INCLUSION, INSTRUCTION, AND EDUCATION OF OTHERS: A
PHENOMENOLOGICAL STUDY OF SIBLINGS WITH AND WITHOUT
DISABILITIES AND THEIR TEACHERS

by

ELIZABETH WILLIAMS DURBIN

A Dissertation Submitted to the Faculty
in the Curriculum and Instruction Program
of Tift College of Education
at Mercer University
in Partial Fulfillment of the
Requirements for the Degree

DOCTOR OF PHILOSOPHY

Macon, GA

2019
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DEDICATION

I dedicate this dissertation project to my brother, Sam, and my sister, Donna. Sam you have pushed me to always learn more and to work hard. Your perseverance to meet your goals and dreams make me always want to meet mine. You make me so proud to be your sister. Donna, you are the reason why I decided to pursue this degree. You are my heroine. You teach me daily that love, kindness, empathy, and grit are the things that will help me reach my goals. You have given me the courage to advocate for people with Down syndrome and other disabilities in an effort to include them in all aspects of life. You have taught me how to love unconditionally.
ACKNOWLEDGMENTS

First, I would like to thank my Mom and Dad, Rita and Don. You have always supported me and my dreams and encouraged me to keep going even when I felt like I was never going to get there. Without your help, I would not be where I am. I love you both.

Second, I would like to thank my loving and supportive husband, Randy. Through all that life has brought us, you continued to encourage me to finish. You fielded all of my theoretical thoughts, you debated with me to make me think critically about what I was doing, and you gave me the quiet I needed to write. You have been my rock through this entire experience, and I am forever grateful for your love and support.

Finally, I want to thank all of my committee members. I have known Dr. Augustine for the better part of 15 years, and without her encouragement, I would not have had the guts to start a Ph.D. Dr. West, you have put me through the paces with my data, and I have learned so much from you. I would not have found all of the nuances in my data if you had not insisted I was not done with my data yet. Dr. Carr, you have been my biggest cheerleader through this whole process. You stuck with me when I stalled and lost motivation. You encouraged me to read more and learn more to expand my knowledge about disability theory. You always knew what questions to ask to get me going again. I cannot thank all of you enough for teaching me, