issues in the interpretation and implementation of the law (Scotch, 2009). Similarly, when people with disabilities look for employment or go to court for equal rights, the person with disabilities must first prove s/he is disabled, the requested accommodations are reasonable, and the accommodations would not be a financial burden on the institution (O'Brien, 2001). Similarly, to obtain accommodations at schools, students with disabilities have been compared to normal students to measure the expected achievement level of students with disabilities (Smith & Bales, 2010). While people with disabilities have gained many rights and increased access to the world because of ADA, there are still people who refuse to make accommodations for the disabled; this upholds the medical model belief that not all people with disabilities should be allowed equal access (Johnson, 2003).

Section 504 and the ADA are to be credited for creating an inclusive culture in our schools today. The graduating class of 2013 had always experienced an inclusive setting in their math, physical education, music, and Advanced Placement (AP) classes (Smith & Bales, 2010). The IDEA is the third tier of legislation to allow this inclusion to occur in schools. ADA has broadened the definition of disability under ADA; conversely, IDEA continues to have a narrow definition of disability (Smith & Bales, 2010).

The Path from the ESEA and the EAHCA to IDEA and NCLB

The Tenth Amendment of the U.S. Constitution implies that education is a matter of the states. Compulsory attendance for students began as early as 1840 and by 1918 every state created a law to have all children attend school—all children except children with disabilities (Yell et al., 1998). The fight to have all students with disabilities receive an education equal to their peers took shape in the 1960s. This was due in part to parents and advocates using the court system to force states to admit students with disabilities into school. The *Brown v. Board of Education* decision during the Civil Rights Movement and other court cases led to federal legislation mandating students with disabilities, not only be admitted into school, but also receive an equal opportunity to the same education as their peers (Yell et al., 1998).

In the 1970s, parents led the fight through the courts to have their children included in public schools and receive the regular curriculum as their peers (Switzer, 2003; Yell, 1998). Of the students with disabilities who did attend school, 2.5 to 3 million were not served properly (Katsiyannis, Yell, & Bradley, 2001). The parents claimed children with disabilities were being segregated in the classroom just as minority children were segregated before the *Brown vs. Board of Education* decision Fleischer & Zames, 2001; (Switzer, 2003). In the *Brown* decision, the court declared that opportunities for an equal education for minority students could not be separate and equal (Yell et al., 1998). The litigation brought forth by parents of disabled children challenged the courts to rule on the equal educational opportunities of disabled children (Yell et al., 1998).

One such case was the *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania*; which, in January of 1971, brought a class action suit to a federal court. A group of parents maintained their children's rights were violated under the

Equal Protection of the Laws clause of the Fourteenth Amendment. The parents claimed their mentally retarded children did not receive an education that was publicly supported (Yell et al., 1998). The U.S. courts found that all children, no matter their disability, were able to benefit from education (Yell et al., 1998). Plus, teaching life skills to students was an essential part of the public schools' education for students with disabilities (Yell et al., 1998). Further, the state could not deny students with disabilities a free, appropriate public education and students who were mentally retarded needed to have early education services (Yell et al., 1998; Switzer, 2003; & Fleischer & Zames, 2001).

The next influential court case that occurred soon thereafter in Washington, DC, in 1972 was *Mills v. Board of Education*. Parents and guardians of seven children with a variety of disabilities brought forth a class action suit representing over 18,000 children who were excluded or not provided an education in the nation's capital (Yell et al., 1998). Again under the Fourteenth Amendment, the suit stated students with disabilities were improperly excluded from school (Yell et al., 1998). The court ruled against the city school board and ruled all children should receive a publicly supported education with the safeguard of due process (National Council on Disability, 2005; Yell et al., 1998). The court "outlined due process procedures for labeling, placement, and exclusion..." and included the following safeguards: "the right to a hearing with representation, a record, and an impartial hearing officer; the right to appeal; the right to have access to records; and the requirement of written notice at all stages of the process" (Yell et al., 1998, p. 7). For the next two to three years there were 46 right-to-education cases occurring around the country—all with the same outcomes as *PARC* and *Mills* (Yell et al., 1998). Yet, schools continued to report they could not support students with disabilities due to a lack of funding, inadequate facilities, lack of teacher training, and insufficient instructional materials to

educate students with different needs (Yell et al., 1998). There was a need for federal involvement to facilitate the education of students in special education (Yell et al., 1998).

In 1965, President Lyndon Johnson signed into law the Elementary and Secondary Education Act (ESEA) which was designed to improve the education for lower socio-economic students in America. However, the Act also included funding for states to improve programs educating deaf, blind, and mentally retarded students (Katsiyannis et al., 2001). Every four to five years Congress must either reauthorize funding by amending the law or they must repeal the law due to funding requirements of certain parts of the law (Katsiyannis et al., 2001; Yell et al., 2006). Due to the *PARC* and *Mills* rulings, Congress recognized the need to respond to the demands of parents to educate their children with disabilities and amended ESEA in 1974 by passing the bill called Education of the Handicapped Amendments (EHA) of 1974, P.L. 93-380. The EHA required states receiving federal funding to provide all students with disabilities a full opportunity to an education (Katsiyannis et al., 2001; National Council on Disability, 2005; Yell, 1998). The EHA eventually became the cornerstone for the Education of All Handicapped Children's Act (EAHCA), which became the first piece of legislation to provide students with disabilities a free, appropriate public education (Katsiyannis et al., 2001; President's Commission on Excellence in Special Education, 2002; Yell 1998). President Ford signed EAHCA into law on November 29, 1975. EAHCA provided funding to states once the state submitted a plan explaining the policies and procedures for providing a FAPE to students with disabilities as outlined in EAHCA (Yell, 1998; National Council on Disability, 2005).

Any student who qualified as disabled under EAHCA was provided the right to the following: "(a) nondiscriminatory testing, evaluation, and placement procedures; (b) be educated in the least restrictive environment; (c) procedural due process, including parental involvement;

(d) a free education; and (e) an appropriate education” (Yell, 1998, p. 10). However, the showpiece of EAHCA was the development of the Individualized Education Program (IEP). The IEP set the objectives and goals for the student’s educational placement and required measurement of the student’s academic progress (Yell, 1998).

In 1990, EAHCA was amended and renamed Individuals with Disabilities Education Act (IDEA). The focus of IDEA was to put the person first; not the disability (Yell, 1998). Hence the word ‘individual’ was implemented first and the word ‘handicapped’ was replaced with child/student/individual with a disability (Yell et al., 1998). Students with traumatic brain injury and autism were added to the list of those who should receive services, and the IEP was expanded to include a transition plan for students with disabilities when children reached the age of 16 (Yell et al., 1998; Yell et al., 2006). Once again, the law was amended and reauthorized under President Clinton’s administration in 1997. Congress noted that IDEA had been successful and wanted to “improve the performance and educational achievement of students with disabilities in both the special education and general education curriculum” (Yell et al., 1998, p. 11).

The most notable change to the IDEA was that student’s progress toward his/her annual goals had to be measured and reported accurately, disciplinary procedures were added, mediation procedures were added, and changes to the IEP itself regarding testing requirements, participation in the general education curriculum, and general education teachers involved in the IEP (Yell, 1998; Yell, et al., 2006). Education of students in America has been state regulated, but control of special education became a federal matter with the passage of EAHCA (Yell et al., 1998). The federal government became further involved in education with the passage of No Child Left Behind. IDEA was impacted greatly with the passing of the No Child Left Behind

Act of 2001 (NCLB) and by the recommendations in two different reports by the President's Commission on Excellence in Special Education which were printed in 2001 and 2002 (Yell et al., 2006).

The President's Commission on Excellence in Special Education was formed by President George W. Bush to provide a report about the state of special education in America before IDEA was to be reauthorized (Yell et al., 2006). Even with legislation such as ADA and IDEA, students with disabilities continued to drop out of high school twice as often as general education students and had 50% lower enrollment in post-secondary education as general education students (President's Commission on Excellence in Special Education, 2002). This population of students was considered to be America's most at-risk population in our schools. The commission that worked on this legislation held the belief that "accountability for results matters" (p.4). The report continued by stating that special education was too compliance-based; this meant schools "emphasize the process rather than the results" (Yell et al., 2006, p. 3). As a result of this report, Congress and the President felt a sense of urgency to improve the current state of special education in America based on the individual needs of students with disabilities (President's Commission on Excellence in Special Education, 2002). Congress passed NCLB with the intent to provide students with disabilities an opportunity to obtain equal educational outcomes. Congress understood education was the "starting point from which all other rights and protections are realized and reinforced" (National Council on Disability, 2004 p. 19). President George W. Bush's signed NCLB into law on January 8, 2002. The intent of NCLB was to improve the educational achievement of students in the U.S., and all students were to be proficient in reading and math by the completion of the 2013-2014 school year (National Council on Disability, 2004). All students who were in special education were required to be taught by a

highly qualified teacher in a school that was safe and conducive to learning; and, finally, all students would graduate from high school (Yell et al., 2006).

On December 3, 2004, President George W. Bush signed into law the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004. The purpose of IDEIA was to improve academic outcomes for students with disabilities (Yell et al., 2006). By amending the IDEA, Congress stressed the importance that students with disabilities receive a meaningful education and their IEP guaranteed a free, appropriate public education (Yell et al., 2006). This was accomplished by requiring the IEP team to write a statement on how the student's progress toward the annual goals would be measured (Yell et al., 2006).

Due to the accountability systems established in IDEA and NCLB, schools and school districts cannot ignore the education of students with disabilities (National Council on Disability, 2008). Now educators, parents, and community members must acknowledge that students with disabilities can achieve at high levels (National Council on Disability, 2008). Both laws have brought highly qualified teachers into the classroom for students with disabilities and now these students receive the same curricula as their peers (National Council on Disability, 2008). While both laws have made a positive impact on students with disabilities, there are still improvements to be made.

EAHCA/IDEA: Background and Purpose

In 1990 Congress made amendments to the EAHCA and, in the process, changed the name to Individuals with Disabilities Education Act (IDEA). Congress stated in IDEA:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring

equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities (IDEA, 20 U.S. §1400; Weber, et al., 2010, p. 1).

IDEA (IDEA, 20 U.S. §1400) is codified as Title 20 which provided an explanation as to why the EAHCA was amended even though IDEA had “been successful in ensuring children with disabilities and the families of such children access to a free appropriate public education and in improving educational results for children with disabilities” (IDEA, 20 U.S. §1400; Weber et al., 2010, p. 1). But 15 years later Congress recognized “that the implementation of this *title* [20 USCS §§ 1400 *et. seq.*] has been impeded by low expectations, and an insufficient focus on applying replicable research on proven methods of teaching and learning for children with disabilities” (IDEA, 20 U.S. §1400; Weber et al., 2010, p. 1). The purpose of IDEA was to have children with disabilities be able to attain education beyond high school, to be able to find employment, and to live a self-sufficient life (IDEA, 20 U.S. §1400; Weber et al., 2010, p. 4).

IDEA recognized students with a disability if they had the following conditions: “mental retardation, hearing impairments (including deafness),... speech or language impairments,... visual impairments (including blindness),... serious emotional disturbances,... orthopedic impairment, autism, traumatic brain injury, other health impairments, or specific learning disabilities” (IDEA, 20 U.S. §1400; Weber et al., 2010, p. 1). To qualify for protection under IDEA, the impairment must “create a clear adverse effect on the child’s academic achievement” or the child may qualify by having a specific disease (Smith & Bales, 2010, p. 392). The student with a disability continues to be protected under IDEA no matter the achievement level of the child in school (Smith & Bales, 2010).

Educational Advances of Individuals with Disabilities Education Act (IDEA)

IDEA can be largely credited for schools providing an inclusive education (Smith & Bales, 2010) and for increased access to education for students with disabilities (Katsiyannis et al., 2001; National Council on Disability, 2004; Katsiyannis et al., 2001). By including students with disabilities into the general education classroom, the state assessments scores of students with disabilities have increased and the graduation rates have also increased (National Council on Disability, 2008). Under IDEA, students were guaranteed a free, appropriate public education in the least restrictive environment and provided an IEP. Unlike other legislation, IDEA provided funding to schools to ensure the needs of students with disabilities were met and costs were kept low by placing students in the least restrictive setting (National Council on Disability, 2004). The most powerful component of IDEA is the IEP (National Council on Disability, 2005). The IEP team included the parent(s), a general education teacher, the student, and other instrumental advocates ensuring appropriate programs and goals are being provided to the student with the disability (National Council on Disability, 2004, 2005). Another layer of protection for students was the monitoring by the Department of Education to ensure every state was compliant with IDEA (National Council on Disability, 2004). IDEA has “fulfilled its primary goal of providing access for students with disabilities in public schools across America” (National Council on Disability, 2004).

Educational Shortcomings of IDEA

IDEA was a law that protected the individual rights of the students (National Council on Disability, 2008). In regards to accountability for students, however, IDEA fell short. It was not until NCLB was passed that schools and teachers were held accountable for student learning achievements (National Council on Disability, 2004).

More than 30 years have passed since IDEA was enacted and while the name has changed, the idea of ableism has not changed. This law has allowed school personnel to remove students with disabilities from the mainstream classroom due to decisions made by the schools regarding students' placements (Ferri & Connor, 2005). Many people and educators believe that by placing students with disabilities in the regular education classroom, it slows the pace of the class (Ferri & Connor, 2005). Time, resources, and lack of training are other reasons why teachers and community members are concerned about mainstreaming students with disabilities (Ferri & Connor, 2005). The school system mirrors the belief systems of society, and society chooses to separate the able from the disabled (Ferri & Connor, 2005).

NCLB: History and Purpose

NCLB was created to assist schools and districts to become successful in educating all students and to improve academic achievement of all students (National Council on Disability, 2008; Yell et al., 2006). It was recognized as a complement to IDEA because NCLB required students with disabilities to participate in state assessments and provided accountability for student outcomes (National Council on Disability, 2004). The intent of NCLB was to close the achievement gap for all students and, by doing so, require schools to provide students with disabilities access to the same curricula as the general education population (National Council on Disability, 2004, 2008). The objective of NCLB was to create "reforms to improve America's special education system" and would change "it from a culture of compliance to a culture of accountability for results" (President's Commission on Excellence in Special Education, 2002, p. 4).

Educational Advances of No Child Left Behind (NCLB)

The legislation for NCLB impacted students with disabilities due to the four pillars established by this statute. NCLB was based on the following:

- accountability for results,
- emphasis on doing what works based on scientific results,
- expanded parental options, and
- expanded local control and flexibility (O'Neill, 2004; Bejoian & Reid, 2005; National Council on Disability, 2004, para. 1).

NCLB focused on closing the achievement gap for all students and by doing so required schools to provide students with disabilities access to the same curricula as the general education population (National Council on Disability, 2008). Much of NCLB's success can be attributed to providing students with disabilities a more rigorous curriculum, an improved attitude of teachers towards students with disabilities' abilities to succeed in the general education classroom, and the increased number of highly qualified special education teachers (National Council on Disability, 2008). Since NCLB was founded, both graduation rates and certificates of attendance have increased (National Council on Disability, 2008).

In its recommendation to the President and Congress, the National Council on Disability suggested they 'stay the course' (National Council on Disability, 2004, "Conclusions and Recommendations" para. 1). From test score results and interviewing educators, the National Council on Disability committee understood the changes that were occurring in schools (National Council on Disability, 2004). NCLB required states to collect data on every student which allowed schools to set up interventions for students who were at-risk of not passing state exams (National Council on Disability, 2004). As a result of NCLB, class sizes have been reduced, students in the lower grades made improvements in math and reading, and parents were

able to use the data to make educated decisions about their child's education (Bejoian & Reid, 2005). Another change that occurred in schools "involves changing attitudes, beliefs, and values about all young people being able to achieve at high standards" (National Council on Disability, 2004, "Conclusions and Recommendations" para. 1). While there were people who believed students with disabilities could not attain this high standard, more educators have seen the evidence from test results that show students with disabilities can achieve at higher levels (National Council on Disability, 2004). The attitudes of educators began to favor the ability of our disabled students and encourage NCLB to keep academic expectations high (National Council on Disability, 2004).

Educational Shortcomings of NCLB

While NCLB is based on accountability for results, scientific research in finding what works in the classroom, parental options are expanded, and more local control and flexibility (Bejoian & Reid, 2005; O'Neill, 2004), there are still disabled students who are not meeting this ideology of a normal student (Bejoian & Reid, 2005). Bejoian & Reid (2005) contend that NCLB supports the medical model and the ableist belief because the legislation defines what is considered the educational norm for all students. By showing that disabled students do not meet the norms of the state test scores, disabled students have been further set apart from their peers and their teachers' educational expectations (Bejoian & Reid, 2005).

The dropout rate for students with disabilities increased as a result of high stakes testing (National Council on Disability, 2008) and disabled students unable to pass end-of-the-year state exams could not graduate with more than a certificate of attendance (Hehir, 2002; National Council on Disability, 2004). Ashby (2010) states that, just because the curriculum has been brought to the student, it does not mean that the student has been granted the same access or

demonstrated their understanding of the material. One size does not fit all in education (Yell et al., 2006). Students learn at different paces, but NCLB forces students to learn at the same pace and in the same way (Bejoian & Reid, 2005). NCLB has been criticized for not allowing alternative methods of measuring students' understanding of materials and eliminating the opportunity of using work-based programs to measure a student's mastery of a subject (National Council on Disability, 2004). However, data from test results show that schools need to:

- provide students more academic support,
- have highly qualified teachers in every classroom, and
- have every teacher and administrator believe every student can learn the grade level curriculum (National Council on Disability, 2008).

The National Council on Disability concludes NCLB's success depends on "how people truly perceive the barriers to inclusion" but also the perception of people toward "the education of students with disabilities could be the greatest barrier of NCLB" (2004, "Accountability" para. 2).

Closing the Achievement Gap for Students with Disabilities

More than 40 years have passed since Section 504 of the Rehabilitation Act was signed into law as the first legislation for people with disabilities. In many ways, policy has been successful at legislating opportunities. Section 504, ADA, IDEA, and NCLB have positively impacted the lives of people with disabilities (National Council on Disability, 1997, 2008, 2010). Students with disabilities have entered the classroom and are graduating at higher rates, more people with disabilities are facing less discrimination in the work place, access to public and private facilities has been vastly increased, attitudes towards people with disabilities have improved, and people with disabilities have reported an overall improvement in their quality of life (National Council on Disability, 2008).

A history of shortcomings in the process of legislative enactment, support, and enforcement of these laws has resulted in the situation we face in schools today—a consistent achievement gap between students with disabilities and their abled peers (National Council on Disability, 2012). Legally giving students with disabilities the right to a free, appropriate public education in the least restrictive environment does not guarantee the “compliance, monitoring, and enforcement of these laws” (National Council on Disability, 2005, p.19). In other words, Congressional legislation intended to provide students an equal education for the purpose of allowing them to live a self-sufficient lifestyle upon graduation does not predict the actuality of the intent. Statistics continue to show, in spite of Section 504 and ADA, the majority of disabled people are not finding an independent and productive lifestyle. The Bureau of Labor Statistics reports 19.3% of the disabled work force is employed while 69.3% of the non-disabled work force is employed. Further, as of June 2014, the unemployment rate for people with disabilities was 12.9% while the unemployment rate for people without disabilities was 6.1% (U.S. Department of Labor, 2014). There is still a gap. This same line of thinking holds true for students with disabilities in schools. Legislating that every child can “achieve to the highest standard”, as defined by the standards, tests, and lock-step district scope and sequence documents that have resulted from NCLB mandates does not guarantee that it will be so for every child (National Council on Disability, 2005).

Laws do not change deeply seeded societal beliefs about the reasons people with disabilities require assistance, or legislate awareness or understanding about the nature of human differences (Scotch, 2009). Attitudes play a role in reality. Research from the American Sociological Association finds that a student’s ability to move on to post-secondary education is due in part to schools’ “collectively held expectations for student success” (Muhammad, 2009,

p.14). And when taken alongside the assertion that “educators’ personal belief systems may be the most powerful variables perpetuating learning gaps in our public school system” (Muhammad, 2009, p.14), it is easy to question what role educators beliefs about disabilities play in the education process for students with disabilities. Policies are not able to address societal attitudes. As the National Council on Disability (2004) suggests, "attitudinal barriers are sometimes the bigger disability than the disability itself” (“Accountability” para. 3)

Laws cannot put an end to bigotry. Policy enacted by Congress has led to an improved lifestyle and access to opportunities; however, there is still a need for improvement. We have passed laws to end discrimination and provide each person with equal opportunities. However, even though African Americans, women, the transgendered, and people with disabilities have fought for their civil rights, they continue to face day-to-day challenges as they live their lives. Disability theorists and disability rights leaders continue to strive to end ableism in this country. The National Council on Disability recognizes “people with disabilities continue to face personal, social, and economic disadvantages and barriers that prevent access to the same opportunities as Americans without disabilities” (National Council on Disability, 2011, p.17).

The Reality of Policy in U.S. Education

In this section, I explore themes impacting the research on disability-related education, consider an explanation of how society devalues and diminishes the education of disabled people, and discuss how to rid society of its ableist attitude toward people with disabilities. The goal of disability studies is to provide “a vehicle to examine social attitudes, beliefs, and assumptions about disability” (Ferguson & Nusbaum, 2012, p. 76) and promote understanding of “disability as a social and political category versus something to diagnose, identify, and label individuals” (p. 76). The foundational paradigm of special education is positivism; which disability scholars

oppose. Disability scholars believe the positivistic approach of special education has led to the support of the medical model of disability by stating that disabilities are primarily a “bio-physical phenomenon consisting of a deficit condition within an individual” (Connor, Peters, Gabel, & Owen. (2012), 2012, para. 1).

The Disability Rights Movement (DRM) laid the groundwork for the passage of legislation to provide people with disabilities equal educational opportunities and outcomes in America. The first piece of legislation to allow students with disabilities equal access into school was signed 40 years ago. While students with disabilities have been integrated into the school system, the struggle for equality and for opportunities for the disabled continues in our society and schools today (Rauscher & McClintock, 1997). And while Section 504 and ADA opened the doors to an education for students with disabilities, it was IDEA and NCLB that set the equality of academic expectations and outcomes for disabled students and holding teachers accountable for the educational outcomes of students with disabilities (Vaughn, 2008). Both IDEA and NCLB are credited with allowing students with disabilities access to the general education curriculum. In addition, IDEA recognized the importance of the parent as an essential role in student’s education and required a parent to be part of the educational team along with their special education student (National Council on Disability, 2008). IDEA was signed into law before NCLB, but NCLB has been given credit for forcing states to comply with IDEA (National Council on Disability, 2008). Though students with disabilities end-of-year state assessment scores have increased, data does not attribute these increases to IDEA and NCLB. Instead, these two pieces of legislation set the achievement standards for schools for educating students with disabilities (National Council on Disability, 2008).

Impact of IDEA and NCLB

Overall, the impact of IDEA and NCLB for students with disabilities has been significant and positive (National Council on Disability, 2008). Since the passing of IDEA and NCLB, there has been a marked improvement in the attitudes of teachers towards students with disabilities, academic expectations for students with disabilities has been raised, all students now have access to a more rigorous curricula, and all teachers of students with disabilities are required to be highly qualified, not only in special education, but, also, in the content area (National Council on Disability, 2008). Furthermore, reading and math scores for students with disabilities at the elementary school level have increased since the passing of NCLB (National Council on Disability, 2008). However, students with disabilities at the high school level have not seen the same success (National Council on Disability, 2008). While teachers, parents, school districts, and state officials recognize the positive effects for students with disabilities, the two laws still have shortcomings; which, in turn, affect achievement of students with disabilities in the classroom (National Council on Disability, 2008). To ensure students with disabilities are able to attain higher standards teachers recognize more supports need to be put into place). This is especially true now that students must pass end of the year exams to graduate (National Council on Disability, 2008). As a result there is too much emphasis on results of assessments and not enough attention on skills students need (National Council on Disability, 2008)

IDEA is noted as being the civil rights law for students with disabilities while NCLB is the law that makes people adhere to the law (National Council on Disability, 2008). IDEA collects data about the student through the IEP and is able to offer instructional strategies to support the student's needs (National Council on Disability, 2008, p. 17). The two laws have the same goal to raise the academic achievement of students with disabilities. While the two laws

bolster and supplement each other, IDEA and NCLB need to become more compatible with each other (National Council on Disability, 2008). A concern among educators is the need for the two laws to use common terms, forms, graduation time frame, and data reporting instruments (National Council on Disability, 2008). The two laws need to have a “twin foundation” of high expectations for students with disabilities as well as differentiated learning and instruction for teachers and students with disabilities (p.18). Table 5 summarizes the differences between IDEA and NCLB.

Table 5

Comparison of IDEA and NCLB

	IDEA	NCLB
Orientation	Process oriented	Outcomes oriented
Unit of Analysis	Individual student	System or group of students
What is measured?	Range of skills Teach according to ability	Core academic skills
Type of Law	Civil Rights	Compliance

(National Council on Disability, 2008, p. 93)

Impact of IDEA and NCLB on Students with Disabilities

One of the most positive results of the passing of IDEA and NCLB is that students with disabilities are no longer disregarded in the classroom (National Council on Disability, 2008). Teachers are held accountable for the results of the IEP because the passing of IDEA and NCLB ensures that students with disabilities are receiving the same curricula as students in the general education setting (National Council on Disability, 2008). Prior to the passing of IDEA and NCLB, teachers taught the curriculum they felt fit and there was no accountability for the students’ academic outcome (National Council on Disability, 2008). Now the general education classrooms are open to students with disabilities (National Council on Disability, 2008). Not

only are students with disabilities receiving the same curricula as general education students, but also more and more students with disabilities are sitting in the general education classroom (National Council on Disability, 2008). As a result teachers, administrators, and community members are able to see the academic abilities of students with disabilities (National Council on Disability, 2008). Because the curricula are the same, general education teachers and special education teachers collaborate and interact more which National Council on Disability sees as one of the biggest gains for students with disabilities and, for that matter, for all students (2008).

Although there has been a shift to a better understanding of the purpose of special education and why students have IEPs, there is still a negative label that comes with being a special education student (National Council on Disability, 2008). It is the IEP that can separate students from other students in the classroom (National Council on Disability, 2008). There is a vast list of disability categories, and there are educators and community members who just do not understand the categories of disability (National Council on Disability, 2008). Plus, there are educators who believe that accommodations written on the IEP, or provided for in the classroom, give students with disabilities special treatment over general education students (National Council on Disability, 2008).

Regarding the end of the year assessments required by NCLB, teachers of special education believe the focus is on the test and that students with disabilities are not receiving life skills to help them advance into the next stage of their lives (National Council on Disability, 2008). According to the National Council on Disability, there is a perception that some students with disabilities focus too much on passing a math and language arts end of the year exam and not on “occupational and technical skills, employability skills, behavioral and attitudinal skills, and particularly for students with disabilities, life skills” (2008, p. 80). This leads to the concern

of graduation requirements for students with disabilities. IDEA allows for students with disabilities to focus on the goals set on the IEP and allows flexibility of time to graduate (National Council on Disability, 2008). Students with disabilities are allowed to work on their IEP goals until they reach the age of 22 (IDEA, 20 U.S. §1400). On the other hand, NCLB measures the success of students based on time (National Council on Disability, 2008). The expectation of NCLB is to have every student complete high school in the traditional four years (National Council on Disability, 2008). States across the country have developed tiered requirement graduation diplomas; which indicates that students with disabilities are not being challenged in school the way general education students are (National Council on Disability, 2008).

Impact of IDEA and NCLB on Teachers

NCLB requires that every special education teacher be highly qualified (National Council on Disability, 2008). Teachers are required to be certified both in special education and the content area in which they teach. The purpose of this requirement is to have well trained teachers who have the pedagogical knowledge as well as the content knowledge to support students with disabilities. There is an argument against requiring special education teachers to be highly qualified in the content area (National Council on Disability, 2008). The belief is that a special education teacher should break down the content for the students with disabilities and work with the general education team teacher who is the expert in the content knowledge (National Council on Disability, 2008). Because teachers need to meet the highly qualified standard requirement, there has been a loss of special education teachers in the field of education and the predictions are that it will only get worse (National Council on Disability, 2008). Schools that are in lower socio-economic neighborhoods are being especially hard hit by this

requirement due, in part, to higher education's lack of preparation for teachers entering the field (National Council on Disability, 2008). The preparation of teachers has not kept up with the changing demands on teachers (National Council on Disability, 2008). All teachers, special education and general education, need to be trained in instructional strategies for students who are performing below expectations (National Council on Disability, 2008).

Impact of IDEA and NCLB on Accountability and Testing

In the study completed by National Council on Disability (2008), teachers stated they did not believe students with disabilities would meet the standards set forth by NCLB. Teachers and administrators reported that NCLB made the school day about testing and prepping students for tests (NCD, 2008). Teachers believed their creativity in the classroom was being thwarted due to the focus on the test (NCD, 2008). In addition, teachers felt they were not able to focus on the life skills that are essential for students with disabilities (NCD, 2008). On the other hand, it was the belief of the parents, state officials, and educational advocates that "holding high expectations for lower achieving students was critical and that the law would help change cultural beliefs" (National Council on Disability, 2008, p. 22). In the end, schools have been held accountable for the academic progress of students with disabilities and NCLB has shone a light on the fact that students with disabilities can be academically successful (National Council on Disability, 2008).

Due to the implementation of IDEA and NCLB, parents have become partners in their child's education. Through the passing of IDEA and NCLB, parents have become better informed about their child's education (National Council on Disability, 2008). The issue parents have with the end-of-the-year assessment is that the assessments do not provide information about their individual child (National Council on Disability, 2008). While parents and educators

do agree that testing information should be disaggregated by subgroups, the breakdown of scores does not allow parents to compare their child's ability to others; nor can they compare how one school is doing in comparison to another school (National Council on Disability, 2008). The study by the National Council on Disability shows that parents are confused by the data from the end-of-the-year exams because the assessments do not show if their child is making academic progress; nor does it provide instructional strategies to assist the student to make academic progress (National Council on Disability, 2008). The resources the U.S. Department of Education provides parents are limited in assisting parents to gain a better and clearer understanding of the "classroom, curriculum, and instruction" (National Council on Disability, 2008, p. 91).

Devalued and Diminished Expectations of Students with Disabilities

Diminished expectations greatly impact the education of students with disabilities' (Hehir, 2005). There have been positive steps towards providing an equal education for all students; however, student performance can be limited to accessing the academic content by teachers who maintain an ableist assumption and do not provide appropriate support and/or engagement in the material (Ashby, 2010). The policy analysis that has been presented to this point suggests that there is a history of legislation seeking to "to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society" (Rehabilitation Act of 1973, P. L. 93-112). However, without an equal education, the chances of students with disabilities leading an independent life are lessened with each passing year.

Students come to schools with a variety of issues; some of these issues are visible while others are invisible. However, students with communication or physical disabilities "face social stigma, rejection and diminished opportunities" (Ashby, 2010, p. 347). The definition of 'normal' is

socially constructed and it inhibits students with disabilities from receiving appropriate access and opportunities in school (Ashby, 2010).

For students with disabilities to truly receive an equitable education, educators must first recognize that ableism does exist in schools (Hehir, 2005). Schools have opened the doors and allowed equal access for every student, but now schools must recognize how expected norms exclude certain students (Ashby, 2010). Inclusive classrooms began to be formed around the country in the 1970s and into the 1980s. Students with disabilities were admitted into the mainstream classrooms for purely social reasons; to the general public this was acceptable (Ashby, 2010). Due to the changes in legislation in the 1990s, students with disabilities were placed in the mainstream classroom for academic reasons (Ashby, 2010). Parents and teachers objected to having students with disabilities placed into the general education classroom (Ferri & Connor, 2005). Teachers felt unprepared to teach students with disabilities because of a lack of training in college preparation programs, and they thought students with disabilities would start receiving less services resulting in ‘chaos’ in the classroom (Ferri & Connor, 2005, p. 467). Editorial pieces from 1987 to 2001 showed the perception of students with disabilities was “so radically different from non-disabled children that their needs either could not or would not be addressed in general education classes” (Ferri & Connor, 2005, p. 468). Similar to societal beliefs about having people with disabilities join the mainstream of society, schools segregated students with disabilities to keep them “out of the schools and classes of those with more power” (p. 468).

Schools are institutions that support the appearance of ‘normalcy’ (Ashby, 2010). In relation to education Storey (2007) summarizes ableism as “the belief that it is better or superior not to have a disability than to have one and that is better to do things in the way that

nondisabled people do” (p. 56). Schools put on an appearance that special education classrooms are equal; however, they are not (Ferri & Connor, 2005; Storey, 2007). Students are reviewed case-by-case about their disabilities and the focus of the student’s school day is on changing that disability to become more like their peers (Hehir, 2002). Students with disabilities do not receive an equitable education due to “Inordinate segregation, low expectations, failure to provide accommodations, and misguided attempts to ‘cure’ disabilities” (Hehir, 2005, p. 42).

To have students with disabilities receive an equal education schools need to acknowledge that ableism does exist in schools (Hehir, 2005). This means schools need to accept and acknowledge that every child does not communicate in the same way and schoolwork can look different than their peers (Ashby, 2010). The goal of educators should be to end this negative stereotype of people with disabilities and to steer them towards a road of self-advocacy, empowerment, and equality (Hehir, 2005).

Ending the Ableist Attitude in Schools

To begin teaching about ableism one must start at the root of ableism—fear (Rauscher & McClintock, 1997). Legislation required more interaction among the disabled and the non-disabled, but now a closer look needs to be taken at the attitudes of people inside the school. As a student with Downs syndrome shared with Hehir (2005), “There are all kind of kids at my school: Black kids, Puerto Rican kids, gay and lesbian kids. Megan uses a wheelchair, Matt’s deaf, and I have Down’s syndrome. It’s all diversity” (p.17). The overall goal is to deal with disability with a frank and honest approach (Hehir, 2005). Students who are deaf should not be called ‘hearing challenged’ and students who have an intellectual disability should not be deemed as ‘special’ (Hehir, 2005, p. 17).

Ableist assumptions can occur in the school setting because of some educators' belief in the negative stereotypes of students with disabilities (Storey, 2007). The impact of this ableist assumption on students with disabilities is great and, as a result, there is a lack of appropriate educational support for students with disabilities; the student is not being fully included in the classroom (Ashby, 2010; Hehir, 2002) even though laws have been passed to guarantee full inclusion. From the viewpoint of the ableist, the "hidden curriculum of education" (Ashby, 2010, p.350) is to make the student with the disability as normal to an able-bodied student as possible (Ashby, 2010; Hehir, 2002). By educating teachers and students in schools today, the path to ending ableism in society is started (Hehir, 2002).

Schools have the opportunity to end ableism by having a "Greater openness about difference and diversity" and understanding that "students with differing needs and abilities can and should learn from and with each other" (Ashby, 2010, p. 356). Educators must understand that the reasoning for passing legislation such as IDEA and NCLB was to "change minds, values, and cultures so that we believe all students can achieve to the highest standards and that we adults are committed to helping them meet those standards in every way we know how" (National Council on Disability, 2004, "Introduction" para. 3). Administrators in schools also need to develop the instructional capacity of teachers and to set the tone throughout the school for high academic expectations for every student in the school (National Council on Disability, 2004, 2008).

Educating Students about Disabilities

To teach students about ableism it is best to start with a group that is mixed—abled and disabled, a variety of cultures, and individuals who know people with disabilities (Rauscher & McClintock, 1997). All participants need to be willing to share their feelings about disability,

their fears of becoming disabled, and suppress their anger toward disabled people due to the reminder that they too may become disabled (Rauscher & McClintock, 1997). The goal is to have people recognize their personal fragility and strength; this will lessen the fear when interacting with people with disabilities (p. 202). Allowing the able-bodied participants the ability to interact with the disabled participants will also lessen their apprehension and will lead to greater acceptance of the disabled (Rauscher & McClintock, 1997).

Schools are missing the opportunity to provide disability diversity lessons for their students and community (Ashby, 2010). Disability advocates support the idea that disability studies should be incorporated into science, literature, and history classes (Taylor, 2004). Students with disabilities need to see role models in their school and this can be achieved by having staff members with disabilities, such as teachers and administrators (Shapiro, 1994). It is important to teach students that disability will impact every person directly, or indirectly, at some time in their life and that people with disabilities are mainstreamed into our society (Taylor, 2004). The goal of ADA, IDEA, and NCLB is to have every student become self-sufficient and productive citizens. It is the responsibility of the schools to see that students are educated about ableism and the ability of people with disabilities to ensure an equal outcome for everyone (Ashby, 2010; Hehir, 2002; Story, 2007). Finally, it is the responsibility of the schools to educate students to understand every citizen in America has equal rights—no one is above another person because of their race, gender, or ability. It is time “to change negative attitudes that result in discrimination, prejudice, and segregation” (Shapiro, 1994, p. 13).

Summary

The perception of people with disabilities by able-bodied people in society has not changed in spite of legislative and policy mandates (Hehir, 2005; Scotch, 2009). Discrimination

against people with disabilities is still commonplace (Ramey, 2007). Disability theorists want to “raise the consciousness of others to their plight, to have their oppression recognized and brought to an end, and to feel good about themselves, even though people do not feel good about disability” (Siebers, 2008, p. 35). Legislation has been passed with the intent to end discrimination against people with disabilities; however, history has shown through other minority groups that it takes more than laws to change attitudes (Scotch, 2009). Disabled people cannot change or rid themselves of their disability, as ableists would suggest (Siebers, 2008). Ableism, like racism, sexism, and heterosexism, focuses “on the people who are discriminating and devaluing other people. They are the ones who can change” (Campbell, 2009, p. 21). It is through education of students and teachers that this change can occur. But first, we must listen and learn from people with disabilities.

As described above, the Disability Rights Movement brought about improved lives for people with disabilities and created independent living and economic independence for individuals with disabilities. Policies of laws passed offered equal educational opportunities and outcomes. Because of Section 504 of the Rehabilitation Act and the ADA, students with disabilities can now attend school without question and sit in the same classroom as their able peers. Because of IDEA and NCLB, students with disabilities are provided the same curricula, which provide better opportunities to move to higher education and, thus, opportunities for economic independence. However, people with disabilities continue to lag behind educationally compared to their able bodied peers and the unemployment rate remains high. Through interviews and review of educational and medical documents through her elementary school years, I reconstructed the life history of one multi-disabled female to learn if ableism impacts students with disabilities’ education and if there is a need for disability-oriented education. The

next chapter delineates the methodology used to determine whether this student benefitted from the passing of the laws relating to individuals with disabilities and if ableism led to a less successful school career. To do this, the following research questions were addressed:

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education?

The following question was also addressed:

What can the participants' experiences suggest about the need for disability-oriented education in schools today?

CHAPTER 3 METHODOLOGY

In Chapter 1, I introduced the problems that people with disabilities face on a daily basis, placed this problem within a historical context, provided the purpose and significance of the study, and outlined the research questions. In Chapter 2, I reviewed the Disability Rights Movement (DRM) and explained how it has enabled people with disabilities to lead a more independent life. I explained the legislation passed over the past 40 years and how it has led to the possibility of equal educational opportunities and equal educational outcomes for students with disabilities. I also described the impact of ableism on students with disabilities in the school system, what ableism looks like in schools, and steps to end this attitude of lower expectations for students with disabilities. In this chapter, I provide the methodology used in the study. I review the purpose of the study and the research questions. The chapter also includes the research design, the role of the researcher, the subjects as well as data collection and analysis.

Purpose of the Study

The purpose of this study is to understand the life history of one multi-disabled student from pre-school through her elementary school years to ascertain the following:

- the impact ableism can have on students with multiple disabilities in our education system,
- whether there is a need to have disability-oriented education programs in our schools today.

The goal of this study is to provide the perspective of a student with multiple disabilities and her family so teachers and administrators have a better understanding of the capabilities of students with multiple disabilities. With this better understanding, my hope is for students with any type of disability (physical, mental, learning, etc.) to be accepted in school by every

individual and to receive educational services they need for academic and social success in school and beyond.

Research Questions

The following research question was addressed in this study:

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education?

The following question was also addressed:

What do the participants' experiences suggest about the need for disability-oriented education in schools today?

Design

This study uses qualitative research methodology. This method is used to explore a naturalistic setting to find meaning of a social problem through people sharing the stories of their lives (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Creswell, 2007). The study is a phenomenological inquiry about one female's experiences in elementary school as a multi-disabled student. A phenomenological study takes a concept or a phenomenon, which in this case is ableism, and uses the concept to explore the meaning through the lived experiences of several individuals (Creswell, 2007). I followed the guidelines of narrative inquiry as established by Clandinin and Connelly (2000); this approach allowed me to hear the stories of several people about the common, or shared, experiences regarding this phenomenon to develop a deeper understanding of the experience of students with multiple disabilities in schools (Creswell, 2007). After collecting the stories from the participants and documents, I interpreted the meaning of the stories and found themes among the data collected about the phenomenon of ableism (Clandinin & Connelly, 2000, Creswell, 2007). In this qualitative study, this analysis

relies the life history work (Hatch & Wisniewski, 1995). It also includes the voices of the participants, my reflexivity, a complete description and interpretation of the problem, and calls for action if needed (Creswell, 2007).

Narrative Inquiry

The study of narrative is to learn how people experience the world around them. These experiences are shared through “stories lived and told” (Clandinin & Connelly, 2000; Creswell, 2007). It is through narrative inquiry that we can learn and understand other people’s experiences. Narrative inquiry is ideal to learn about people's education experience because of the social circumstances that occur in the classroom between peers, teachers, and the rest of the community inside the school (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990). It is in the classroom that personal and social stories occur for people to share their experiences (Clandinin & Connelly, 2000). In this case study, I focused on the life experiences of a child with disabilities during her elementary school years to learn how a multi-disabled student interacted with her peers and how she found success in school. Narrative inquiry allowed her voice and her experiences to be heard (Clandinin & Connelly, 2000).

Clandinin and Connelly (1990) state that in narrative research the phenomenon is the story, while the inquiry is the narrative. By sharing the story of a child with disabilities it is my larger purpose to probe the social significance of ableism in our school system and in our society (Clandinin & Connelly, 2000). While narrative inquiry focuses on the individual and not the social context of the story (Connelly & Clandinin, 1990), it is life history that stresses the social context over the individual story (Hatch & Wisniewski, 1995). It was my responsibility as the researcher to collect the stories and write the narrative of the study participant's experiences (Connelly & Clandinin, 1990), and as the researcher I tried to be cognizant of personal

relationships and personal experiences that have shaped my beliefs about ableism in the school setting (Clandinin & Connelly, 2000).

Life History

Elements of life history were chosen for this study because the method is not a personal story (Hatch & Wisniewski, 1995). Life history is a triangulation of stories from the autobiography of the individual, other people's shared stories of the individual, and the researcher (Hatch & Wisniewski, 1995). This method adds to narrative inquiry because it takes stories from the individual's life to add to a broader context, which can be political, social, historical, or personal (Hatch & Wisniewski, 1995). As the researcher, I took the life story of a child with multiple disabilities and analyzed the social, political, and historical contexts of her life. Because the child does not remember or know all of the details of her elementary school years, there was a need to juxtapose her life story with the memories of her mother, her tutor, and me. This analysis of her life takes this study from a life story to a life history study (Hatch & Wisniewski, 1995). The child's individual life story will add to a larger understanding of ableism in the educational setting (Hatch & Wisniewski, 1995)

Participant Selection

The narrative approach maintains the focus on one or two individuals by using data collected through stories that the participants shared. Next, the researcher compiles the story chronologically (Creswell, 2007). Because I chose to focus on a child from her earliest years, it proved difficult for her to remember times from when she was very young. So, it was necessary to fill in this information by interviewing two other participants: her mother, who was her advocate in every facet of her life; and her tutor who was the person who supported her educationally after school hours and who worked on her vocabulary. Since I, too, participated in

the child's early years, both academically and socially, I captured my memories by maintaining a reflective journal.

Confidentiality

All names of individuals and schools were changed to maintain confidentiality, and each participant understood that there might be the possibility that people may be able to identify them from their stories in the final product. For the purpose of this document, the main participant, the young girl with multiple disabilities, I named Karen. Her mother I named Mary and her tutor I named Claire. Each participant interview was recorded and will remain confidential. All interviews will be destroyed after 10 years, all IEPs and schoolwork will be returned to the family. None of the participants were given financial compensation for their time to interview. Each participant was able to end the interview at any time and did not answer any question she did not feel comfortable answering. Each participant who was interviewed signed a consent form that was submitted to and approved by the Virginia Tech's Institutional Review Board (IRB). Appendices A, B, and C include the consent forms signed by Karen, Mary, and Claire, respectively.

The Role and Background of the Researcher

Narrative inquiry requires that the researcher delve into the story with the participants. The researcher and the participants become “a shared narrative construction and reconstruction through the inquiry” (Clandinin & Connelly, 1990, p. 5). As the researcher, I have participated in Karen's story long before this study began. My career in education began in August of 1993 as an instructional assistant (IA) in a deaf first grade classroom at Morningside Elementary School. My goal was to become a sign language interpreter, but I needed to improve my receptive and expressive signing skills before I could become an interpreter for the deaf. That

first year I worked in a first grade classroom with six deaf students and a deaf teacher. I learned the difficulties students with hearing loss face when learning how to read and write and learn math. I also learned the social difficulties they incur. During that school year my conversational signing skills improved dramatically due to being immersed in the language all day. In the evenings and on the weekends I attended interpreting classes to improve my interpreting skills.

The following school year I became a full-time interpreter at the elementary school. I interpreted the elective classes (physical education, music, and art) while substituting for interpreters who were out for the day. This was the year I met Karen who was in the first grade. On occasion, I would go into her classroom and interpret for her. That same year I met Karen's mother who asked me to interpret Karen's tutoring sessions after school. The tutor worked with Karen and her brother on reading and writing. I gladly accepted the job because I needed the extra experience as well as the money to help ends meet financially.

Once a week after school, I drove Karen to her tutoring session, but first Karen and I stopped off at McDonald's to get her a snack. During our drives and eating at McDonald's, Karen and I talked about her friendships, her family, and her school day. I enjoyed our afternoons together and it was during this time I got to know Karen as a person. There were staff members at the school who believed I should not have interpreted for Karen's after-school activities. No one said it to me directly, but I could feel the disapproval of some of my colleagues. I am not sure if the disapproval was for the sole reason that Karen was struggling in the first grade and they did not believe she should be mainstreamed or if they just thought I should not interpret for her outside of school. I continued interpreting for Karen because I enjoyed working with Karen and her family.

I was Karen's interpreter for her first, second, and third grade years. With each passing year, I saw Karen gain more and more confidence in her academic and social skills. Karen had a different interpreter during fourth grade while I was the interpreter for three deaf students in the second grade. When Karen entered the fifth grade, I became an American Sign Language teacher at a nearby high school. I continued to stay close to Karen and her family as a friend. I still interpreted for her at church, catechism, and doctor's appointments. I remained a teacher for seven years and became an assistant principal at a high school when Karen was in 10th grade. At this time, I continued to interpret for Karen for her tutoring sessions in Latin. My father was her tutor and we met weekly. It was during these high school years that I felt as though Karen did not need me around as much because other people came into her life to interpret for her. While we remained in contact, we just did not see each other as often, but when we did it was like no time had passed between us. Once Karen completed Latin III, I stopped interpreting for her in this capacity. I stopped interpreting altogether because my career took me down other avenues.

In 2011 I began taking classes for my doctorate, during which I began to reflect on how I became a school leader. While I was pursuing my doctorate I was also preparing to become a principal. I used this time to reflect on my own personal beliefs about students, and I discovered that Karen had made a huge impact on my personal and professional life. The early part of my career was being the voice for deaf students and, as I became a teacher, an assistant principal, and finally a principal, I learned that my goal has always been to provide every student a voice. My goal was to work with students, as I had with Karen, to help them find their own voice—who they were as a person and standing up for their rights as a student and, later, as a person in the world. Karen has touched, changed, and impacted many people's lives. It is my belief her story can have a positive impact on the education of many students with disabilities.

Eventually, Karen and I would like to tell the story of her entire life. Karen is a remarkable young lady who has faced many struggles with a quiet determination and an optimistic outlook. This is the first step in fulfilling my promise to Karen to share her story so others may learn.

Gaining Access and Entry to the Setting

As one of Karen's interpreters in and outside of her elementary school since she was in the first grade, I became a close family friend and have remained so. During the interviews, Karen and I met in her home where she was comfortable. I know Karen loves to tell stories about when she was young and enjoys having friends come over to her house. Before going to her house, I always checked with her to be sure she was feeling well enough and had the time to talk. During each interview I also checked to make sure she was not becoming tired and ended the interview with her having the last word on any thoughts or ideas she wanted to add.

Accessing the Cultural Context

This study, which employs narrative inquiry with elements of life history, focuses on the elementary experiences of a student who had multiple disabilities. The cultural context of this study is the family and the elementary school she attended. Her family included: her father, who worked for a housing firm; her mother, a stay at home mother; an older sister, Michelle; an older brother, Matthew; and a younger brother, Ben. Ben had the same syndrome as Karen has. When Karen was young she participated in baseball, swimming, and dance. Presently she is a 25-year old woman who majored in graphic arts and is seeking her second degree in business. All of her siblings also graduated from college. The family continues to be close to one another and enjoys spending time together during get-togethers for family functions.

Data Collection

The quality of narrative inquiry and life history research depends on a collaborative relationship between the participants and the researcher (Connelly & Clandinin, 1990; Hatch & Wisniewski, 1995). Conducting a narrative life history creates ethical decisions and responsibilities on the researcher's part, but also on the study participants' part (Connelly & Clandinin, 1990). In this study, I had already formed strong relationships with each participant going back almost 20 years. From a positive perspective, we all formed bonds from our shared experiences, which created a unity of equality, caring for one another, and a lasting connection among us (Connelly & Clandinin, 1990). On the other hand, because of our unique relationship, there were times during this study when I struggled for fear of hurting Karen's or her mother's feelings. When she was younger, Karen was the student and I was the interpreter. In the beginning, our relationship was purely professional. It changed over time because of my friendship with her mother and as Karen grew older she began to learn how to advocate for herself, which led to my stepping away from the professional role of an interpreter. Because I was so involved in Karen's elementary school years, I needed to be cognizant of any personal bias and allow Karen to tell her story without interrupting or assuming the stories she would tell (Connelly & Clandinin, 1990; Hatch & Wisniewski, 1995).

The point of interviewing another person is to gain insight into that person's perspective (Patton, 2002). Three participants were interviewed for this case study - Karen, her mother, and her tutor. By employing the use of conversational open-ended interview format, the participants were able to share their perspectives openly. I used personalized questions to deepen the conversation and build upon previous statements (Patton, 2002). Each interview began with an explanation of the purpose of the study and the procedures for the interview. I also explained

that pseudo names would be used in this document for the sake of confidentiality. Written consent from each participant was obtained before any interview occurred.

In the next section, I review each data source used to create a print portrait of Karen's life (Clandinin & Connelly, 1990). First, I share the types of documents collected for this study. Next, I explain how the reflective journal was used and, lastly, I describe each participant's background to provide the reader with a better understanding of each study participant.

Data Source 1

Documents. I reviewed a number of documents as part of this research such as IEPs, audiotape of an IEP meeting, letters, report cards, and schoolwork. Through the years, Karen's mother, Mary, kept a folder of Karen's IEPs, an audiotape of an interview from an IEP meeting, letters to and from the school, report cards, and some of Karen's school work. While Karen was in middle school, the family moved to a new home. During the move, Mary threw away a lot of educational documents and schoolwork. However, she saved what she considered to be pertinent to share with Karen when she became older. The remaining documents Mary entrusted to me when I first began interviewing Karen in 2011. I secured these items in my home office and they stayed there for 2 years untouched until I started to review the data. I had the audiotape of an IEP meeting transcribed by a transcriptionist and I reviewed the minutes of the meeting. I reviewed each IEP in chronological order to look for academic changes, the wording of language that was selected, and of expectations of Karen's academic ability compared to that of her grade-level peers. Table 6 lists the documents I analyzed.

Table 6

Documents Analyzed

Grade in School	Date Produced	Document	Topic
Preschool	November 2, 1992	Teacher narrative	Academic progress
	February 9, 1993	Teacher narrative	Academic progress
	April, 1993	Teacher narrative; IEP checklist	Academic progress
	June, 1993	Teacher narrative; IEP checklist	Academic progress
Preschool/ Kindergarten	March 18, 1992	Signed IEP	Annual goals/short-term objectives
	May 1, 1992	Psychological Report	Psychological evaluation
	June 3, 1992	Signed IEP	Annual goals/short-term objectives
	January 1994	Signed IEP	Annual goals/short-term objectives
	February 2, 1994	Report Card	Grades with narrative from teacher
	June 1, 1994	Signed IEP	Annual goals/short-term objectives
	June 1994	Report Card	Grades with narrative from teacher
First Grade	January 13, 1995	Multi-purpose Referral Form	Statement of concern written by first grade teacher
	March 17, 1995	Eligibility packet/intervention checklist/sociocultural assessment-triennial Review/psychological Report/intelligence tests/Educational Evaluation/Teacher Narrative/Student Observation/Health Examination/Hearing Tests/Speech and language evaluation/Physical therapy evaluation/Physical disabilities assessment/Adapted PE evaluation	Confidential student records for triennial
	April 5, 1995	Unsigned IEP draft	Annual goals/short-term objectives
	May 23, 1995	Unsigned IEP draft	Annual goals/short-term objectives
	June 5, 1995	Letter to interim principal	Parent letter expressing concern of IEP
	June 16, 1995	Report Card	Final Grades with teacher comments
	July 19, 1995	Signed IEP	Annual goals/short-term objectives
	November 23, 1994–June 9, 1996	Teachers' notes about Karen's academic progress	Notes on academic progress, socialization, and use of interpreter

A wide range of documents were gathered for this study. They included teacher narratives, IEPs, IEP checklists, report cards other confidential school records, and parent letters. The documents were organized chronologically as follows: preschool, preschool/kindergarten, and first grade.

Data Source 2

Researcher's Journal. After each interview with Karen, I reviewed the videotape when I had time to reflect. As I watched the interview I paused the video to write down my thoughts and memories of Karen's experience in elementary school. I dated each journal entry so it corresponded with the appropriate interview. I created a separate file for each journal entry and saved it on my password-secured computer. These reflections became part of the data I analyzed. Appendix E includes a copy of the reflexive journal protocol.

Data Source 3

Portrait of Student with Multiple Disabilities. Thirteen years after the passing of Education for All Handicapped Education Act (EAHCA) and two years before the passing of the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA), Karen was born. Karen was born on April 3, 1988, the third of four children and, by all indications, she was a healthy baby. She has two older siblings, Michelle and Matthew, and a younger brother, Ben, who was born two years after her. Karen's mother describes Karen as "a beautiful baby. Absolutely gorgeous and she was literally my perfect child, and I've come to realize you don't really want a perfect child" (M. Griffin, personal communication, April 1, 2014). When Karen was born she weighed 10.5 pounds and maintained her weight even though she never finished a bottle. As a baby, Karen did not want to be held. She slept through loud family gatherings and rarely cried. Her mother, Mary, did not think anything was wrong with

Karen until she went to the doctor for Karen's one-year check up. She did not have any speech but the doctor said it was not uncommon for the third child not to be speaking. Mary began to compare Karen to her two older siblings and noticed Karen never said *Mom* or *Dad*, plus, she was not walking. Karen had ear infections in her ears but both ears were never infected at the same time (M. Griffin, personal communication, April 1, 2014).

Mary began to suspect that Karen was deaf. Mary realized when she went into Karen's room to wake her up from a nap she would turn on the light and call her name. Mary decided to go into the room without turning on the light. To test her suspicions, Mary called Karen's name, and she did not look toward her mother. Mary said:

My heart just sank and I was just like, "I think I have a deaf daughter." When her husband, Keith, came home that afternoon she told him that she suspected Karen was deaf and he said, "OK. So what do we do now?" (M. Griffin, personal communication, April 1, 2014)

Around the age of 14 months, Mary began taking Karen to the doctors to try to find a diagnosis because her daughter was not meeting the physical milestones that her two older children met. They began with a neurologist because that was whom they could get an appointment with first. Mary remembers Karen's first CAT scan when the doctors put "this tiny little body in this big machine" (M. Griffin, personal communication, April 1, 2014). Mary found herself "crying and thinking this just wasn't normal" (M. Griffin, personal communication, April 1, 2014). She recalled, "I found out shortly after that, that I was pregnant with Ben. So now we're dealing with a child that we don't know what's wrong with her, and there's another one on the way" (M. Griffin, personal communication, April 1, 2014). The doctor did a blood

test called a CPK, creatine phosphokinase. The doctor contacted Mary later and said they needed to repeat the blood test. After the fourth request to repeat the blood test she said:

I got my nursing books out and I found out exactly what CPK is testing for...and it says muscular dystrophy (MD) and my heart sank. CPK levels should be around 10–120 micrograms per liter but Karen's level was 22,000. That's why they kept retesting it because it was so off the wall. [CPK] actually measures damage to your muscle. It leaks out of your muscle. [For instance,] ...we wouldn't have any because our muscles are healthy. But if you're in a car accident or you break a bone your CPK level is going to go up because you're damaging the muscle. (M. Griffin, personal communication, April 1, 2014).

Karen was diagnosed with muscular dystrophy-like symptoms. After the blood tests, the doctor performed a muscle biopsy and sent off the sample to National Institute of Health (NIH), Bethesda Naval Hospital, and Georgetown University. All three results came back inconclusive. More samples were taken and sent to Columbia University and Baylor University and the results came back inconclusive.

Mary explained:

Part of the muscle looked normal and part of the muscle looked abnormal. So it didn't quite fit into muscular dystrophy, and Karen was a female. The disease mainly occurs in boys and she was cute. She didn't have male characteristics. And there are different types of muscular dystrophy but she didn't fit into any of it. Like there's congenital, which means that you're born with it, and obviously she was born with it, but she was stronger than congenital kids. Usually they're very floppy and they don't live real long. But she actually walked, rode her bike, climbed the stairs. She just never learned to run.

Then there is Duchene's, they're perfectly normal and it's mostly boys, and then about when they're 12 they start to fall and the signs come. So she didn't fit into that category of muscular dystrophy (personal communication, April 1, 2014).

Unique to Karen was what her mother described as weak spells:

Like she would walk and do well and go up the stairs and she would eat a ton of food and then all of a sudden she didn't have much of an appetite, she would get diarrhea, and then her weakness would come. Like if she could have walked up the stairs last week, all the sudden she needs help going up the stairs. She could still do it. She just needed help; she got tired. And then for no reason the diarrhea would stop, the appetite would come back and her strength would come back, and so we started testing her CPK at these levels and it didn't show any difference. So they still cannot figure out why she went through those syndromes, which affected her later on in school. (M. Griffin, personal communication, April 1, 2014)

At the same time, Mary took Karen to an ear nose and throat (ENT) specialist and they conducted the brainstem auditory evoked response (BAER) test on Karen. The BAER test was difficult to perform on Karen because she was such a visual child. Finally, after three attempts the doctors had to give Karen medication to make her sleep during the BAER test to get a final diagnosis that she was deaf. They put hearing aids on Karen and Mary started to learn about schooling for her daughter at the age of 14 months (M. Griffin, personal communication, April 1, 2014).

While they were still searching for a diagnosis for Karen, Ben was born on January 25, 1990. He would later be diagnosed with the same syndrome. Mary's main concern for her two

youngest children was the “physical [problems] because I knew that that disease could have killed them. I knew they could live with being deaf and we would just have to figure out how to communicate with them” (M. Griffin, personal communication, April 1, 2014).

The following results were documented for Karen’s psychological evaluation at age 4-years and 0 months. A Central Institute for Deaf Performance IQ of 103 (± 7) suggested average nonverbal intelligence, with average to high average scores on all but one subtest (manual dexterity was low average. (psychological assessment, March 3, 1995, p. 2) Average abilities were also noted on DAS Picture Similarities, VMI-R perceptual-motor integration, and social-emotional scales (psychological assessment, March 3, 1995, p. 2). Meadow-Kendall ratings of Karen's social-communicative behaviors indicated an above average (>90 th percentile) classroom communication profile (psychological assessment, March 3, 1995). Two intelligence tests designed to measure different cognitive processes (WISC-HI and KABC) both resulted in a consistent profile of average mental processing abilities with no significant scatter across subtest areas. The WISC-HI Performance IQ (99 ± 7) indicated average overall nonverbal intelligence, with no difference between perceptual organization skills and processing speed abilities”. The KABC Mental Processing Composite IQ of 100 (± 6) showed no significant difference between simultaneous processing and sequential processing abilities. (psychological assessment, March 3, 1995, p. 2)

Subtest analysis revealed a fairly consistent profile of average to high average skills, with only one subtest at the lower limits of the average range. Age-appropriate abilities were also noted on subtests that measure spatial memory, reasoning by analogy, perceptual-motor integration, sequencing story pictures, and number recall. (psychological assessment, March 3, 1995, p. 2)

Karen had greatest difficulty on the subtest that measured sequential recall of words, where she scored at the lower limits of the average range (age score = 5-3). "Although depressed performance on this subtest may relate to problems Karen has putting in synch the signs she receives with the language she hears, it must be said that this subtest is generally harder for deaf children" (Ulissi, Brice, & Gibbins, 1989). The average standard score for deaf children on this subtest is 6 ± 3 , as opposed to 10 ± 3 for hearing children.

(psychological assessment, March 3, 1995, p. 2)

Put in perspective, Karen's sequential recall of words, although low average compared to hearing peers, was a point above the mean derived for deaf children" (psychological assessment, March 3, 1995, p. 2). Teacher ratings on the Meadow-Kendall Social-Emotional Inventory for Deaf/Hard-of-Hearing Students were obtained to assess classroom functioning relative to deaf norms. Karen's ratings suggested a fairly consistent profile of average functioning related to developmental areas and control of impulsive/dominating or anxious/compulsive behaviors (psychological assessment, March 3, 1995, p. 2). Although linguistic functioning remains a concern, the results of this evaluation did not support a cognitive or attentional basis for Karen's minimal expressive language abilities (psychological assessment, March 3, 1995, p. 2). Intellectual testing revealed a consistent profile of average cognitive processing abilities, including nonverbal perceptual organization, simultaneous processing, sequential processing, and processing speed (psychological assessment, March 3, 1995, p. 2). Audiological records indicated that Karen made excellent use of amplification, with speech awareness thresholds at 30-35 dB (mild range) with the FM system. Despite these gains, "linguistic performance remains a classroom concern" (psychological assessment, March 3, 1995, p. 1).

Because Karen was medically fragile, my research with her has followed an unusual trajectory. Doctors have never known Karen's life expectancy. Karen has been deaf since she was born and had difficulty with physical movement and breathing. She has used a wheelchair since she was in the fourth grade. That same year she received a feeding tube and was diagnosed with Multiple Sclerosis, which led to a rod being surgically adhered to her spine. In the eighth grade she had a tracheotomy to improve her breathing capability. Karen has been in and out of the hospital for short and long term bouts with pneumonia and has missed long periods of schooling. Karen is now a 25-year old woman attending university. However, her medical problems still impact her life; she has periods of time when she is doing well and times when she needs prolonged rest. As a result of her medical condition, I worked with my dissertation Committee Chair to design the study and protocol for Karen's interviews before completing my preliminary exam or prospectus. I received Institutional Review Board (IRB) approval in December of 2011 to begin interviewing Karen. The focus of my questions revolved around Karen's academics, medical condition, peer socialization, family dynamics, relationships with teachers and interpreters, after-school activities, and her educational motivation.

Interviews with Student with Multiple Disabilities. Karen and I began our interviewing process in December 2011. Karen chose to be interviewed at her house. She and I reviewed the consent forms required by the IRB to ensure she understood the entire project (McKee, et al., 2013). After discussing how to share her story, Karen decided that it would be easiest to share her life experiences chronologically. To start the interviewing process, I asked Karen background questions (Patton, 2002) to have her describe her family members and her illness. By asking these types of question, I was able to have Karen begin to feel comfortable talking about her life and to learn about her knowledge of the extent of her illness. Karen and I

met for approximately half an hour to an hour each session to review the memories of her elementary school years.

In the first interview Karen discussed her family's background, how and when her illness was discovered, the nature of her illness, and some of her memories of pre-school. I found myself having to ask her more questions to get her to tell her story. My goal was to have the interview proceed as a normal conversation between Karen and me while being cognizant I needed to capture her signing and my voice on videotape. As a result of these dynamics, I voiced and signed my questions to Karen so she could understand my questions in her native language. The video recorder picked up the sound of my voice since I was not in the eye of the camera.

In each subsequent interview, Karen discussed two grade levels at a time. During these interviews I focused on Karen's experiences in elementary school and the feelings she had about these memories (Patton, 2002). During these interviews she talked about her relationships with teachers and friends in each grade, the impact of her illness during each grade level, and how she was able to keep up with her schoolwork while she was ill. Table 7 displays the interview schedule. After each interview with Karen, I went home and downloaded the video on to my password-secured computer. In the days following each interview I watched each interview on my computer and wrote down my thoughts and reactions in a reflective journal.

Table 7

Interview Schedule with Karen

Date	Location	Length	Interviews	Topic
December 21, 2011	Karen's house in kitchen	28 mins.	Individual	Family history, illness, setting up timeline
January 20, 2012	Karen's house in kitchen	25 mins.	Individual	pre-school–grade 2
February 24, 2012	Karen's house in kitchen	39 mins.	Individual	Grades 3-4
April 6, 2012	Karen's house in sunroom	25 mins.	Individual	Grades 5-6
April 15, 2013	Karen's house in kitchen	96 mins.	Karen and her mother	Review of timeline

I interviewed Karen and her mother together to review relevant milestones during Karen's education because Karen's mother has memories of Karen at a very young age that Karen cannot recall. Plus, her mother was able to share stories about times when Karen was too ill to recall those times. In her final semester at college, one of Karen's professors had the students create a timeline of their lives. Karen made a large canvas of her life from birth until her graduation from college. I laid this canvas out on the kitchen table and asked questions about each time period. Both women shared their stories about the significance of the year pertaining to Karen's academic, social, and physical well-being. This interview was a lot of fun for the three of us. We shared many great memories that were funny at times and difficult at other times, but ones I am sure we will all cherish.

Data Source 3

Portrait of Mother. Mary, Karen's mother, is in her mid-50s. Mary is the eighth child of 16 children. She went to college and majored in psychology and nursing. She later became a cardiovascular nurse in an intensive care unit (ICU). She married Keith right after she became a nurse in 1983. Keith works for a homebuilding firm. They had their first child, Michelle, in

1985, their second child, Matthew, in 1986, Karen in 1988, and their last child, Ben, in 1990. Mary and Keith held high academic expectations for their children and kept them active in numerous activities growing up. Both Mary and Keith were involved in Karen's education; however, only Mary was interviewed due to her attendance at all IEP meetings and her extensive contact with teachers.

Unlike hearing children who learn language from their parents, deaf children of hearing parents learn language at school from their deaf peers, teachers, and interpreters (McKee, Schlehofer, & Thew, 2013). Deaf people usually learn American Sign Language (ASL) through "horizontal peer communication" (McKee, et al, 2013).

When I was Karen's interpreter in elementary school, I made videotapes for her parents to view so they could use the same signs for spelling tests and new vocabulary material. There were times when Mary would phone me at home and ask how to sign different words. During the summer, Mary would take Karen, Ben, and me to different museums to start reviewing materials the children would be studying for the upcoming school year. She wanted them to learn the vocabulary before they started the school year. We would go to places throughout the DC area and I would interpret and teach the children the signs for the subject matter. Over the years, Mary and I became good friends. She and I still maintain contact and go out to dinner on occasion to catch up with one another.

Interviews with Mother. For this study, I conducted open-ended interviews with Mary. Each interview took place in a location of Mary's choosing and I audiotaped each interview. The focus of the interviews was on Karen. I asked Mary to share stories about Karen's elementary years and about Karen's experiences with her teachers, peers, and interpreters. I asked her to review Karen's health issues with the focus on the impact of the health issues on her

family, education, and peer relationships. A list of interviews and meetings is included in Appendix D.

Data Source 5

Portrait of the Tutor. Claire Kendrick is in her mid-50s and is a teacher for the deaf at the high school level. Claire graduated from the University of Northern Colorado and earned a degree in Elementary Education and Deaf Education. Upon graduation she earned her Master's degree from Columbia University. Claire has been an integral part of Karen's life because she has been her tutor since the first grade. As well as working with Karen after school on school assignments, she has been a language model for Karen. She was Karen's homebound teacher through elementary school whenever Karen was hospitalized and could not return to school. She was also her homebound teacher for a variety of classes in high school.

Interview with the Tutor. For this study, I conducted an open-ended interview with Claire. The interview took place in a location of Claire's choosing and I audiotaped the interview. The focus of the interviews was on Karen. I had Claire share stories about Karen's elementary years and her experiences with her teachers, peers, and interpreters. I asked her to review Karen's health issues with the focus on the impact of her health issues on her family, education, and peer relationships. I also questioned Claire about her relationship with the family and whether this relationship added professional conflicts with the school system that employed her. A list of interviews and meetings is included in Appendix D.

Data Analysis

In this section I provide an explanation of how I analyzed the data collected for this research, the strategies I utilized to ensure validity, and the ethical considerations for this study. Unlike other methods in research, qualitative studies can reflect people's most inner, personal

thoughts and unveil their reactions to situations (Smith, 2000). The narrative life history of Karen's elementary school years has a plethora of data; which includes interviews, letters, an IEP meeting audiotape, IEP documents, grade-level report cards, and schoolwork. Making sense of all the data collected is the process of data analysis (Merriam, 1988). While reviewing transcripts from interviews or reading over documents that have been collected, there may be a need to go back and collect more information from the participants in the case study due to questions that arise or a need for clarification (Merriam, 1988). While I was involved in Karen's life as she grew up, I did not know what the data would reveal until the final analysis was completed (Merriam, 1988).

I employed the use of case study analysis to find meaning in the interviews of each of the participants, the documents collected through the years, and the audiotape of an IEP from when Karen was in the first grade. Unique to this study is that Karen's primary language is American Sign Language. I provided an explanation of the importance of understanding deaf culture and the transcription process of her life history. Finally, I provided an explanation of how I maintained validity throughout the study.

Data Transcription

Each participant interview was transcribed. When interviewing a hearing person, the entire interview was audio taped using a digital recorder. After returning home from the interview, I downloaded the interview onto my secure computer. The audio taped recording was sent to a transcriptionist via Digital Dropbox. After completing each transcription, the transcriptionist posted the interview back into the Digital Dropbox for my use. I took each transcription and saved it onto my secure computer into a file for interviews. I printed the interview and placed each interview into my notebook, which holds all of the transcribed

interviews. Finally, I had the participants review the interview transcription to check for authenticity and let me know if there were any clarifications they wanted to make.

Data Compilation

Once all the interviews were conducted and document collection was completed, the data needed to be organized. Data in this case study was organized chronologically from preschool to the sixth grade (Merriam, 1988). To keep materials organized, a coding system was created to be able to locate data easily during the analysis phase (Merriam, 1988). The coding system is included with the calendar of data collection activities in Appendix F.

My skills and insights were a large factor in my findings and as Patton (2002) indicates, this was both a strength and a weakness. The data that were collected needed to be “compressed and linked together in a narrative that makes sense to the reader” (Merriam, 1988, p. 130). Merriam also indicates that the readers should not be left to draw their own conclusions from the reading of the narrative, rather conclusions needed to be drawn through the interpretation of the data. The research questions were reviewed to maintain the focus on the intended audience, which is school personnel, and on the “analytic insights and interpretations that emerged during data collection” (Patton, 2002, p. 437).

Translation of ASL Interviews

Karen signs using ASL, which is a visual language. It is for this reason I videotaped each of Karen’s interviews (Mulrooney, 2009). To be able to properly share Karen’s personal story, I had to have the cultural competency to understand deaf culture and the deaf community (McKee, et al., 2013). Deaf people who use ASL to communicate have a “set of values, customs, attitudes, and experiences that contrast with the hearing world” (McKee et al., 2013). When communicating, deaf people have a set of rules while signing that include maintaining eye

contact, using facial expressions, and using space (Gallaudet University Laurent Clerc National Deaf Education Center, 2014). ASL is not a gestural language and does not have complex sentence structure that mimics the English language (McKee, et al., 2013).

Deaf people also have difficulty with reading the English language. Most deaf people who graduate from high school have the reading level of a fourth grader (McKee et al., 2013). Karen graduated from college, but reading and writing in English is still a struggle for the most educated of deaf people (McKee, et al., 2013). For this reason, I relied on interviewing Karen one-on-one rather than have her write down any of her memories. Originally, my goal was to interpret (sign-to-voice) all of Karen's interviews. However, it has been many years since I worked as a professional interpreter and I felt out of practice for voicing for a deaf person. Plus, to avoid bias, I thought it best to have a qualified individual interpret the videotapes of Karen's interviews. As stated previously, the interviews with only Karen were no longer than an hour. After all of my interviews were completed with Karen, I downloaded the videos onto a thumb drive. I took the thumb drive and met the interpreter at her place of employment to download the videos onto her password-protected computer. I used this process, in part, because a sign language interpreter has the ability to voice for a long period while maintaining accuracy of Karen's intent. The interpreter took approximately one month to interpret all of the videos. The interpreter voiced the translation using Dragon software, printed out the end product, and gave me the translation. I took the translations of the interviews and put them in a notebook that I keep secured in my house.

Reliability and Validity

After completing each interview, I sent a copy of the transcript to each person interviewed. The person interviewed read over the transcript to check for any deletions and/or

any topic she wanted to expand upon. Once I completed all initial interviews and recorded documents by grade level and date, I began the analysis of the interview transcripts. The analytic tools I employed for this analysis were writing memos in the margins of the data, maintaining all data in chronological order, and using charts to assist me in understanding the data (Yin, 2014).

The analytical tools I used included:

- Arranging information in chronological order
- Writing memos to myself—contain hints, clues, and suggestions—preliminary interpretation of data—conceptualization of the data
- Juxtaposing data between two different interviewees
- Making a matrix of categories and placing the evidence within such categories
- Creating data displays—flowcharts and other graphics for examining the data. (Yin, 2014)

To begin sorting through the data, I conducted an inductive analysis to discover the categories, patterns, and themes to create categories (Patton, 2002; Smith, 2000). I used the procedures recommended by Patton (2002). In the first reading of the data, I made notes in the margins as to possible themes. After this first reading, I created a color-coding system using highlighter colors to see the different themes I formed. In this second reading of the data, I formalized the process by color-coding interviews using my computer and sticky notes for documents. Upon completion, I met with my peer auditors who assisted me through this process. The peer auditors and I discussed the emerging themes and patterns then I compared and analyzed the differences and similarities of our findings (Patton, 2002). This process allowed me to begin the interpretative phase of the research. Once completed, I was able to extract meanings from the data, make comparisons, draw conclusions, and find significance in the data (Patton, 2002). Part of qualitative data is having “self-awareness, even a certain degree of self-analysis” (Patton, 2002, p. 495). To ensure I was aware of my own voice, feelings, and perspective, I

answered three questions after I reviewed each interview. The three questions were part of my reflexive journal. The first question in this journal was about my perspective and what has shaped my viewpoints on this topic. The second question centered around the participants and their influences that shaped their perceptions and how our relationship might influence their response to a question. The third question focused on the audience and who would read this paper. I considered the audience's perceptions of the findings and how they might perceive me and how I might perceive them. I understood that I had a social responsibility in the reporting of my findings and, through the process of triangulation, I sorted through this issues during the analysis phase (Patton, 2002).

Peer Review

This narrative life history was unique because I was so closely involved with Karen's personal life. As a researcher I needed to recognize the improbability of being able to truly distance myself and "continue to act in integrity and demonstrate trustworthiness, virtuosity, and rigor in their scholarship" (Clandinin, 2007, p. 15). This process of consensual validation was "an agreement among competent others that the description, interpretation, and evaluation and thematics of an educational setting are right" (Eisner, 1991, p. 112; Creswell, 2007, p. 204). Because of my closeness with Karen and her family, I needed to be sure that I was telling her story, which at times is our story, and I needed to be able to distance myself.

To ensure my biases did not affect the results I employed the "use [of] audit trails, triangulation, and member checks" (Clandinin, 2007, p. 12). Once all of data were collected, I read over the transcriptions and looked for common themes. I incorporated a peer review process with two of my committee members. Each of the peer reviewers was selected due to her area of expertise. One reviewer's expertise is in the area of qualitative research and the other

reviewer's expertise is in the field of special education. The peer review was designed to continually question me about my choices in the methods as well as my interpretation of interviews and educational documents (Creswell, 2007). My two peer reviewers and I met together to discuss the themes and patterns. They questioned me about my own bias, experiences, and assumptions. This triangulation of observers allowed them to check for bias in my collection of data as well as to check the validity of the themes I identified (Clandinin, 2007).

Summary

In this chapter, I explained the purpose for conducting this case study and implementing the use of narrative inquiry with elements of life history. Three study participants were interviewed—a child with multiple disabilities, her mother, and her tutor. Audio and video taped interviews were conducted and extensive documents were collected. These data were compiled and prepared for analysis. A peer review was included to decrease personal bias in the analysis. Chapter 4 presents the findings from this analysis.

CHAPTER 4 FINDINGS

The Disabilities Rights Movement (DRM) worked toward creating public policy that benefitted people with disabilities, ending the isolation of people with disabilities (PWD), and bringing awareness about the plight of people with disabilities (National Council on Disability, 2010). Theorists began to realize that even with the success of the DRM, people with disabilities still faced discrimination and attitudinal barriers in their daily life (National Council on Disability, 2007; Shapiro, 1994). People continued to devalue the lives of people with disabilities by holding lowered expectations for them. This is referred to as ableism. According to disability theorists, ableism not only discriminates against people with disabilities, but may be the reason for lowered educational accomplishments of people with disabilities (Hehir, 2002). Diminished expectations of a student with disabilities can lead to an education with less support and reduced meaningful academic engagement with the grade-level content (Ashby, 2010).

Brown vs. the Board of Education stated that all students should receive an education on “equal terms” (Weber, Mawsdley, & Redfield, 2010). Ten years later after the Supreme Court’s decision, parents who had children with disabilities began to stand up for the rights’ of their children. They demanded that their children be allowed to attend school with their peers. Court cases were decided that allowed children with disabilities into school and laws were passed to end discrimination against all people with disabilities (Weber et al., 2010). Even with these strides forward, students with disabilities still faced social oppression and isolation. In 1973, Section 504 of the Rehabilitation Act was passed prohibiting discrimination on the basis of disability. As a result of this legislation, all schools were required to make reasonable accommodations for students with disabilities (Switzer, 2003). Two years later, the Education of All Handicapped Children Act (EAHCA) was passed to ensure that all students with disabilities

were educated with their peers (Yell, 1998; National Council on Disability, 2005). Almost 15 years later, Karen Griffin was born with multiple disabilities and, due to these two laws, Karen was admitted into school at the age of 14 months to begin her education in the public school system. When Karen was two years old, the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA) were both signed into law. The ADA guaranteed access to the curriculum for students like Karen, who had disabilities. The IDEA guaranteed a free, appropriate public education in the least restrictive environment and called for the improvement of educational outcomes for students with disabilities. Karen began school while these laws were taking shape in American schools. By 1997, when Karen was in the second grade, IDEA 1997 was passed strengthening the role of the parent during the IEP process and requiring use of student's educational outcome data (Yell, 1998, Yell et al., 2006). When Karen was in the seventh grade, No Child Left Behind was passed to increase the academic performance of all students in the school system, hold schools accountable for student outcomes, and support the belief that all students should graduate from high school (National Council on Disability, 2008). However, Karen still faced attitudinal barriers during her education and her mother had to fight the school system to ensure Karen received an equal and quality education.

This phenomenological case study is about ableism in the school setting and the lived experiences of one female with multiple disabilities' during her elementary school years (Creswell, 2007). The case relied on narrative inquiry methods to learn about the phenomenon of ableism. This was accomplished through interviewing participants, reviewing extensive educational documents and medical records, and developing a researcher journal. Upon completing each person's interview, the interview transcripts were analyzed to capture Karen's early life history and examine ableism. The analysis addressed the following research questions:

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education?

The following question was also addressed:

What can the participants' experiences disclose about the need for disability-oriented education in schools today?

Overview of the Problem

Ableism is defined as “a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent and assumed physical, mental, or behavioral differences” (Bogdan & Biklen, 1977, p.14). Laws have been passed to end discrimination against people with disabilities, but laws alone cannot change the mindset of people. Ableism in the classroom has a lasting impact on students with disabilities. Ableist practices in the school setting can hold students with multiple disabilities from reaching their true academic potential (Ashby 2010; Hehir, 2002). Disability theorists attribute the low educational attainment of people with disabilities to the lowered expectations school personnel around the country hold toward them (Hehir, 2002). This study suggests that ableism does exist in our school system; however, with the appropriate supports students with multiple disabilities can be successful in school.

In this chapter, I answer the overarching research question by providing examples of ableism that Karen faced during her elementary school years and the impact ableism had on her education and self-esteem. I also show that, in spite of the ableist attitude students with multiple disabilities face, they can be successful in school if they have appropriate resources.

Finding A: Ableism Exists in the School Setting

Ableism can be found in a variety of forms in a school setting. In this case study, I analyzed the attitude of ableism towards a student with multiple physical disabilities rather than one with mental or behavioral disabilities. Ableism can lead to relationships that are strained due to misconceptions about the abilities of the student with multiple disabilities in and out of the classroom. This finding was illustrated through the themes of isolation of the student with multiple disabilities and distrust formed between her family and school personnel. The data revealed that forms of ableism were found in the academic and social isolation Karen experienced because she was expected to maintain the academic and social norms of her peers. Once Mary felt the school was not supporting her daughter and not following her academic goals, Mary began to fully advocate for her daughter's rights in school and sought outside assistance to compensate for the lack of support from the school.

Karen's Isolation

Some of the best memories of school are not the book lessons learned in school, but rather the fun times students shared with their peers. School is not just about academics, it is a place where children learn social cues in life. The data reveal that Karen was separated from her classmates due to physical disability, and, as result of this separation, she was left out of many academic and social activities during the school day.

Academic Isolation. The data indicate that Karen faced academic isolation from her peers when she was physically removed from the academic setting because of her disability. Due to this physical isolation from her classmates, Karen was set apart from her peers in an academic setting and, as a result, felt devalued in the classroom. However, the data show that Karen could be included into the classroom if the teacher made simple classroom

accommodations and provided academic assistance. During her elementary school years, Karen remembered the people who made her feel she was a part of the classroom. Karen also remembered the people and the situations when she felt she was isolated from her peers. During her preschool years, she was taught in a self-contained deaf classroom. Her classmates were deaf like Karen but she had physical limitations as well. At this early age, Karen had a slow gait, wore casts on her legs, occasionally used a walker, had an FM system attached to her hearing aids to amplify sound, and tired easily. Karen could not run or jump like the majority of her peers. Her teacher, Ms. Presley, was a hearing person who Karen credits for teaching her how to communicate in American Sign Language (ASL). In June 1993, Ms. Presley wrote in her end-of-year narrative that Karen “made progress in expressive language” and that she needed to work on providing complete answers when responding to questions (J. Presley, teacher narrative, June, 1993). Academically, Karen progressed well and was still working “on counting and retelling stories, ... and following more complex directions.” Socially Karen “made friends with all of her classmates this year and is very much a caregiver, comforting those in distress” (J. Presley, teacher narrative, June 1993). Karen said she appreciated Ms. Presley because, “She knew I had a disability and she kept me involved with other students and activities in class” (K. Griffin, personal communication, April 16, 2012). The following year, Karen was mainstreamed for morning kindergarten. She was the only deaf child in her mainstream class and the only one who had a physical disability. In the afternoon, she finished the day in the self-contained deaf kindergarten classroom.

Ms. Gunston, the mainstream kindergarten teacher, reported during second quarter that Karen was “overcoming her reluctance to contribute to class discussions and to answer questions” (report card, June 1994, lines 5-6). By the third quarter, the teacher noted that Karen was “easily

able to contribute to class discussions now, and often answers questions during group time” (report card, June 1994, lines 12-13). She continued to report that Karen was “independent in nature” and her “sunny attitude assists in her success” (report card, 1994, line 15). Ms. Gunston noted that Karen “works and plays well with her peers; she makes friends easily and is a valuable group member” (report card, June 1994, lines 6-7). Academically, the mainstream teacher suggested that Karen needed to pay “closer attention to the interpreter during stories and instructional time” (report card, June 1994, line 8). In the second quarter Karen attempted to write, and by the third quarter she wrote in her journal daily and dictated “stories frequently” (report card, June 1994, line 11). For the summer, Karen’s teacher recommended that she find opportunities to work on “reading, writing, counting, and retelling stories” (report card, June 1994, lines 21-22). However, when she entered the first grade class, Karen and her mother noticed a change in the acceptance of Karen in the classroom.

Karen’s first grade teacher was less sensitive to Karen’s physical limitations. To learn about a special education student’s goals and objectives, teachers are required to read the student’s IEP. The June 1, 1994 IEP reported that Karen’s “muscle tightness and weakness vary depending on recent activity” and she received physical therapy services during PE class (p. 5). According to the IEP, the physical disability (PD) teacher was supposed to consult with the regular education teacher on how to provide modifications for Karen’s physical needs in the classroom (p. 5). The main physical concerns for Karen in the first grade were the muscle tones in her legs and upper body and her low energy levels. For her muscle tone, Karen wore serial casts during the school day and she received new casts every 10 days to stretch out her muscles. At school she was assisted with a walker, when needed, and she was not able to run, jump, or hop (Socio-Cultural Assessment-Triennial, March 3, 1995, p. 2).

In the classroom, Karen tried to be a part of the group. When the students sat on the floor for instruction, Karen sat with them if she was feeling up to it. Due to Karen's physical disability, she could not sit for long periods of time on the floor like many other children did during instructional time. Karen remembered that during group time her first grade teacher, Ms. Perry, "would force me to sit on the floor. If I didn't, she would kick me out and make me sit at the table so I wasn't involved. I was isolated" (K. Griffin, personal communication, May 20, 2012). Karen's physical limitations set her apart from her peers and she was excluded from working with her peers academically.

The following school year, Karen repeated the first grade with a new teacher, Ms. Mitchell. Karen felt Ms. Mitchell made her feel a part of the class through her accommodations. Karen explained the connection between her physical disabilities and teacher accommodations concretely:

Sometimes when there were presentations and the class would sit on the floor. I would tell Ms. Mitchell that I didn't want to sit on the floor because I was not comfortable on the floor. She would say fine. She said I could sit in a chair near the group. She really wanted me to be comfortable and made sure I was happy. (personal communication, January 20, 2012).

Ms. Mitchell made simple, physical accommodations such as keeping a chair near the other students to allow Karen to continue to participate in the lesson. This helped Karen feel cared for and comfortable while keeping her within the group of students. Ms. Mitchell made other simple accommodations for Karen as well. For example, Karen recalled, "If I was tired Ms. Mitchell would let me do something else. She wouldn't make me do something hard but

something light like studying spelling instead of a big activity that would wear me out” (K. Griffin, personal communication, January 20, 2012).

These steps Ms. Mitchell took to make Karen physically comfortable in class facilitated a strong relationship between the two. Karen trusted that she could talk to Ms. Mitchell and that she “always understood what I was doing and then when I didn’t understand she would explain it to me in more detail. She would talk to me in private or do anything she needed to do to make sure I understood what to do”(K. Griffin, personal communication, January 20, 2012). Karen, subsequently, felt like she was a valued member of the class, an equal with her peers, commenting, “I didn’t feel like I was looked down on or like I was disabled” in Ms. Mitchell’s class (K. Griffin, personal communication, January 20, 2012). Karen recalled that during the school year she “felt successful when I learned something” (personal communication, May 20, 2012). According to Karen:

[Ms. Mitchell] expected that I understand and that I was able to do what I needed to do to pass the first grade and move on to the second grade. She made sure that I understood the lesson and made sure I understood everything. She knew what I needed to do and what I needed to work on.” (personal communication, May 20, 2012).

Academically, Karen progressed to the second grade and then on to the third grade without any major concerns about her ability to be successful in school.

Social Isolation. The data suggest that Karen felt disconnected from the academic and social activities of her fellow students due to her physical differences. This usually occurred because of exclusion from activities. Evidence from Karen’s life history suggests that social isolation could have be decreased by school personnel who provided support to facilitate social interaction with her peers. Prior to the first grade, Karen was considered to be a social and

caring child by her teachers (J. Percy, report card, June 1993; R. Gunston, report card, June, 1994). During the first grade, her teacher, Ms. Perry reported that Karen did not form positive relationships with her peers and was grouchy with other students (J. Perry, triennial teacher narrative, March, 5, 1995). Karen's grouchiness could be attributed to the illness she incurred during the month of January. Karen missed a couple of weeks of school due to pneumonia. Mary said that it took a while for Karen to recover; upon her return to school she was extremely tired (M. Griffin, April 1, 2014). At the end of her first grade year, Mary knew that Karen needed a more nurturing environment as evidenced in a note she wrote about Karen's educational needs as a deaf child at the end of the 1994-1995 school year:

Deaf children need more time to develop academically, emotionally, and socially. In a multi-age class, there's an environment which allows her to do it. The teacher has a philosophy of allowing the children to develop their own speed – perfect for deaf child. This environment should help [Karen's] self-esteem because there's no pressure to be at a certain point in the year. One-two combo might help her self-esteem (M. Griffin, personal note, unknown date).

Karen did enter the 1st/2nd grade combination class the following year and repeated the 1st grade due to Mary's insistence. During her 1st and 2nd grade years with Ms. Mitchell, Karen flourished and her self-esteem grew considerably (C. Kendrick, personal communication, January 4, 2014).

Karen entered the third grade more confident in her academic abilities as well. I was Karen's interpreter for the third year in a row and made a concerted effort to be sure Karen fit in academically and socially among her peers. I often found myself as a social facilitator for Karen and her peers. For example, students who arrived early to class played games together in the

classroom. At the beginning of the year, Karen often played independently or with Scott, the other deaf student. I played Uno with a group of girls in the class for the goal of having Karen join the group so she too could play games with her peers. Every morning the girls and I played games and, usually, the girls wanted to be on my team (third graders thought I was pretty cool). In time, I started to draw Karen into the group by choosing her as my partner. Gradually, I withdrew myself from the group and let them play without me being in the middle.

A prime time for elementary school students to socialize is during gym class. While the other students played football or basketball, Karen was often working one-on-one with the adaptive PE teacher on her individual skills. She did not have the opportunity to work on the team-building activities that sports provide students. According to her IEP, the activities during PE class needed to be adapted for her to be able to participate (June 1, 1994). Karen recognized that:

[PE] was perfect from the aspect of being deaf but with my disability it was not because sometimes [students] would run or exercise and I had to do other things like adapted PE. They had to change it for me. I felt left out from all the fun and the socializing and other things (K. Griffin, personal communication, February 24, 2012).

When Karen was capable of participating in a PE activity, Karen and I were a team. If the class played H-O-R-S-E during the basketball unit, I stood wherever Karen told me to stand and shot for her. When we played dodge ball, she stood directly behind me and held on to my shirt. She told me who she wanted to try to get out, and I threw the ball for her. During the square dance unit, Karen would participate as much as she could. However, when she became tired, I stepped in for her. When the other students had to run the mile, Karen's course was shortened and she and I ran together (E. Reilly, reflection journal, May 20, 2013). Karen stated,

“When you and I played dodge ball that made me feel good because I felt included and not left out” (K. Griffin, personal communication, February 24, 2012). She might have said this to me in the interview to make me feel better, but I know that that year in PE was an important year for her because this was the last year that Karen fully participated in PE.

The following school year Karen missed the majority of the school year due to a three-months hospitalization for pneumonia. In the spring of that year, she also had surgery for her Multiple Sclerosis. Karen took her last step in the fourth grade and has been in a wheelchair ever since. However, she still shares stories with her peers about her days when she played basketball, dodge ball, and danced in her PE class.

Ableism and School and Family Relations

Academic choices often presented unanticipated challenges for Karen’s parents. Karen’s mother and father learned when Karen was approximately 12 months old that she had some form of physical disability and was deaf. In the following months, they learned that their daughter had a rare degenerative disease and her survival rate was unknown. The reality of having a child with multiple disabilities is overwhelming for any parent, and Karen’s parents were no different. As parents, they had to learn how to care for her physical needs as well as how to communicate with her. They were faced with learning a new language and about deaf culture. Their lives were turned upside down by multiple, life-threatening challenges for their daughter. When Mary learned early on that the average deaf child graduated from high school with a fourth grade reading level, she realized that their education goals for Karen had been complicated as well. Mary wanted her daughter to graduate from high school with a better prospect than an elementary-level education (M. Griffin, personal communication, April 1, 2014). All of this happened with little educational support or expertise. Rather, school and district representatives

forced a process of trial and error on Mary and her husband as they struggled to find the most appropriate school for Karen. This process took two years, during which time Mary wrestled with her own beliefs about what was best for her child, given the multiple impairments she faced. What Mary knew to be a “normal” school experience was impossible because of Karen’s deafness and physical limitations. Yet, she did not want Karen to fall short of what she might learn and achieve because of those disabilities. In some ways, Karen’s mother wrestled with her own ableist notions of what education should look like. In others, she was simply a parent trying to do what was best for her child at a time when there were few supports and resources available to her through the school system.

The data also reveal that Mary lost trust in the school due to the ableist attitude of some school personnel that Karen faced. It was during Karen’s first grade that Mary found she had to educate herself about Karen’s right to an appropriate education. Mary did this by requesting help from outside of the school. The impetus for Mary’s efforts was Karen’s school placement. Karen’s first grade teacher did not believe Karen should be mainstreamed, but rather that she should be placed in the self-contained classroom. Mary found herself attending contentious IEP meetings with school staff. She did not understand the process nor did she know her daughter’s civil rights. She began to lose trust in the school staff because they provided little information or support, but rather simply told her what they wanted her to do.

Language Choices. Mary faced ableism of a different nature when she enrolled Karen into the public school system. Mary had to choose a language program for her daughter without guidance or information shared by school personnel. This was a difficult decision for Mary because she did not know anything about deafness nor did she understand how deaf children learned to communicate. The three program choices were the oral program, cued speech

program, or the Whole Language (WL) program. Each program was held at a different elementary school and the drive for each school was approximately 30 minutes. The oral program's objective was to teach deaf students how to develop their speech and language skills just as hearing children. The cued speech program's taught deaf children to use visual cues to match the phonemes of the spoken language. The WL program taught American Sign Language (ASL) as the primary mode of communication. Mary chose the oral program because, of the three programs, it was the least scary for her and she did not know which program was the best suited for her daughter (M. Griffin, personal communication, April 1, 2014). Looking at the larger picture, it is quite daunting for parents to realize that they will not be able to communicate with their child in their own primary language. The parents chose a program that would help Karen fit into their lives—a natural choice for so many parents.

The first step for Mary to begin Karen's education at the age of 14 months was to have her evaluated by an educational team to see if she qualified for special education services. It was confirmed that Karen had a "severe-to-profound sensorineural hearing loss (psychological report, page 1, lines 9-10). The "Pediatric and Adolescent Center noted 'a significant motor delay thought to be a secondary to non-specific myopathy'" (psychological report, page 1, lines 12-13). Due to Karen's medical diagnosis, she was allowed to begin pre-school at the public school at the age of 14 months. By not providing sound professional advice about the best educational setting for Karen, the school system showed a lack of concern for the education of a student with multiple disabilities. This shows Mary's first encounter with ableism by school officials. The lack of concern for Karen's academic needs was illustrated each time Mary asked which program was best for her daughter. The response from the school staff was always, 'It's whatever you want. Whatever makes you feel good'" (M. Griffin, personal communication, April 1, 2014).

Oral program. The goal of the oral program was to have deaf students learn to talk as their primary mode of communication. The idea that Karen could learn to talk was much more appealing to Mary than having Karen learn American Sign Language (ASL). However, after a year and a half in the program, Karen did not learn how to speak. Mary recalled:

[Karen] would just not really eat that much and she was flinging food and I'm like what a brat, I don't understand. I'm trying to do all this stuff and you have the hearing aids and - and nothing...I just kept hearing like tick tock, tick tock, she's getting farther and farther behind. Because the teachers are saying "you got to get the speech in"...and we're trying everything but she still has no speech. She's a totally silent child. (M. Griffin, personal communication, April 1, 2014).

Cued speech program. Realizing Karen was not progressing at the oral school, Mary removed Karen from the program and placed Karen in the cued speech program in January 1991. Mary asked for guidance from school personnel, but they continually told Mary to choose a program that made her comfortable. Mary decided to try cued speech because "that was the next least scary thing" (M. Griffin, personal communication, April 1, 2014). The cued speech teacher told Mary that her "brother had been raised with cued speech. But later when her brother went to high school he learned sign language." Mary thought, "Well then why wouldn't you just teach him sign language?" Mary began reading about ASL and decided "if they're going to learn sign language anyways and they're still exposed to the oral, why wouldn't I put her in there?" Karen stayed at the cued speech school for almost the entire "semester and the only reason she was even there a semester was because that's when Ben became ill and was hospitalized" (M. Griffin, personal communication, April 1, 2014).

Whole Language Program. Karen was 3 years old when she went to the WL program in May of 1991. The WL program at Morningside Center was housed in Morningside Elementary School. The philosophy of the school was to provide a learning environment that supported deaf and hard-of-hearing students as they acquired communication skills in the least restrictive environment. The program supported students from preschool to sixth grade. The students could use a variety of methods to communicate such as ASL, gestures, written and spoken English, and finger spelling. Students were provided amplification devices and technology to support their needs. Each student received an Individualized Education Program (IEP) upon entry into the school. The IEP team decided if the student's needs would be better met in a self-contained classroom, a mainstreamed classroom, or a combination of both.

Shortly after Karen began the WL preschool program, Mary remembered a time when the family went to their father's office after school and she recalled:

[her four kids were] sitting in the conference room and they bring soda to the kids, which I thought was awesome and so we put it in front of Karen—and she signs *milk* and then it dawned on me she'd been throwing stuff because she didn't like soda. She only liked milk and I'd been trying to give her juice and she didn't like it, and finally she could communicate with us and we just started crying, and I'm like, "I'm so stupid" but now she has language and I went in and told the teachers and they were like, 'We've been waiting for this' and she had only been in school like three weeks. (M. Griffin, personal communication, April 1, 2014)

After two full years of preschool, her speech language teacher reported:

[Karen] has made progress in expressive language. The length of utterances and sentence complexity are greater on self-initiated expressions than in response to

questions; continued work is needed on answering questions more fully and telling facts from information imparted to her. For example, if asked in the classroom “What did you do this morning?” and prompted by suggestions, she will respond with one event and answer yes or no about other actions. [Karen] has accepted sign language readily. She uses some signs and lots of gestures to express her wants and needs. She seems to be able to understand a great deal more than she is expressing (natural for her age). She seems to enjoy being able to sign. She also has the ability to know who she must sign to and who she can get away with just pointing. She is very receptive. Karen is progressing very nicely. (speech language teacher, teacher narrative, June 1993)

Karen immediately took to ASL, and her language flourished. She started in the public school system two years prior to provide her services under the IDEA to assure an education equal to her peers. However, Karen’s language acquisition was delayed two years because the educational professionals did not advise her mother about the best programs based on Karen’s needs and skills. The focus for school personnel was not on the child with the multiple disabilities, but rather on the needs and wants of the mother.

Reduced Trust in the School. The data suggest that Mary lost trust in the school due to the ableist attitude some school personnel displayed toward the belief that Karen could thrive academically in the mainstream classroom. The actions of one school administrator and several teachers lost Mary’s trust through their actions towards Karen. Mary realized during Karen’s first grade year that school personnel wanted to place Karen in the self-contained classroom, which led her to start advocating for her child’s educational rights.

Mary sought the expertise of school officials when making educational decisions for Karen. She continually asked the school for assistance on how to best educate her child. To

ensure she knew the teacher and Karen's classmates, Mary volunteered in the classroom. When Karen first entered the preschool program at Morningside Center, school personnel and Mary worked collaboratively to ensure Karen's success. However, when Karen entered first grade the relationship between the school and the family took a negative turn and was never the same again. Table 8 provides a timeline of incidents chronicling the loss of trust between the school and Karen's parents.

Table 8

Incidents in First Grade of Broken Trust Between Family and School

Date	Incident	Action	Result
June 1, 1994	IEP signed	Worked with Ms. Neill to write goals and objectives for IEP	Karen mainstreamed full day for 1 st grade
January 13, 1995	Multi-purpose referral written by Ms. Perry	Wrote referral due to concerns of low language level	IEP meeting set and educational testing occurred
March 17, 1995	Confidential Student Records Release/IEP meeting	Mary left IEP meeting due to distrust of IEP team.	Mary contacted a parent advocate. Test results showed Karen to have average intelligence.
April 5, 1995	IEP meeting	Parents willing to sign. Interim principal refused to sign.	Unsigned IEP
May 23, 1995	IEP meeting	School changed IEP without parent's knowledge. Parents willing to take school to due process.	Unsigned IEP
June 5, 1995	Letter to Interim Principal	Put the June 1, 1994 into stay put.	Another IEP meeting was scheduled.
June 16, 1995	Report Card sent home		
June 20, 1995	Letter to Superintendent	Letter to express parent's concerns over IEP process	
June 26, 1995	Letter to State Representative	Letter to express parent's concerns over IEP process	
July 19, 1995	IEP with new principal Ms. Frederick	Meeting was held and concerns were shared while goals and objectives were agreed upon by parents and school.	IEP was signed and Karen repeated the 1 st grade with a new teacher and interpreter.

Loss of Trust of the Administration. Ms. Neill, Karen's pre-school administrator, was the first who worked with Karen and her family. She walked the family through the IEP process and assured them Karen was progressing as a normal deaf child. However, when Karen entered first grade, her teacher, Ms. Perry, became concerned that Karen was not on grade level with her peers. During the course of the year, Ms. Perry shared her concerns with Mary about Karen's low language ability. Ms. Kenny was the interim principal who was put in place for the 1994-1995 school year, but Mary did not have the same relationship with Ms. Kenny as she had with Ms. Neill. When Ms. Perry began expressing her concerns about Karen's low language ability, Ms. Kenny did not take any action to try to find any supports to assist the student in the classroom. Instead, Ms. Kenny just wanted to move Karen to the self-contained classroom.

In January of 1995, Ms. Perry wrote a multi-purpose referral stating that:

[Karen] appears to be an emergent reader, but her comprehension doesn't match her signed reading ability. Often, even after multiple readings, she isn't able to retell a story or discuss it. Her writing usually consists of / *like*...followed by a list of family members. She is not at the developmental point of creating independent journal entries and she rarely solicits help on how to spell words she would like to use. In math she has not been able to keep pace with the class. She hasn't grasped families of numbers, subtraction, story problems, and more than and less than. She is not consistent and can appear to grasp a concept one day only to seem to have lost it by the next day. Because of her low language she does poorly in science, social studies, and health. She has received a lot of extra help from me, parent volunteers, and especially from the sign language interpreter. The interpreter is willing to go beyond her roll [sic] as interpreter

and has been a great help in working with Karen. (J. Perry, multi-purpose referral, January, 1995)

Ms. Perry continued by stating that Karen “doesn’t appear to have a strong language base. When conversing she talks about a topic superficially and shows difficulty staying on topic” (J. Perry, multipurpose referral, January, 1995). While Ms. Perry believed school personnel went above and beyond to support Karen, Mary believed they were not meeting the needs of her daughter.

On several occasions Mary requested that the school provide the vocabulary for the upcoming units so she could work with Karen at home and learn how to sign the vocabulary herself. Ms. Kenny denied this request. Mary questioned the compatibility of the interpreter with Karen’s language level and requested that the school switch interpreters and/or place Karen with a new teacher and a new interpreter. Her mother wanted to see if it was Karen’s ability or if the teacher and/or the interpreter were not an appropriate match for Karen. Again, Ms. Kenny refused to try anything new and did so without explanation. (M. Griffin, personal communication, April 1, 2014).

The data reveal that the next loss of trust between Mary and school was in the first grade when she did not allow the school psychologist to test Karen for her triennial evaluation. The testing consisted of an IQ test and a psychological assessment. The school psychologist did not know how to sign; therefore Karen’s first grade interpreter was supposed to interpret all of the tests to Karen. Mary learned that she could have an outside psychologist who signed fluently conduct Karen’s testing. Mary believed that Karen did not understand her interpreter and she did not want another interpreter to sign for Karen. Mary preferred to have a person who signed

straight to her daughter and not have to be concerned whether Karen understood an interpreter. (M. Griffin, personal communication, April 1, 2014).

The psychological assessment stated that Karen used expressive language minimally in the class that was observed. The psychologist wrote that this was not due to a cognitive or attentional reason and did not have a reason as to why Karen was not expressing herself. Furthermore, Karen's area of weakness was her ability to remember word sequences. Compared to hearing students on this assessment, Karen performed on the low-average range; however, when compared to her deaf peers she was considered average. This portion of the assessment supported the fact that Karen had the cognitive capability to develop language (psychological assessment, March 3, 1995, p. 4). During her observation of Karen in the classroom, the psychologist noted that Karen paid attention to her teacher appropriately and shifted her "visual attention to read her interpreter's signs (which do not correspond directly to the English form)" (psychological assessment, March 3, 1995). The psychologist believed that Karen was "expending considerable energy just trying to get the linguistic information in synch" (psychological assessment, March 3, 1995).

Loss of Trust of the IEP Process. The triennial meeting was held on March 17, 1995. Mary reported that in her heart of hearts she knew that Karen was smart and could be successful in the mainstream class. She felt that the school just wanted to take the easy way out and put Karen into the self-contained classroom. An hour before the meeting to discuss the findings of the assessments, the psychologist from the deaf university pulled Mary aside and said, "She's very smart. Do not let them put her in self-contained....They're going to try to do this. Do not let them do this with this child" (M. Griffin, personal communication, April 1, 2014). The school

psychologist led the meeting and Mary remembers Karen's first grade teacher reading the multi-purpose referral aloud with her concerns.

Mary recalled sitting at the end of the table going "Oh my God" because the teacher basically said what a terrible person Karen was. She said she had no friends. She would never have any friends and she's not smart, and she went through this two-page thing and it just ripped Karen. She's six years old, and the psychologist, the man who I wouldn't let test her, said, "Well obviously she's going to be found eligible. But I don't know if she's LD, ADD, or ADHD" (personal communication, April 1, 2014). Mary was so upset by what was being said about her daughter that she "walked out of the building" leaving the IEP unsigned (M. Griffin, personal communication, April 2014).

When Mary got home, a Morningside Center employee, who was at the meeting, called Mary and she said, "[Ms. Griffin], what they did to you was awful at that meeting" (M. Griffin, personal communication, April 1, 2014). According to Mary, this school employee continued by saying the school had "meetings before this and none of us could say anything to support you but you have to fight for Karen, because what they're doing is wrong...And then I got pissed and then I started doing some research" (personal communication, April 1, 2014).

After learning about the findings of the psychologist and the disagreements Mary was experiencing with school personnel, Mary said that she needed to get a parent advocate for the IEP meetings with the school:

Because I didn't know enough to go in and I didn't know the law, and I didn't know what was available and I knew that I needed help. Because I was just a parent and I didn't know. I didn't know. So, I felt like after that meeting they were going to gang up against

me. It was me against, you know, a lot of people (M. Griffin, personal communication, April 1, 2014).

During the IEP process, Mary said:

I felt like they [school officials] were being kind of sneaky in how they did it you know? Like a lot of mumbo jumbo, and if I didn't have the parent advocate there I wouldn't have known I could stand up to them (M. Griffin, personal communication, April 1, 2014).

Mary contested the IEP because she learned as the school year progressed that school personnel were not adhering to the IEP that was in put in place on June 1, 1994. The IEP stated that Karen's participation in the regular education classroom was to be 91.6%. She was to be "fully mainstreamed with a sign language interpreter with ongoing consultation with the WL staff as necessary" (IEP, March 3, 1995, p. 15). In this IEP, one of Karen's annual goals was for Karen to "benefit from support services provided by WL personnel" (IEP, March 3, 1995, p. 7). A short-term objective was to "benefit from a short term block of specialized instruction when needed" and "benefit from consultation between classroom teacher and WL teacher" (IEP, June 1, 1994, p. 7). However, the support for Karen was not coming from the WL teacher. Admittedly, the WL teacher was too busy to leave her self-contained hearing-impaired classroom to come into the mainstream classroom to work with Karen. To adhere to the IEP, the interim principal decided to have the physical disabilities (PD) teacher work with Karen on reading and writing. Karen was pulled from class two times a week to work with the PD teacher. The sign language interpreter facilitated communication during these bi-weekly sessions and assisted the PD teacher on how to work with Karen (IEP meeting minutes, July 19, 1995, p. 18). Neither of these employees was qualified to teach the deaf, let alone to teach the deaf reading and writing.

This example also provides evidence that, while the school may have met the letter of an IEP mandate, it did so with disregard for what was most effective for the Karen.

Under the leadership of Ms. Kenny, the IEP was not signed on two more occasions. On April 5, 1995, the parents were willing to sign the IEP, but it was Ms. Kenny who would not sign the IEP. The parents wanted to add a section on how the interpreter should work with Karen. Ms. Kenny was unsure if the role of the interpreter could be added to the student's IEP. Also, Mary stated that IEP had already been written prior to the meeting. Mary did not know at the time that an IEP was supposed to be written in conjunction with the parent (IEP meeting, July 19, 1995).

The May 23 IEP meeting was quite contentious in the fact that the school changed Karen's percentage of hours she was to spend in the mainstream class without discussion with or acknowledgement of the parents. This IEP was not signed and the parents were ready to take the school to due process. The parents wrote a letter to Ms. Kenny stating they would not sign the IEP "as it did not allow Karen to be educated with children who are not disabled, to the maximum extent possible" (letter from parents of Karen, June 5, 1995). The letter stated, "We will reconvene with you and the IEP team if you are prepared to reconsider the classroom placement to a more heterogeneous grouping. If you choose not to amend this proposed IEP, Karen's last signed IEP of June 1, 1994, will remain in effect" (letter from parents of Karen, June 5, 1995). Under the leadership of Ms. Kenny, the IEP was never signed, the parents resorted to hiring a parent advocate to attend all subsequent IEP meetings with them, and the trust was broken between the school and the parents.

Loss of Trust of Individual Teachers. Karen's third grade year, Ms. Frederick, created a classroom that supported Karen's language needs. A regular education teacher, Ms. Lewis, and

a deaf education teacher, Ms. Ellis, taught the class together as a team. The idea was to have both teachers teach the whole class. Once again, I was the interpreter in the classroom. When Ms. Lewis taught the class or talked with a student, I signed for her and voiced when one of the deaf students signed. When Ms. Ellis taught a lesson, she signed and talked at the same time while I continued to voice for the deaf students. Ms. Ellis was also there to support Karen and Scott in language. In the afternoon, two other deaf students from the self-contained class joined the classroom for math.

According to the IEP, the history and language arts vocabulary units were supposed to be pre-taught by Ms. Ellis. After school, Claire, Karen's tutor, continued to work with Karen in all subjects (M. Griffin, personal communication, April 1, 2014). Mary heard that the regular education teacher was a good teacher and had heard a few things about the teacher of the deaf. Mary was happy to have Ms. Ellis in the classroom because Ms. Ellis understood deafness. The plan was for Ms. Ellis to give spelling words and upcoming vocabulary words for social studies units to Mary before starting a lesson. Claire would then work with Karen at home, and Mary could learn the signs along with Karen. However, Mary noted that nothing was being sent home from the school. Mary called Ms. Frederick and shortly thereafter Ms. Ellis sent home lists of Native American names the class would be studying and spelling words. Ms. Ellis did not provide an explanation of how these vocabulary words were to be signed (M. Griffin, personal communication, April 1, 2014). For example, there is no sign for Cherokee Indians. As a group, Ms. Ellis, Karen, Scott, and I would create a sign that we would use for Cherokee and we would maintain it for the duration of the unit.

Mary said she was not familiar with the public school curriculum since her older children attended Catholic schools. She wanted to know what Karen needed to know so she could

support her at home. She wanted to be able to sign to her daughter about her lessons, but without the support of the teacher she did not know how to help Karen at home. According to the IEP, Mary was also supposed to get a weekly log of Karen's progress in the classroom, but this did not happen. She said that she was supposed to get a weekly log from Ms. Mitchell's classroom but did not push it with Ms. Mitchell because she knew Karen was doing well in the classroom. But with Ms. Ellis, Mary said, "I was going to push it with her because I didn't trust her" (M. Griffin, personal communication, April 1, 2014). She said that she knew that Karen gravitated toward Ms. Lewis and to me in the classroom and did not go to Ms. Ellis for assistance. In the end, Mary communicated with the regular education teacher and just avoided Ms. Ellis all together (M. Griffin, personal communication, April 1, 2014).

Karen missed the majority of her fourth grade year for two reasons: (a) a severe illness during which she was put into an induced coma, and (b) surgery in spring for multiple sclerosis.

Karen started her fifth grade year concerned about her appearance. She had to use a wheelchair at all times and she now had a feeding tube that she did not want anyone to see (M. Griffin, personal communication, April 1, 2014). When 5th grade began, Karen was excited to have Ms. Roberts as her teacher. There was every indication that this was going to be a successful year for Karen because Ms. Roberts knew Karen personally. Karen and Ms. Roberts's daughter played together in school and had play dates at each other's house in the third grade. However, from the first few weeks of school, Ms. Roberts believed Karen's writing level was too low to stay in the class. She expressed her concerns and the tension between Mary and Ms. Roberts grew through the year (C. Kendrick, personal communication, January 4, 2014).

Claire understood that the mainstream teachers were concerned about Karen's language level; however:

you don't need to be worried [about Karen's language level]. She will get there. You know she's getting – the difference to me was is that if you put her in – OK let's say we put her in the self contained class, which probably has...low to high (deaf students)– Karen's probably on the higher end of that class. They're teaching to the middle. So all the good language she's not getting. So I kept saying “Just leave her there and let her get as much as she can because it will all – you know somehow this will all come out in high school” (personal communication, January 4, 2014).

Ms. Roberts believed that Karen should be independent in the classroom. Karen was in a manual wheelchair because Mary wanted her to use her upper body strength as much as possible. Plus, the appearance of a manual wheelchair did not look as “bad as an electric wheelchair” (M. Griffin, personal communication, April 1, 2014). One day there was a fire drill at school. Ms. Roberts and Ms. Murphy, the WL teacher, felt it was the responsibility of Karen to push herself to the safe room in the school. Neither teacher ensured that Karen got to the safe room; instead they left Karen alone in the classroom. When Karen got home that afternoon, she informed her mother. Mary immediately called Ms. Frederick, and Ms. Frederick was “absolutely livid” (M. Griffin, personal communication, April 1, 2014). While Ms. Frederick said this would never happen again, the teachers and the interpreter continued to say it was not their responsibility to push Karen's wheelchair at any time. Mary said she believed, “They did not want her there, and I think that's when they started changing classrooms too and it was kind of a bother” (personal communication, April 2014). In Mary's opinion, she believed Ms. Roberts truly did not want

Karen in the class. Claire said that the trust was broken back in the first grade and the fire drill incident just added to that feeling of distrust (C. Kendrick, personal interview, January, 2014).

Finding B: Resources Needed for Success.

The factors needed for Karen to prevail over the ableist attitude of staff members include: (a) an effective school leader, (b) supportive adults, and (c) the self-determination to achieve personal goals. The following sections provide examples of how Karen was able to be successful in school. These examples were taken from excerpts of interviews and from the documents that were written about her education.

An Effective School Leader

The data collected indicate that an effective school leader plays an essential role in the education of a student with multiple disabilities. The school leader's role emerges as a key factor in creating a positive school environment for the student and the family. There were school leaders who demonstrated their understanding of the needs of students with multiple disabilities and worked collaboratively with Karen's family. Examples are included for three leaders, Ms. Neill, principal of Morningside Center, Ms. Kenny, interim principal of Morningside Center, and Ms. Frederick, principal of Morningside Center. The data indicate that an administrator needs to work collaboratively with the student and the family when discussing the student's educational goals. Plus, the administrator needs to have knowledge of special education and be able to write and implement an IEP properly. Finally, an administrator needs to realize they set the tone of building positive relationships between the family and the school.

Collaboration with the Family. Families with children who are disabled come to the school and seek the expertise of school officials. The data provide examples of how school leaders contributed to trusting, collaborative relationships in the course of Karen's education.

Ms. Neill was the first administrator who worked with Karen and her family. She walked the family through the IEP process and assured them Karen was progressing as a normal deaf child. Mary said that working with “Ms. Neill was awesome” (personal communication, April 1, 2014). Ms. Neill explained that Karen was going to start working with an interpreter and that Karen needed to learn how to use an interpreter. Mary felt that Ms. Neill was there to help build the skills Karen needed to be successful in school. In short, Ms. Neill worked with the family (Mary, personal communication, April 1, 2014).

Ms. Neill understood the academic strengths and weaknesses of a student who was deaf. After Ms. Neill retired, Mary contacted her to ask her advice about Karen’s academic progress in the first grade. Mary was fearful that the school was going to label Karen as being learning disabled (LD). Ms. Neill told Mary to “Let them test Karen; they will find she’s not LD. She’s performing as a normal 6-year-old deaf child” (teacher journal, December 12, 1994). Ms. Neill understood two important facts about Karen as a deaf first grade student. First, she knew that Karen’s academic testing showed Karen as a student with average intelligence. This principal knew that Karen was quite capable of being successful in the mainstream classroom. Second, she knew that Karen, like so many deaf children, was language delayed. Ms. Neill never doubted that, with Karen’s ability and with the support of her family, she would be able to do well in school. Ms. Frederick was an administrator who knew Karen was determined to do well in school and was instrumental in supporting Karen through elementary school (C. Kendrick, personal communication, January 4, 2014).

Ms. Frederick was creative in designing a supportive environment for Karen in the classroom and built a positive relationship with the family. Ms. Frederick came to Morningside Center with a degree in elementary education and deaf education. Ms. Frederick was always

looking for the best way to support the needs of the students in the building. When Karen was in the third grade, Ms. Frederick understood her language was still below grade level. She created a classroom for Karen that supported her needs by placing a teacher of the deaf in the classroom to support the mainstream teacher. Ms. Frederick, like Ms. Neill, knew Karen's strengths and weaknesses. She continued to build a positive relationship with the family. After Karen's first grade year, Mary never truly trusted the school fully again and maintained a parent advocate. However, Mary stated that Ms. Frederick was always her anchor for the rest of Karen's elementary school years (M. Griffin, personal communication, April 1, 2014).

Knowledge of the Individualized Education Program (IEP). The data collected indicate that an administrator needs to know the laws established by IDEA to ensure the student with disabilities' academic needs are being met in the classroom and that teachers are following the IEP properly. The evidence collected in this study suggests that two of the administrators, Ms. Neill and Ms. Frederick, implemented the IEP properly and effectively.

Ms. Neill educated the parents about the IEP process. Mary stated that the meetings were small in nature and only the people who would be working with Karen attended the IEP meeting. She said, "It was always very nice, non-confrontational. It was easy. They would talk to me and say, 'This is what we think Karen could do'" (M. Griffin, personal communication, April 1, 2014).

Ms. Frederick worked with the family and the parent advocate and made sure the teachers followed the IEP. The IEP team reconvened on July 19, 1995. Ms. Frederick attended the meeting as the newly hired principal. At the meeting, the facilitator of the meeting stated:

Ms. Frederick is the person who will take this process forward and assure that Karen will have the program that's appropriate for her, and that the IEP as we determine that it needs

to be – whatever we determine is the appropriate program for Karen for the fall, Ms. Frederick will be the one to carry out that and to ensure that that program happens...(KR, IEP meeting, July 19, 1995, p. 3)

When Ms. Frederick learned that the Griffins wanted to have goals for how the interpreter should work with Karen, she quickly informed all parties that goals were written for students; not the people who work with the students. That issue was quickly resolved and goals were written for Karen on how to implement the use of an interpreter. The IEP meeting continued and Ms. Frederick listened to the parents' goals for their child, and she helped them write appropriate, reasonable goals and objectives for Karen.

Influencing Positive Interactions. The data suggest that administrators play a key role in the attitude of staff members toward students with multiple disabilities. During Karen's 10 years at Morningside Elementary, there were three administrators, Ms. Neill, Ms. Kenny, and Ms. Frederick. The only year Karen did not feel supported by a teacher and other staff members was the year Ms. Kenny was the interim principal. Table 9 displays the language teachers used to describe Karen's attitude under each administrator's leadership.

Table 9

School Personnel's Descriptions of Karen's Attitude

Ms. Neill	Ms. Kenny	Ms. Frederick
<p>“She works diligently until tasks are completed” (Ms. Presley, report card, Feb. 29, 1993).</p>	<p>“When she perceives the work to be difficult, Karen typically tends to stop responding. She does not usually respond positively when coaxed to try” (PD teacher, IEP, April 5, 1995).</p>	<p>When she became an <i>older</i> in 2nd grade, “I really remember starting to see her progressing, you know, in her willingness to try something” (C. Kendrick, personal communication, Jan. 2014).</p>
<p>“On occasion, she will refuse to participate, often wanting her turn after everyone else has had a turn and we are moving on to the next activity” (Ms. Presley, report card, Feb. 29, 1993).</p>	<p>“When given writing assignments [Karen] usually begins with <i>I like</i> and then lists names of family members. Currently, she is paired with another student who models story writing, however, she is a very concrete learner and when presented with a writing assignment based on wishes, [Karen] told about things she had done. It was apparent that she did not understand <i>wishes</i> in spite of interpreter explanations” (PD Teacher, IEP, April 5, 1995).</p>	<p>“And the interesting thing about her, and I think this is where people got the wrong impression of her, is that she did not want to make a mistake and she was not going to answer a question if she thought she was going to be wrong” (C. Kendrick, personal communication, Jan. 2014).</p>
<p>Karen “has made friends with all of her classmates this year and is very much a caregiver, comforting those in distress” (speech language teacher, IEP, June, 1993).</p>	<p>Karen “is a six year old first grade student who is an enthusiastic class participant. She has added a special dimension to our classroom and is a delight to work with in class” (Perry, multi-purpose referral, Jan. 13, 1995).</p>	<p>“Alicia and Elise probably made more overtures towards her, you know, and that’s probably where she felt like ‘OK I can be friends with them’ and then Leslie was so shy herself that they made a good pair” (C. Kendrick, personal communication, Jan. 2014).</p>
<p>“I’m sure that she has lots of potential locked up inside of her. I’m anxious to get it out. I look forward to great things in the fall”(Ms. Presley, report card, June 1993).</p>	<p>“She has also been diagnosed as having a muscular dystrophy-like syndrome. In spite of all of this,” Karen “appears to be a very happy, sociable person” (unidentified teacher, IEP, May 11, 1995).</p>	<p>2nd grade – “I just remember she was happy and Mary was happy” (C. Kendrick, personal communication, Jan. 2014).</p>

Under the leadership of Ms. Neill the teachers in the building displayed a positive attitude towards Karen's abilities. Ms. Presley remains one of Karen's favorite teachers and Karen credits Ms. Presley as the person who taught her how to communicate in ASL. The family still holds fond memories of Ms. Neill and understands that she introduced ASL to Karen and offered support as she progressed in her early years of education.

Ms. Frederick tried new methods to support Karen in the classroom. Ms. Frederick created classrooms that had team teaching between a regular education teacher and a teacher of the deaf. She also ensured that Karen had interpreters that supported her language needs, and she maintained open communication with teachers to ensure her expectations were being followed.

Interestingly, under the leadership of Ms. Frederick, Mary had disagreements with two teachers, Ms. Ellis, the third grade WL teacher, and Ms. Roberts, the fifth grade teacher. Ms. Ellis believed that Karen was being given too many accommodations, and Ms. Roberts did not think her reading and writing level were up to par to stay in the mainstream classroom (C. Kendrick, personal communication, January 2014). However, Karen reflected that she never felt the tension at school between the teachers or her mother during third and fifth grades (K. Griffin, personal communication, May 20, 2012). Karen more than likely did not feel the tension in third grade because her mother relied on the regular education teacher and I was in the classroom supporting Karen's language needs. The reason Karen may not have been aware of the tensions between her mother and the fifth grade teacher could be due to Karen's change in her physical appearance. Karen missed the majority of fourth grade due to her serious illness and surgery. As a result, she received homebound services for the remainder of the school year. She had not been with her classmates for almost a year when she entered the 5th grade in a wheelchair and she had a feeding tube attached to her torso. Mary reported that Karen started off the year not

feeling positive about her appearance. Halfway through the 5th grade Karen broke her thighbone which became a major undertaking due to her fragile health. As a result, she had another surgery which kept put her out of the classroom setting once again. Mary believes if Karen had stayed in school that year instead of receiving homebound teaching, the year would have been another negative year academically (M. Griffin, personal communication, April 1, 2014).

Ms. Frederick came to Morningside Center in June of 1995 after school let out for the summer. The first time Mary and her husband met Ms. Frederick was at the July 19, 1995, IEP meeting for Karen. Mary came to the meeting with her parent advocate and was prepared to take the school to due process. However, the parent advocate assured Mary that Ms. Frederick was a person the family could work with and that she was trustworthy (M. Griffin, personal communication, April 1, 2014). Ms. Frederick was always looking for the best way to support the needs of the students in the building. When Karen was in the third grade, Ms. Frederick understood her language was still below grade level. She created a classroom for Karen that supported her needs by placing a teacher of the deaf in the classroom to support the mainstream teacher. Ms. Frederick, like Ms. Neill, knew Karen's strengths and weaknesses. She continued to build a positive relationship with the family. Mary said, "I really respected Ms. Frederick and I really liked the fact that I could call her and she would call me back, and I never had that experience with a principal" (M. Griffin, personal communication, April 1, 2014). After Karen's first grade year, Mary never truly trusted the school fully again and maintained a parent advocate. However, Mary stated that Ms. Frederick was always her anchor for the rest of Karen's elementary school years (M. Griffin, personal communication, April 1, 2014). Mary explained:

Ms. Frederick was always there advocating for us. But we had issues with various teachers and we shouldn't have had. But it wasn't Ms. Frederick's fault. She tried and

they (teachers) didn't do their part and she would work with them, but I was shocked at how many issues we still had. (M. Griffin, personal interview, April 1, 2014).

For example, Karen faced teachers in the third and fifth grade who, once again, did not believe she could be successful in the mainstream classroom.

Supportive Adults

The data collected suggest Karen needed to have a person who provided academic and social support during her schooling. From the very beginning, Mary was realistic about Karen's disabilities. She knew that the physical disability could kill her daughter. She also knew the world her daughter was entering was a hearing world (M. Griffin, personal communication, April 1, 2014). Mary and Keith did not try to change Karen; however, they taught her that she needed to learn how to be independent (M. Griffin, personal communication, April, 1, 2014).

As a parent of child with multiple disabilities, Mary educated herself about Karen's physical disabilities and surrounded herself with people who could support Karen's academic and social needs. Previously, Mary was a nurse, so she knew how to care for her children's physical needs. What proved to be the most challenging was educating herself about the IEP process, becoming fluent in ASL, and learning how deaf children are effectively educated. But Mary learned quickly she could not teach Karen how to advocate and communicate for herself all alone. As a result, she sought out people to assist her. These included a private tutor, sign language interpreters, understanding teachers, and a parent advocate.

Mary's relationship with the teachers and administrators had a direct impact on Karen's education. During Karen's first grade year, Mary began to find support outside of the school. These people were knowledgeable in deaf education, sign language, and special education law. She learned quickly who were the teachers who worked well with students in the special

education program. All of these people helped Mary to be less stressed during Karen's elementary school years. Karen said:

I remember that in my first year with Ms. Perry, Mom was so stressed out. She felt she had to teach me everything instead of the teacher. Then when I was in Ms. Mitchell's class, she felt more relaxed. I was happy and she was happy. The first year I wasn't happy at all and my Mom could see that and she didn't know what to do. She knew Ms. Mitchell was fine and she knew what to do. My Mom wasn't stressed out anymore.
(personal communication, May 20, 2012)

Mary needed the outside support just as Karen needed the support.

Understanding Teachers. Claire recalled that:
more than one person said to me at [Morningside Center], "You know, her life expectancy is not going to be that long. Why don't they just let her relax and enjoy her life – you know – why are they pushing so hard on academics?" (personal communication, January 4, 2014).

Some teachers believed that Karen was not going to live very long so she should be able to enjoy her life and not have to focus so much on school (personal communication, January 4, 2014.)

While there were people who were sympathetic to Karen's disability, their sympathies were a limitation on Karen's potential, almost as damaging as the many school personnel who believed Karen was lazy and just did not want to do the work. As explained in the socio-cultural assessment that Karen took in 1st grade, Karen would go through weak spells, often when she had just returned from a bout with pneumonia. When Karen was tired, she became stubborn. She would not participate in activities in the classroom or in PE. Some teachers said that she was just being lazy and/or that she was receiving special treatment because her mother was so

involved in her education (M. Griffin, personal communication, April 1, 2014). However, the truth was that there were days she just was not feeling well. Some of her teachers were able to learn when Karen was truly not feeling well and they let her work at her pace. Of course, just like any child, Karen on occasion would try to get out of some work by saying she was not feeling well, but some of the teachers knew her well enough to know when to believe her and when to tell her to get to work (E. Reilly, personal communication, February 5, 2012). The most effective teachers, then, were able to balance empathy and expectations.

Tutors. Claire became Karen's tutor when Karen was entering the first grade for the second time and she remained her tutor until she graduated high school. At first Claire went to the house to tutor Karen and her brother a couple of times a week, however, by the fourth grade, Claire was at the house almost every day during the week. She worked mostly on language and teaching vocabulary to Karen. For example, the summer before Karen was to learn about Egypt in the fourth grade, Claire turned the Griffin's basement into an Egyptian museum. She taught Karen all about mummies, tombs, kings, and pyramids (E. Reilly, personal communication, January 2014). Karen needed this language so she could follow along with the class, not try to learn new signs as she was learning about the unit. This idea of pre-teaching the units Karen was about to study proved to be quite successful (M. Griffin, personal communication, April 1, 2014). When Karen became ill during the school year, Claire was there to start homebound lessons. When Karen was well enough to go back to class, she was up to date on all of her lessons and joined in with the class without missing major material. Karen stated that without the academic support of Claire through elementary school to high school she more than likely would not have been as academically successful as she was in school (K. Griffin, personal communication, February 24, 2012).

Interpreters. The sign language interpreter by definition is the facilitator of communication in the classroom. This person is supposed to ensure that when a person talks, the message is communicated, and when the deaf person signs, the interpreter will relay that message authentically. Educational Sign language interpreters ideally serve other functions as well. They model language use and facilitate social dynamics that are developmentally appropriate for the children they serve and educate the child how to use an interpreter effectively (www.rid.org). Karen began learning how to use an interpreter in Kindergarten at the age of 5. Just as Kindergartners have a difficult time sitting still and paying attention to the teacher, deaf students have a difficult time paying attention, too

Karen had difficult experiences with some of her interpreters. Karen's first grade interpreter was not an appropriate match for Karen's language level and personality. Her interpreter did not leave out extraneous information that a first grade student did not have the attention span for and Karen did not have the energy level to watch her interpreter all day. Plus, the interpreter was a signed very fast, used a lot of space (which equates to being a loud person) and was staccato in her signs (C. Kendrick, personal interview, January 4, 2014). Karen was just the opposite. She signed precisely, crisply, and used a small signing space (indicating she was a quiet person). As Claire pointed out, "Mary learned really quick that it was important who the interpreter was. That it couldn't just be anybody. They're not trained the same way." (C. Kendrick, personal communication, January 2014). In Mary's interview, she stated that she was happy I was Karen's interpreter for three years in school. She said to me, "You get it" (M. Griffin, personal communication, April 1, 2014). Mary understood that to me my job as an interpreter was more than facilitating communication. I felt it was important to teach Karen the social norms of a hearing classroom since there is a cultural difference between hearing and deaf

people. Outside of the classroom, I spent a lot of time with the family over the summers and on the weekends. Karen and I worked on building her vocabulary by visiting places around the city, attending movies, and sporting events. Our relationship was unique because I became a language model for Karen and her mother accepted that relationship between us.

There were times when people would say I overstepped my role as the interpreter in the classroom. For example, when Karen worked together with a partner who was hearing, I always checked and modified her English grammar when I interpreted for her. I helped her make corrections before she let her partner see her work or I would help her spell words correctly. With me there, Karen did not ask her partner to check over her work or ask the teacher a question or for assistance (E. Reilly, reflection journal, May 20, 2013). Another example was when Karen worked on word problems in math. I struggled with the fact that it was always difficult for deaf students to do word problems because of the reading level that was needed to understand the question. Often times I would help Karen write out the math problem to help her find the answer (E. Reilly, reflection journal, May 20, 2013). Because I tried to help Karen fit in socially with her peers, I impeded the teacher from knowing Karen's academic strengths and weaknesses.

At the time, I believed I was helping Karen become socially accepted in the class. I did not want her to be looked down upon by her peers because she wrote differently or came up with an incorrect answer (E. Reilly, reflection journal, May 20, 2014). Little did I know back then that I was displaying an ableist attitude. The ableist attitude I displayed during those years was trying to make Karen appear more like her peers so they would allow her to enter their social group.

Parent Advocates. When Karen was having a difficult time in first grade and the IEP was being disputed, Mary heard about parent advocates. Mary and her husband were both

educated people but when it came to the rights of their child with multiple disabilities they understood their limitations. Mary realized she needed an advocate, reflecting, “I didn’t know the law, and I didn’t know what was available and I knew that I needed help. Because I was just a parent and I didn’t know” (M. Griffin, personal communication, April 1, 2014).

The role of the advocate is to assist in cases in which the school is not meeting a child’s needs. The advocate Mary found said she wanted to meet Karen first, get to know her as a person, and then see what her academic needs were. She told Mary bluntly, “I understand what you’re going through, but I won’t fight for what you want. It has to be for what the child wants” (M. Griffin, personal communication, April 1, 2014). The parent advocate took on the case and supported Karen until she graduated high school. She was the one who taught Mary special education law, showing Mary that as early as first grade the school was not following Karen’s IEP. As a result, the advocate planned to take the school to due process to ensure the IEP was being followed. When Ms. Frederick became the principal, the advocate realized that Ms. Frederick was a person with whom the family could work with and trust. She educated Mary about the IEP, but she also worked with the school for the benefit of Karen and ensured she received her appropriate accommodations.

Strong Personal Qualities

Study data indicate that, in addition to needed school resources, strong personal qualities were instrumental in fostering Karen’s academic success. In particular, students with multiple disabilities to be successful in school must have an inner-drive and passion for school as well as the ability to set their own goals for the future. Karen's self-determination, self-confidence, and ability to focus on school work contributed to Karen's success.

Self-Determination. Karen was always determined to complete what she started and she usually gave her best. She had the necessary people nearby to support her through school, but in the end it was her determination that got her all the way through high school and into college. Karen commented that there were school personnel during her first grade year who “did not think I would be successful or that I would finish high school and go to college. I felt demeaned that they didn’t think I could do it. I could do more than they realized” (K. Griffin, personal communication, May 20, 2012). When Karen needed a personal boost to keep striving to do her best in school, she looked back to these days to show them that she can do anything she set her mind to.

Self-Confidence. As a young child, Karen was deemed to be stubborn and, in the end, this proved to be a strength. Karen was also a perfectionist; she wanted to do everything correctly the first time. She wanted to be sure she was doing it right which often manifested as hesitancy to participate in class. It was frustrating for many of her teachers especially when they wanted her to try new things or see what she was capable of doing (C. Kendrick, personal communication, January 2014). She was also a confident and nurturing child who was always smiling. No matter how ill she was or how tired she was, she always asked how you were doing (E. Reilly, personal communication, February 25, 2012).

One of the reasons Karen’s mother had her repeat the first grade was to build Karen’s self-confidence (M. Griffin, handwritten note, date unknown). Karen’s self-confidence increased when she repeated the first grade with a new teacher, Ms. Mitchell. Karen spent much of the first and second grade learning the social norms of a classroom with hearing children. By the third grade she was eager to socialize with her peers, but once again she faced social barriers due to her disability.

Karen's confidence and self-esteem improved dramatically during her two years with Ms. Mitchell (C. Kendrick, personal communication, January 4, 2014). Karen recalled that, during the school year, she "felt successful when I learned something" (personal communication, May 20, 2012). Students who were in the first grade were called *youngers* and the second graders were called *olders*. The idea was that the *olders* would assist the youngers and be a model for the first graders. This idea worked on the concept of independence and improving self-esteem in the students. Karen explained the idea of the class and said:

To me, when I was a younger then you were learning. When I learned something, I learned from either the teacher or one of the older second graders....In the first year, I could do math myself. In the second year if I didn't understand, I could ask Ms. Mitchell and I knew she would help me....[Ms. Mitchell] expected that I understand and that I was able to do what I needed to do to pass the first grade and move on to the second grade. She made sure that I understood the lesson and made sure I understood everything. She knew what I needed to do and what I needed to work on. (K. Griffin, personal communication, May 20, 2012)

Karen continued by adding:

When I was in the second grade, I became a teacher for the first graders. For example, I would get involved if they were doing an activity and I knew how to do it and if they needed help. We would help each other. (personal communication, May 20, 2012)

The use of instructional strategies that allowed students to share their expertise supported Karen's confidence as a learner. The following year Karen began the third grade and she was excited about starting the year. She said:

[I] found out the same kids were in the class with me and I was fine with that. I knew them and then I was able to socialize because I felt like we have been friends for a long time, for a year. (Karen interview, February 24, 2012, lines 96-98)

Setting Academic Goals. In spite of significant medical obstacles, Karen maintained a passionate drive to complete her schoolwork. Karen loved school. She loved to go home and do homework. Unfortunately, she missed a lot of school every year due to pneumonia, life threatening illness, or surgery. However, she did not like to get behind in class; doing the work and showing that she was capable of doing the work was the one thing that she could truly control in her life. She was persistent in her work ethic (M. Griffin, personal communication, April 1, 2014).

Claire remembered:

I don't know what grade it was or what homebound it was but by the time she was ready to do it she was still in the hospital, and I went over there and there was like 30 pages of math homework and she goes- and she had just received her interim and there was an 'I' (incomplete grade) – and she said 'I am not going to get an 'I'. Sit down over here.' And we sat there for three hours and did all 30 pages of the math and the doctors would come in because you know they're doing their rounds. She goes, 'I'm busy.' And she wouldn't see them until we were done. She's just determined. You know... as much as I hate No Child Left Behind, because I'm teaching to a test now, it's like a goal for her. It's like I have got to pass that SOL, you know, and all of her whole life it's about getting to that next thing. You know it's like right now we're going to finish that degree and we're getting a job. And I think that Mary has kind of set them up that way and that helped them- cause they've always have something they're working towards and that kind of

keeps them focused and they don't get so focused on the illness... But here's our little engine that could, you know, just quietly getting it done. (personal communication, January 4, 2014)

This quotation alludes to what was going on in Karen's life medically as she was "quietly getting it done". Each time Karen had to be hospitalized for an illness or surgery, she had to be admitted into the pediatric intensive care unit. She was hooked up to a breathing machine, a heart machine, and other monitors but she persisted in her schoolwork. She wanted to get back to school so she would not fall behind academically.

Karen was not a straight A student and, to this day, the verbs in her sentence do not always agree with the subjects. However, she set a goal to pass her classes and to do well on the end-of-the-year state assessments. Karen liked having an end-of-the-year assessment because she was able to set a goal to pass each of the exams (K. Griffin, personal -communication, May, 20, 2012). When she graduated high school, she passed every end-of-the-year exam that she was given, and she graduated with an advanced diploma from her school.

Table 10 displays the results of her high school assessments from spring 2004 to spring 2006.

Table 10
Standards of Learning

Grade/Date	Test	No. Correct/ Total No.	Level
Spring 2004	World History 1	53/60	Pass/Advanced
Spring 2004	Algebra I	39/50	Pass/Proficient
Spring 2004	Biology	36/50	Pass/Proficient
Spring 2005	World History II	49/60	Pass/Proficient
Spring 2005	Geometry	40/45	Pass/Proficient
Spring 2006	Writing	38/45	Pass/Proficient
Spring 2006	Reading	44/50	Pass/Advanced
Spring 2006	Algebra II	43/50	Pass/Proficient
Spring 2006	VA/US	49/60	Pass/Proficient

Summary of Findings

This narrative case study of Karen's elementary school years indicates that ableism existed in Karen's school and resulted in academic and social isolation of Karen as well as her family's reduced trust in the educational system. With the support of school resources (i.e., an effective administrator, a strong parent advocate, understanding teachers), along with an inner drive (i.e., personal self-determination self-confidence, and the ability to set goals), Karen still found success in school and overcame the ableist attitude that surrounded her.

CHAPTER 5 DISCUSSION, IMPLICATIONS, AND CONCLUSIONS

This chapter is divided into the following sections: summary of the study, major findings supported by the literature, findings not supported by the literature, implications, and recommendations for further research. The chapter ends with concluding remarks from study participants.

Summary of the Study

This phenomenological inquiry focused on the experiences of a student with multiple disabilities and the impact ableism had on her education during elementary school. The purpose of the study was to gain a better understanding of the experiences of students with multiple disabilities in the elementary school setting and to learn about the role of ableism in education. The goal of the study was to illustrate how an ableist attitude can negatively impact the student as well as to also show educators that students with multiple disabilities can thrive academically. Through material gleaned from interviews and educational documents saved through the years, the reader is able to learn through the lived experiences of a student with multiple disabilities that ableism negatively impacted her right to a free, appropriate public education.

Overview of the Problem

The goal of the Disability Rights Movement (DRM) was to ensure civil rights for people with disabilities, to provide the general population with awareness about disabilities, and to end the isolation of people with disabilities (Baird, Rosenbaum, & Toombs, 2009; Longmore, 2009). Historically, the medical model has been the predominant view of people with disabilities. It maintains that people with disabilities need to be cured and made to appear more normal in society (Switzer, 2003). However, since the 1970s activists have been fighting to end this marginalized view of people with disabilities. During the past decades, there has been

significant legislation passed to end the discrimination against people with disabilities and provide necessary accommodations for them. Unfortunately, laws do not change the stereotypes people form about other people nor do laws end the exclusion of people.

Education is key to bringing about awareness and promoting the self-reliance of people with disabilities. Presently, students with disabilities drop out of school at twice the rate of their able-bodied peers (Rosen, 2014). Americans with disabilities also report they still face barriers to their success—the attitudinal barriers of fellow Americans (National Council on Disability, 2007). This behavior, known as ableism, is “a set of assumptions and practices that promotes the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences” (Bogdan & Biklen, 1977, p. 14). Disability activists maintain that people with disabilities do not reach their academic potential because of the lowered expectations people have towards them (Hehir, 2002). As a result, people with disabilities are not able to achieve their economic and personal-independence (National Council on Disability, 2005).

Statement of Purpose and Research Questions

The purpose of this study is to understand the life history of one multi-disabled student from pre-school through her elementary school years to provide evidence regarding the following:

- the impact ableism can have on students with multiple disabilities in our education system,
- whether there is a need to have disability-oriented education programs in our schools today.

Specifically, the study was designed to address the following research question:

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education?

The following question was also addressed:

What can the participants' experiences disclose about the need for diversity-oriented education in schools today?

Review of the Methodology

This phenomenological inquiry employed the use of narrative inquiry with elements of life history to address the research questions. By sharing stories of people's lived experiences, a meaning and understanding can be shed on a social problem in our society (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Creswell, 2007). Three participants were interviewed for this qualitative research: the student with multiple disabilities (Karen), her Mother, and her tutor. Additionally, as Karen's sign language interpreter during her elementary school years, I wrote a reflective journal after each interview to share my experiences. During the interviews, I used open-ended questions and the participants shared their memories of Karen's life in chronological order. Karen's mother entrusted me with all of the IEPs, report cards, letters, and other documents that she saved over the years. All of the documents were reviewed in chronological order and the interviews were read over numerous times. I organized the data in chronological order to understand the full story of her elementary school years. In the process I created a coding system to organize the data. The analysis of the data I collected (i.e., the interview transcripts and documents) revealed three themes: ableism in the schools, the need for school resources, and the need for personal resources. These findings from Karen's life story are discussed in relation to the review of the literature on ableism.

Major Findings Supported by the Literature

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education? The data collected about Karen's elementary school years reveals that ableism occurred in the school setting discretely. Karen's narrative does not reveal that there was blatant ableism such as trying to change her disability to make her appear more like her peers. School personnel accepted Karen as a deaf student with physical disabilities. The ableist attitude school staff displayed consisted of the "differential and unequal treatment" (Bogdan & Biklen, 1977, p. 14) of Karen in the academic setting.

Laws were designed to provide students with disabilities full inclusion in the academic setting. However, the data reveal that Karen was not fully included in the academic setting, and as result of this exclusion, she was not fully engaged in the lessons as her peers. This was demonstrated in her 1st grade classroom when her teacher had her sit at her desk away from her peers during a lesson. Just because Karen could not sit on the floor with the other students, she was removed from the academic setting and not allowed to fully participate in the lesson. In 3rd grade Karen was denied full access to the curriculum when her teacher refused to provide vocabulary words for the upcoming units. Karen needed this vocabulary due to her language delay. If she received the vocabulary words beforehand, she and her tutor could have reviewed the meanings of the words and teach her the appropriate signs for each vocabulary word. Rather, Karen was left to focus on learning the vocabulary instead of interacting with her peers in the activities to demonstrate her understanding and knowledge of the subject. Another example of this was when she was in PE class and had to attend adaptive PE sessions instead of having activities adapted for her while participating with her peers.

The intent of the laws regarding disabilities was to provide students with disabilities an equal education to their peers; however, this equity cannot occur when there are educators who hold low expectations for their students with disabilities (Hehir, 2005). The literature review included the purpose of each piece of legislation passed by Congress and the educational impact the legislation had on the schools and students with disabilities. It further explored how ableism devalues and diminishes the lives of students with disabilities, thereby limiting their educational potential for graduating from higher education. The literature review also showed the need to educate our school personnel on how ableism can negatively affect our students with disabilities. However, the literature review falls short of showing the human impact of ableism on students with disabilities and on the family. Further, it did not include the importance the role students with disabilities have in their own education.

Discussion Regarding Federal Legislation

In spite of all the safeguards established by the legislation, ableism still occurs in the school setting as supported by the literature review and the data collected about Karen's elementary school years. Federal legislation was passed to ensure students with disabilities were provided equal access to school and an equal education as their peers (National Council on Disability, 2008; Smith & Bales, 2010). The findings of this case study indicated that Karen received the benefits of each piece of legislation; however, laws cannot guarantee the "compliance, monitoring, and enforcement of these laws" (NCD, 2005, p. 19). Each piece of legislation mandated the accommodations Karen needed to be successful in school. Nonetheless, some school personnel did not provide the appropriate academic support because of their low expectations of her ability. To be able "to empower individuals with disabilities to maximize employment, economic self-sufficiency, independent, and inclusion into our society"

(Rehabilitation Act of 1973, Pub.L. 93-112), students must have an equal education and those who educate them must believe that they can be empowered, independent, and included.

Without an education, all students' chances of an independent life are diminished (Hehir, 2002).

Meeting Her Needs Under ADA. Karen met the criteria under the ADA to be labeled as a person with a disability to receive the accommodations she needed to access her education. Morningside Elementary School provided Karen accommodations to support her academic and physical needs in a number of ways. First, the school system should be commended for providing accommodations appropriate for Karen's needs even though they were costly to the school. The school system offered all of the deaf students the choice of three different language programs. Those students who participated in the American Sign Language (ASL) program were provided an interpreter in every class including physical education (PE), music, and art. A principal created a team-taught class for her and her fellow deaf classmate. By all appearances, the school followed all requirements set forth by the ADA to ensure Karen received an equal education.

Karen also had physical access to the building during her education at Morningside Elementary. From pre-school through second grade, Karen had to walk some stairs to get to PE; however, by the time she was in third grade the school was renovated. An elevator was installed and there were ramps around the school for her to access each classroom, cafeteria, restroom, gym, and playground. Additionally, she was provided transportation on a school bus with handicap accessibility.

Under Section 504, students with disabilities were assured that they would not be discriminated against in education programs that received federal funding (34 C.F.R. § 104.4(a)). The ADA furthered strengthened the Rehabilitation Act and broadened the definition of

disability (Switzer, 2003). The data I collected suggested that Karen did not face blatant discrimination in school. Examples of blatant discrimination would include not allowing her to use sign language to communicate or not allowing her access to an interpreter. However, the data suggested that Karen faced an ableist attitude because of her low language level. Compared to her hearing peers, Karen was behind in language, but this did not take away from her ability to learn. During her elementary school years, she had three teachers and one administrator who did not believe in her ability to remain in the mainstream classroom. By using differentiated instruction, Karen would have been able to show her understanding of a topic. Karen understood what was happening in class; she just could not express this knowledge like her peers were able to express.

Meeting Her Needs Under IDEA. Under IDEA, students with multiple disabilities were guaranteed the right to a free, appropriate education in the least restrictive environment (20 U.S.C. §1400). The goal of IDEA was “to improve the educational results for children with disabilities (IDEA, 20 U.S. § 1400; Weber et al. 2010). Karen was provided an inclusive education as guaranteed by the IDEA. Upon entry into the school system, Karen was evaluated and provided an IEP with academic goals and necessary accommodations. All educational testing of Karen indicated that she was cognitively capable of succeeding in the mainstream classroom. In accordance with the IEP, her parents were provided the opportunity to add their input regarding her academic goals. As Karen became older, she too helped develop her educational goals. When the staff worked with Karen and her family on her academic goals, the system worked perfectly. There was open communication between the school and the family, there was an understanding of her weaknesses and strengths, and there was a collaborative

relationship that worked for the benefit of the student. Yet even with all safeguards provided by IDEA through the IEP process, Karen faced ableism.

Under IDEA, ableism is displayed through the classroom placement of the child with multiple disabilities (Ferri & Connor, 2005). The data revealed that some of Karen's teachers wanted her removed from the mainstream setting and placed in the self-contained classroom. The reason teachers wanted her to be placed in another academic setting was due to their belief that she could not succeed because of her low language ability. From the perspective of a teacher, I understand their fear of having Karen in their classroom. The reason they might have been fearful of having her stay in the mainstream setting may not have been due to their dislike of Karen, but rather of their fear of being held accountable for meeting all of the criteria needed for passing to the next grade level. It would have been difficult for a teacher to say at the end of the school year that Karen had mastered all of the concepts for that grade level. Additionally, there may have been the fear that the next teacher would blame the previous teacher for Karen's educational shortcomings. However, teachers needed to understand that Karen was able to show her understanding of the needed concepts. She just could not write it as well as her peers. Karen was able to show her mastery of material in the classroom. Her sentence structure may not have been perfect when writing answers on tests or papers, but teachers were able to read her answers and know that she demonstrated her knowledge of the unit. Teachers needed to allow her to show her mastery in a different manner.

Karen attended elementary school while IDEA was in effect. While the law states teachers needed to be held accountable for their students' learning outcomes, there was nothing in effect to hold teachers accountable for this desired outcome. In March of 1995, Karen's educational testing showed that she was a student who should be achieving in the classroom, but

her teacher continued to state she was not capable. There was no accountability of the teacher and there was nothing to demonstrate that Karen was achieving or not achieving as compared to her peers. In fact, Karen's end of the year grade for Language Arts shows she received a satisfactory grade in reading and writing. However, the teacher wanted to hold her back because she said Karen did not master the material. The passing of NCLB began to hold teachers accountable with end of the year assessments. Karen began taking her end of the year exams in middle school and continued until she graduated high school. She passed every single exam showing that she had the knowledge of the subject required by the state.

Meeting Her Needs Under NCLB. Unlike IDEA, NCLB did have a significant impact for children like Karen in the special education program. The intent of NCLB was to close the achievement gap and hold schools accountable for students' outcomes (National Council on Disability, 2004; National Council on Disability, 2008). As indicated in the literature review, NCLB is credited with not allowing students with disabilities to be disregarded in the classroom (National Council in Disability, 2008). Now teachers are truly held accountable for all students' learning and the curriculum for special education students is now the same as the regular education students (National Council on Disability, 2008).

This study focuses on Karen's elementary school years, and the law did not come into effect until Karen was in the seventh grade. However, in the interviews each participant discussed the impact of NCLB on Karen's education. Mary stated that the end-of-the-year assessments required by NCLB did help Karen in the classroom because she was determined to pass the exam (M. Griffin, personal communication, April 1, 2014). Her tutor, Claire, stated that, as a teacher, she did not like NCLB because she felt she was teaching to a test. For Karen "it's like a goal for her" (personal communication, January 4, 2014). When Karen was in high school

she spoke about how she attended the self-contained classrooms for some of her end-of-the-year assessment classes, because she felt they prepared her better for the exams (personal communication, May 20, 2012). Karen passed each and every assessment she took and this showed her and the teachers that she was quite capable of understanding the material that she and her peers were taught.

Discussion Regarding Devalued and Diminished Expectations

Students with multiple disabilities by law are required to receive an equal education to their peers' education (Hehir, 2005). However, the literature review suggests that schools put on an appearance of normalcy for students in the special education program (Ashby, 2010). Karen's case study supports this belief. While in the first grade, Karen's mother realized that her daughter's IEP accommodations were not being met. The teacher of the deaf was supposed to come into the classroom and work with Karen on her language acquisition, reading, and writing. However, the teacher of the deaf was too busy with her own class to come into the mainstream class to work with Karen and the mainstream teacher. Instead of devising a plan to find other appropriate supports for Karen, the interim principal had a physical disabilities teacher work with Karen on reading and writing. This finding suggests that school staff did not value Karen's educational outcome; rather they simply wanted to make it look like they were meeting her IEP accommodations. The ableist attitude of Karen's teachers did not allow her to receive "appropriate support and/or engagement in the material" (Ashby, 2010).

Major Findings Not Supported by the Literature

This case study set out to add meaning to a social problem in our educational system. This was accomplished by having study participants share their stories of Karen's life and by reviewing the collection of documents to support the stories (Clandinin & Connelly, 2000;

Connelly & Clandinin, 1990). Insights about the effects of ableism not highlighted in the literature were ascertained from this research. These findings suggest that the ableist attitude displayed in the school setting impacted not only the student but the family as well. Also, the data reveal that Karen was successful in the school setting but she needed to have support at school as well as her own inner drive.

Impact of Ableism on the Family

The literature review focused on the impact of ableism on students with disabilities, but a finding in this case study revealed that ableism had an impact on Karen's family members. Karen faced an ableist attitude for the first time when she is in first grade. Her mother, Mary, was the one who needed to come to her child's defense to ensure she received the equal education she was entitled to under the law. Mary attended meetings with school personnel and felt they worked against her and the academic goals she set for her daughter. During this time, Mary was stressed and her daughter, Karen, felt the tension between her mother and the school. In the absence of professional supports from educators or peers, Mary was coming to terms with her own ableist thinking. Even with all of the legislation supporting students with disabilities, this study suggests that, for a child with multiple disabilities to be successful in school, the family needed resources to support the child's needs and to educate themselves. Mary felt she needed to hire a parent advocate to support her during IEP meetings and other educational decisions. The parent advocate was able to assist Mary through the IEP process which was quite overwhelming and sometimes contentious.

To support Karen's academic needs, Mary hired a tutor to come to the house to work on curriculum. Mary also had the responsibility of hiring interpreters for Karen's outside activities and to assist in language development. Mary recognized and accepted that her daughter's

language ability was low. She understood that she could not be her daughter's teacher due to her lack of ability in using ASL to communicate. Mary also knew that her daughter had to work after school with a tutor if she was ever going to catch up to her peers.

Responsibility for Her Own Education

Literature (Hehir, 2005) and the data collected in this case study reveal that an ableist attitude in the school setting does not allow a student with multiple disabilities to receive an equitable education as their peers. However, this ableist attitude can be overcome through the support of other people along with self-determination and self-confidence. A network of people worked with Karen to improve her language and to ensure she was prepared for each upcoming unit. More importantly, Karen set academic goals for herself through confidence in her own abilities and support of her family and friends.

Karen's family valued education and she loved school. Unlike other children, she had no choice but to work after school to keep up with her peers. In her early school years she was labeled a perfectionist and someone who did not like to make mistakes. Through the support of her teachers in her early years, Karen was able to overcome her resistance to try something new. However, she never stopped trying to do her best in the classroom.

Karen was in and out of school due to her bouts with illness and surgery. When she was out of school for long periods of time, she was provided a homebound instructor. Claire Kendrick took on this role as the homebound teacher which was advantageous because the transition from tutor to homebound instructor was seamless. Claire already knew the curriculum Karen was working on and she knew Karen's academic strengths and weaknesses. This allowed Karen to keep up with her class work and transition back into the classroom. Karen never wanted to fall behind in her schoolwork. She also had a lot of people along the way who

believed she could be successful. She had teachers like Ms. Percy, Ms. Mitchell, and Ms. Kendrick who taught her that she was quite capable and helped her build her self-confidence. In contrast, Karen remembers the people who did not believe she was capable of graduating college, much less high school and she was determined to show them differently. Karen needed to be willing to put in the extra work and have the inner drive to do well in school. No one can want this more than the student.

Unexpected Findings

An ableist is defined as someone who marginalizes a person with disabilities and sets low expectations for that person because of their disability. However, another part of the definition of an ableist is to want to make the person with a disability appear more like their peers (Hehir, 2002). When it comes to this part of an ableist attitude, I would have to say that I fit this description when I became Karen's interpreter. I wanted her to know the social norms of the classroom, and I wanted her to fit in with her peers. For example, I played games with other students to have Karen invited into the social circle. I would talk with other children to learn what the cool movie, TV show, or song was at the moment and pass the information to Karen so she could be part of that social conversation. Helping her fit in socially is construed as an ableist practice, however, I felt and still feel that my actions in the classroom were appropriate for Karen's growth. Like her mother, I understood that one day Karen was going to be on her own and she needed to fit into the larger group around her. However, there were times when I helped Karen academically that definitely were inappropriate and a demonstration of an ableist attitude. For example, when Karen was working with a partner on a project, I would let her know if her work was not properly written. I would help her fix up the grammar before she showed her partner the work. Looking back, I should have let her student peer fix up the grammatical

mistakes, or better yet, have the teacher assist Karen. This would have allowed the two to work together and provide the teacher a better understanding of Karen's academic needs. However, I was afraid that student would look down on Karen and her abilities. In the end, I was more concerned about Karen fitting in with her peers that I did not think about the larger implications of her learning from her peers and her peers learning more about her as a deaf student.

Conclusion Regarding the Findings

What can the experiences of a multi-disabled, medically fragile student and her family reveal about the role of ableism in education? My own experiences as an interpreter, teacher, high school principal, along with what I learned from this study lead me to conclude that we can overcome ableism in the school setting and that all students with multiple disabilities can graduate from high school and beyond. There is not one factor that makes a student with multiple disabilities successful. Rather there are multiple factors that interact with each other to assist a person with multiple disabilities "to be able to live independently, be economically self-sufficient, and participate fully in society" (IDEA, 1990). These key factors include a supportive family, an outside educational support team, and the student's own self-determination.

Implications

How do the participants' experiences suggest the need for disability-oriented education in schools today? The experiences of the participants in this study indicate that teachers, regular education students, parents, and students with disabilities would all benefit from diversity-oriented education.

Disability-oriented Education for Teachers

Prior to 1973, a student with disabilities similar to Karen's may not have even received an education. If she did receive an education, there were no opportunities to learn alongside

nondisabled peers. Since, 1973, education has made great strides and school staff has a better awareness of the needs students with disabilities require in school. Teachers are aware of student accommodations and the need to differentiate lessons for every student. The IEPs, psychological and sociological reports that were written for and about Karen shared with teachers her strengths and weaknesses. However, there were times during Karen's education that she was provided appropriate academic supports and her assigned work had to look the same as every other student. With that being said, school staff need to recognize that students with disabilities may not demonstrate their understanding of classroom material the way other students do. Rather, teachers need to create academic supports for students with disabilities so they can demonstrate their understanding of the material.

Relationships with the family are a key to any students' success and this is especially true for students with disabilities. School personnel need to form a partnership with the parents in the education of the student. Karen's life history demonstrates this point through the positive relationships that were formed and the resulting success that Karen found in school. The administrators, Ms. Neill and Ms. Frederick, were key in forming a supportive relationship with Karen and her parents. Both school leaders were open and honest about Karen's abilities and shared with the parents the supports the school was providing to ensure that Karen could be successful in the mainstream classroom. Karen had teachers whom she trusted and this allowed her to build her self-confidence. Ms. Mitchell built a trusting relationship with Karen by listening to Karen which in the end allowed Karen to feel safe and valued in the classroom.

Furthermore, teachers who are slated to teach a child with a disability need to take classes about that specific disability. Morningside Elementary School was a center for all deaf students, but as Karen demonstrated each student can come to the classroom with different abilities and

disabilities. There was a support team in the school to work with the mainstream teacher on how deaf children learn, but the supports for Karen's unique disability were not in the school. The teachers needed to learn about the impact Karen's physical disabilities had on her ability to learn from day-to-day. A great example of a teacher making accommodations for Karen's needs was Ms. Mitchell. She took simple steps such as providing Karen a chair near her group who sat on the floor for instruction and allowed Karen to take on less taxing work when she was tired. Ms. Mitchell thought of the child's needs while still ensuring Karen was able to understand the material. For teachers to learn about the student entering the classroom for the year, administrators need to be cognizant of the amount of time teachers for training, consulting with experts, and planning lessons. Administrators need to support teachers by providing them sufficient time to prepare properly for each child entering the classroom and the disability of that child.

Disability-oriented Education for Students

The lessons about disabilities do not end with educating the teachers. Students also need to be educated and open conversations need to occur with students about disabilities. Students around the country are used to having students with a variety of disabilities sitting in class with them. Although students with disabilities are commonplace in classrooms today, the way students with disabilities are different from their peers is often not discussed. Students need to feel comfortable talking about their differences, which will lead to a better understanding and acceptance of each other. It is the school's responsibility to teach about these differences. In all of my time at Morningside Elementary, the students were only provided lessons on how to sign words. This was achieved through the morning show that was on the closed circuit television. Each day a deaf student introduced a new vocabulary word. This, of course, was minimal. For

students to truly achieve an understanding of deafness and to learn about the variety of physical disabilities, appropriate and progressive lessons should have been provided at each grade level.

Shapiro (1994) suggests students without disabilities also need to be allowed to ask questions about students with disabilities, to have information about aids (such as technology, wheelchairs, or hearing aids) for people with disabilities, and to be able to express their fears and concerns about disabilities. Hehir (2002) suggests educators can end ableism in education. He encourages schools to (a) include disabilities studies as part of a school's diversity efforts, (b) allow students with disabilities to express themselves in ways that work for them, (c) allow special education students to receive the same curriculum as the general education students, (d) demand high standards for every student, and (e) make schools accessible through universal design.

Diversity lessons about disabilities should be provided in school to students just as schools provide lessons about racism, sexism, and heterosexism (Ashby, 2010). Disability advocates support the idea that disability studies should be incorporated into science, literature, and history classes. It is important to teach students for two reasons; (a) because disability will impact every person directly or indirectly at some time in their life; and (b) because people with disabilities are mainstreamed into our society (Taylor, 2004). It is the goal of Section 504, ADA, IDEA, and NCLB to have every student become self-sufficient and productive citizens. It is the responsibility of the schools to see that students are educated about ableism and the abilities of people with disabilities to ensure an equal outcome for everyone (Ashby, 2010; Hehir, 2002; Story, 2007)

Recommendations for Further Research

Karen's life story can offer insight into the education of students with multiple disabilities that would benefit parents, teachers, administrators, and students. This case study of Karen's elementary school could have taken many directions and, at times, it was difficult to keep a narrow lens. There are two areas I would suggest for further research. The first area of research is the impact of ableism on the family members and the second area of study is about the socialization of deaf students with their hearing and deaf peers.

One of the findings indicates that ableism directly impacts the family. The Griffins have four children and two of the children have the same syndrome. Karen's mother faced ableism second hand due to school personnel's lowered expectations of her daughter's ability. The possibilities of research on how ableism impacted this family are great. Some possible ideas for research for the parents of children with multiple disabilities include: the impact on marriage, the impact on household finances, and the impact of the relationship between the parents and the school on the education of the student with disabilities.

Some possible ideas for future research about siblings of children with multiple disabilities include: the stress of siblings of a child with a multiple disability, the relationships between siblings with and without disabilities, types of jobs siblings embark upon due to their siblings disability, the impact on siblings education and socialization during times of hospitalization of their sibling with disabilities.

Socialization is a large part of the elementary school experience. Karen socialized with both deaf and hearing students. As she became older, however, she seemed to prefer socializing with her deaf peers. In third grade, Karen was quite social with everyone. She was friends with deaf and hearing children and was invited for sleep-overs, birthday parties, and play dates with

friends. By the fifth grade, Karen became less social with her hearing classmates and spent more time with her deaf friends in the self-contained classroom. This became evident when Karen left her mainstream class when the lesson was over to go to the WL class to talk with her deaf friends. This period in Karen's education was not addressed in this case study because of Karen's illness during fourth and fifth grade. She became ill in the fourth grade and missed most of the school year. In fifth grade she missed about half of the year due to surgery on her broken thighbone. Because of her long absences, I could not ascertain if she was just more comfortable socializing with her deaf peers or if her friendships with her hearing peers could not be maintained because of being out of school for so long. Research on the trend of who students with multiple disabilities socialize with as they get older would be a topic worth researching.

Concluding Remarks

The Tutor's Concluding Remarks

Claire emphasized that students with multiple disabilities truly do understand what they are learning. When talking about deaf children, in particular, she said they might be delayed in their language, "but that doesn't mean they're stupid and it doesn't mean they can't receive the information....they get what you tell them. You know Karen understood everything" (Personal communication, January 4, 2014).

The Mother's Concluding Remarks

Mary wants people to not underestimate children with multiple disabilities and for teachers to not be afraid to work with the parents of children with multiple disabilities. She said that children with multiple disabilities need to be challenged and they have the ability to learn so much. In regards to teachers, she understands why they can be afraid of parents with children with multiple disabilities. She said there are parents who ask for every accommodation and do

not have a realistic understanding of their child's abilities. But she said she knows it is ultimately her responsibility to educate her child and she was willing to take on that responsibility. She wanted to have a collaborative relationship with the teachers knowing that a positive relationship would benefit her child's education.

The Researcher's Concluding Remarks

Being a part of Karen's life has made a tremendously positive impact on my own personal and professional life. Being a part of her life for all of those years has, in my opinion, made me a more understanding teacher, administrator, and person. When I have to make decisions at school about a student's well-being, Karen is at the center of that decision. In my personal life I have learned to slow down and enjoy the moment and to have compassion for all I come across because you never know the difficulties they face on a daily basis. I am thankful for being able to be a part of such a wonderful, caring family. I truly believe I am the one who has benefitted the most for being a part of Karen's life.

The Student's Concluding Remarks

I will leave the concluding remarks to Karen who said:

I do have a lot of advices to say but I can say one big key thing to be successful like me so far is keep going and fight back to show people that you can do it. You do have support from your loved ones even though you do not feel you have the supports. If you feel you can do it, then go for it. I did went through a lot during my school years and I learned what I can do and can't do by try it. If I don't try, I will keep think "what if, what if" but if I did try, I will think "hey I did try but I can't do it for any reason but it do not mean I'm giving up". You may can do it but in different ways to get same results as others. I need help to keep up with my school works so I can be on track to graduate on

time. Without the help and supports, you may will never finish school or will finish school but not with your class. I never give up and always fight to get the education I need to be successful. I always know that I have supports from all teachers, interpreters, school staff and family to be successful because they believe in me while others are not believe in me. My parents taught me to never give up and to always believe that my future could be whatever I dreamt it to be. Just do what you believe to be successful in school. Never give up on your dream...because you never know what the Lord can bless you with. You need to think whenever you feel like giving up, remember why you held on for so long in the first place. When I was in 1st grade and teacher don't help me a lot and do not think I will graduate from high school with standard diploma and I decided to show her I can do it by keeping think positives. Whenever I feel I want to give up in early college years, I have the moment when I think of 1st grade teacher's comment. It always boost my confidence and stay in college. Now I'm about to graduating in December 2014, I do not want to leave college and I am already start to thinking to get master degree. I want to say thank you everyone who supported me from start to now. It will never enough to pay back for how much I'm thankful to have a lot of support teams. People who is ready to giving up please think how it can help you in future. Never, never, never, give up (K. Griffin, personal communication, July 13, 2014).

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APPENDICES

Appendix A Karen's Consent Form

Appendix B Mary's Consent Form

Appendix C Claire's Consent Form

Appendix D List of Interviews and Meetings

Appendix E Reflexive Journal Protocol

Appendix F Calendar of Data Collection Activities with Analytic Tool Notations

Appendix A Karen's Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants in Research Projects Involving Human Subjects

Title of Project: Interview of a Multi-handicapped

Investigator(s): Ellen T. Reilly, Doctoral Student

I. Purpose of this Research/Project

The purpose of this study is to interview you, Karen, about your life as a deaf, multi-handicapped student matriculating through the educational system.

- Anthropological study
- Teachers, interpreters, and administrators impact on student's success in the classroom
- Parent advocacy
- Impact on siblings
- Depression in multi-handicapped people
- Isolation during school years of multi-handicapped students

II. Procedures

The interviews will take place at your home or at any location you choose to be interviewed. The interviews will last as long as you remain comfortable and as time permits. The interviews will be videotaped.

I will use an open-ended interview for our interviews. I will focus on your academics (elementary through high school), medical condition, socialization with peers, faith, and family. To start I will interview you about your memories of each grade, talk about teachers, interpreters, friends, and overall memories of those years. We will then review a time-line of your major hospitalizations and the impact of that on your academics, health, family, relationships with peers, and your faith.

I will ask questions such as:

- Which teachers make a positive impact on you during your elementary years? Why and how were they not supportive?
- Do you remember teachers or interpreters who were not supportive of you during elementary school? Who and how were they not supportive?
- How were you able to keep up with schoolwork when you were not in school for a good portion of the school year?
- What is your motivation for continuing your education

- Do you remember being involved in team sports before becoming wheelchair bound? Share those memories and why was participating with these teams important to you?

III. Risks

There are no physical risks to you during the interviews. If you become tired, you need to tell me, the investigator, to stop the interview. You may cancel scheduled interviews at any time through text messaging or e-mail.

IV. Benefits

One of the objectives to interviewing you is for you to be able to document your educational years and preserve your story for your family and friends. No promise or guarantee of benefits has been made to encourage you to participate.

The overall benefit is to assist educators on how to educate and include multi-handicapped students in the school environment.

V. Extent of Anonymity and Confidentiality

Your name will be changed in all writings. There is the possibility that people will be able to identify you from stories in the final product.

The videotapes of the interviews will be stored on my, Ellen Reilly's, computer. There will not be any other duplicates of the interviews nor will the interviews be sent to any other person.

VI. Compensation

You will not receive any compensation during this process.

VII. Freedom to Withdraw

You are free to withdraw from the project at any time.

VIII. Subject's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities:

- Be available to be interviewed for the next year
- To be videotaped during every interview
- Inform the investigator when I would like to be interviewed
- Inform the investigator when I would like the interview to stop

IX. Subject's Permission

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

_____ Date _____
Subject Signature

Should I have any pertinent questions about this research or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

Ellen T. Reilly

Investigator

Dr. Kami Patrizio

Faculty Advisor

Departmental Reviewer/Department Head

Telephone/e-mail

Appendix B Mary's Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants in Research Projects Involving Human Subjects

Title of Project: Interview of a Multi-handicapped

Investigator(s): Ellen T. Reilly, Doctoral Student

X. Purpose of this Research/Project

The purpose of this study is to interview you, Marie, about your daughter's, Karen, life as a deaf, multi-handicapped student matriculating through the educational system.

- Anthropological study
- Teachers, interpreters, and administrators impact on student's success in the classroom
- Parent advocacy
- Impact on siblings
- Depression in multi-handicapped people
- Isolation during school years of multi-handicapped students

XI. Procedures

The interviews will take place at your home or at any location you choose to be interviewed. The interviews will last as long as you remain comfortable and as time permits. The interviews will be videotaped or audiotaped.

I will use an open-ended interview for each person interviewed. I will focus on Karen's academics (elementary through high school), medical condition, socialization with peers, faith, and family. To start I will interview you about your memories of each Karen's experiences in each grade level, talk about teachers, interpreters, friends, and overall memories of those years. We will then review a time-line of Karen's major hospitalizations and the impact of that on her academics, health, family, relationships with peers, and her faith.

I will ask you questions such as:

- What was Karen's diagnosis as an infant?
- How did you learn American Sign Language (ASL)? Did your family members learn ASL? How did you model language for Karen?
- When it comes to academics, how did you assist Karen in her education when you may not have had the language to assist her?
- Was religion an important part of your family? If so, how?
- What were the effects of Karen's syndrome on your other children?

XII. Risks

There are no physical risks to you during the interviews. If you become tired, you need to tell the investigator to stop the interviews. You may cancel scheduled interviews at any time through text messaging or e-mail.

XIII. Benefits

One of the objectives to interviewing you is for you to be able to document your daughter's educational years and preserve her story for her family and friends. No promise or guarantee of benefits has been made to encourage you to participate.

The overall benefit is to assist educators on how to educate and include multi-handicapped students in the school environment.

XIV. Extent of Anonymity and Confidentiality

Your name will be changed in all writings. There is the possibility that people will be able to identify you from stories in the final product.

The videotapes of the interviews will be stored on my, Ellen Reilly's, computer. There will not be any other duplicates of the interviews nor will the interviews be sent to any other person.

XV. Compensation

You will not receive any compensation during this process.

XVI. Freedom to Withdraw

You are free to withdraw from the project at any time.

XVII. Subject's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities:

- Be available to be interviewed for the next year
- To be videotaped during every interview
- Inform the investigator when I would like to be interviewed
- Inform the investigator when I would like the interview to stop

XVIII. Subject's Permission

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

_____ Date _____
Subject Signature

Should I have any pertinent questions about this research or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

Ellen T. Reilly

Investigator

Telephone/e-mail

Dr. Kami Patrizio

Faculty Advisor

Telephone/e-mail

Departmental Reviewer/Department Head

Telephone/e-mail

David M. Moore

Chair, Virginia Tech Institutional Review
Board for the Protection of Human Subjects
Office of Research Compliance
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, VA 24060

Appendix C Claire's Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants in Research Projects Involving Human Subjects

Title of Project: Interview of a Multi-handicapped

Investigator(s): Ellen T. Reilly, Doctoral Student

XIX. Purpose of this Research/Project

The purpose of this study is to interview you, Claire, about Karen's life as a deaf, multi-handicapped student matriculating through the educational system. You tutored Karen from the 1st grade and all the way through high school.

- Anthropological study
- Teachers, interpreters, and administrators impact on student's success in the classroom
- Parent advocacy
- Impact on siblings
- Depression in multi-handicapped people
- Isolation during school years of multi-handicapped students

XX. Procedures

The interviews will take place at your house or at any location you choose to be interviewed. The interviews will last as long as you remain comfortable and as time permits. The interviews will be videotaped or audiotaped.

I will use an informal conversational interview for our interviews. I will focus on your memories of Karen's academics (elementary through high school), medical condition, socialization with peers, faith, and family. To start I will interview you about your memories of Karen's experiences in each grade level, talk about teachers, interpreters, friends, and overall memories of those years. We will then review a time-line of Karen's major hospitalizations and the impact of that on her academics, health, family, relationships with peers, and her faith.

I will ask questions such as:

- How did you come to tutor Karen after school hours?
- When Karen's mother had disagreements with the school about her IEP, did you ever feel there was a conflict between tutoring Karen and working for the school system?

XXI. Risks

There are no physical risks to you during the interviews. If you become tired, you need to tell me, the investigator, to stop the interviews. You may cancel scheduled interviews at any time through text messaging or e-mail

XXII. Benefits

One of the objectives to interviewing you is for you to be able to document Karen's educational years and preserve her story for her family and friends. No promise or guarantee of benefits has been made to encourage you to participate.

The overall benefit is to assist educators on how to educate and include multi-handicapped students into the school environment.

XXIII. Extent of Anonymity and Confidentiality

Your name will be changed in all writings. There is the possibility that people will be able to identify you from stories in the final product.

The videotapes of the interviews will be stored on my, Ellen Reilly's, computer. There will not be any other duplicates of the interviews nor will the interviews be sent to any other person.

XXIV. Compensation

You will not receive any compensation during this process.

XXV. Freedom to Withdraw

You are free to withdraw from the project at any time.

XXVI. Subject's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities:

- Be available to be interviewed for the next year
- To be videotaped during every interview
- Inform the investigator when I would like to be interviewed
- Inform the investigator when I would like the interview to stop

XXVII. Subject's Permission

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

_____ Date _____
Subject Signature

Should I have any pertinent questions about this research or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

Ellen T. Reilly
Investigator

Telephone/e-mail

Dr. Kami Patrizio
Faculty Advisor

Telephone/e-mail

Departmental Reviewer/Department Head

Telephone/e-mail

David M. Moore
Chair, Virginia Tech Institutional Review
Board for the Protection of Human Subjects
Office of Research Compliance
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, VA 24060

Appendix D List of Interviews and Meetings

Interview Schedule with Karen

Date	Location	Length	Interviews	Topic
January 20, 2012	Karen's house in kitchen	25 mins.	Individual	Family history; illness; pre-school–grade 2
February 24, 2012	Karen's house in kitchen	39 mins.	Individual	Grades 3-4
April 6, 2012	Karen's house in sunroom	25 mins.	Individual	Grades 5-6
April 15, 2012	Karen's house in kitchen	96 mins.	Karen and her mother	Review of timeline

Interview Schedule with Other Participants

Date	Location	Length	Interviews	Topic
April 1, 2014	Ellen's house in dining room	mins.	Individual with Mary	Family history; illness; birth – 6 th grade
January 4, 2014	Local restaurant	mins.	Individual with Claire	Personal history, K-12 th grade

IEP Meeting – June 1995

Date	Location	Length	Interviews	Topic
July 19, 1995	Morningside Elementary	120 mins.	List all people in attendance and change names	Placement of Karen, hours of services

Appendix E Reflexive Journal Protocol

Date:

Participants:

Location:

Facilitator:

Protocol

1. Self Reflexivity

Prompts: "What do I know? How do I know what I know? What shapes and has shaped my perspective? How have my perceptions and my background affected the data I have collected and my analysis of those data? How do I perceive those I have studied? With what voice do I share my perspective? What do I do with what I have found?" (Patton, 2001, p. 495)

2. Reflexivity About Participants

Prompts: "How do those studied know what they know? What shapes and has shaped their world view? How do they perceive me, the inquirer? Why? How do I know?" (p. 495)

3. Reflexivity About Audience

Prompts: "How do those who receive my findings make sense of what I give them? What perspectives do they bring to the findings I offer? How do they perceive me? How do I perceive them? How do these perceptions affect what I report and how I report it?" (p. 495)

(Patton, 2001)

Appendix F Calendar of Data Collection Activities with Analytic Tool Notations

Interview Schedule with Karen

Date	Location	Length	Interviews	Topic
January 20, 2012	Karen's house in kitchen	25 mins.	Individual	Family history; illness; pre-school–grade 2
February 24, 2012	Karen's house in kitchen	39 mins.	Individual	Grades 3-4
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IEP Meeting – June 1995

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Documents – Pre-School Notes from Teacher

Code	Grade/Date	Document	Topic
KA_D_LET	November 2, 1992	Teacher narrative	Academic progress
KB_D_LET	February 9, 1993	Teacher narrative	Academic progress
KC_D_LET	April, 1993	Teacher narrative and IEP checklist	Academic progress
KD_D_LET	June, 1993	Teacher narrative and IEP checklist	Academic progress

Documents - Pre-School/Kindergarten

Code Grade/Date	Document	Topic
PKA_D_IEP March 18, 1992	IEP signed	Annual goals and short-term objectives
PKB_D_PSY May 1, 1992	Psychological Report	Psychological evaluation
PKC_D_IEP June 3, 1992	IEP signed	Annual goals and short-term objectives
PKD_D_HT	Hearing test	Results from hearing test
PKE_D_IEP June 22, 1993	IEP signed	Annual goals and short-term objectives
PKF_D_RC January 1994	Report Card	Grades with narrative from teacher
PKG_D_TRI February 2, 1994	IEP signed	Triennial - Annual goals and short-term objectives
PKH_D_RC June 1994	Report Card	Grades with narrative from teacher

Documents - First Grade

Code Grade/Date	Document	Topic
1A_D_IEP June 1, 1994	IEP Signed	Annual goals and short-term objectives
1B_D_TRI January 14, 1995	Triennial reevaluation consent form	Eligibility explanation, consent signature
1C_D_REF January 13, 1995	Multi-Purpose Referral Form	Statement of concern written by first grade teacher
1D_D_REC March 17, 1995	Confidential Student Records Release	Eligibility Packet/Intervention Checklist/Sociocultural Assessment-Triennial Review/Psychological Report/Intelligence tests/Educational Evaluation/Teacher Narrative/Student Observation/Health Examination/Hearing Tests/Speech and language evaluation/Physical therapy evaluation/Physical disabilities assessment/Adapted PE evaluation
1E_D_IEP April 5, 1995	IEP Draft unsigned	Annual goals and short-term objectives
1F_D_IEP May 23, 1995	IEP Draft unsigned	Annual goals and short-term objectives
1G_D_LET	Orthopaedic Outpatient Consultation	Letter from doctor on physical progress
1H_D_IEP July 19, 1995	IEP signed	Annual goals and short-term objectives
1I_D_RC June 16, 1995	Report Card	Grades for all four quarters with teacher comments
1J_D_LET June 5, 1995	Letter to Acting Principal	Letter from parents to express concern of IEP
1K_D_LET June 20, 1995	Letter to Superintendent of School	Letter from parents to express concern of IEP
	Letter to State	

1L_D_LET June 26, 1995	Representative	Letter from parents to express concern of IEP
1M_D_REC November 23, 1995-June 9, 1996	Notes from teachers to parents	Notes on academic progress, socialization, and use of interpreter.

Documents – Fourth grade

Code Grade/Date	Document	Topic
4A_D_LET October 5, 1998	Letter form parents to principal	Fieldtrip without accommodation

Documents – Fifth grade

Code Grade/Date	Document	Topic
5A_D_LET December 22, 1999	Doctor's letter	Letter explaining medical plan after back surgery
5B_D_LET April 26, 2000	Letter from parent to teacher	Science test and 3 rd quarter report card issues
5C_D_LET March 29, 2000	Science Test	Karen's graded science test
5D_D_RC June, 1993	3 rd quarter report card	Grades from 1 st and 2 nd quarter/3 rd quarter grades in question
5E_D_LET	Letter from teacher to parent	Response about science test and report card
5F_D_RC	Revised report card for 3 rd quarter	3 rd quarter report card with grades
5G_D_IEP April 2000	Progress of annual goals	quarterly review

Documents – High school report cards

Code Grade/Date	Document	Topic
9A_D_RC June 18, 2004	Report card	9 th grade final grades
10B_D_RC June 24, 2005	Report card	10 th grade final grades
11C_D_RC June 20, 2006	Report card	11 th grade report card

Documents – High school Standard of Learning (SOL) results

Code Grade/Date	Document	Topic
9A_D_SOL Spring 2004	SOL Results	World History I/Algebra/Biology
10B_D_SOL Spring 2005	SOL results	World History II/Geometry results
11C_D_SOL Spring 2006	SOL results	English Writing (2002 stds)/Algebra II/English Reading (2002)/VA \$ US History (2001) results
11D_D_REP	ACT Assessment Student Report	ACT scores
11E_D_REP August, 2006	Career Assessment Report	Report of possible career interests

Analytical Tool Notations

The code for interviews was: (Interview)(initial of interviewee)_(date of interview).

Example: IK_May16

The code for documents was: (Document)(Alphabetical order in collection)_(grade level)_(Type of document).

Example: DA_1_REC.

The following Codes for documents were used:

D- Document

LET – Letter

I - interview

TRI – Triennial

REC- Record

RC – Report Card

IEP – Individual Education Program

REF – Referral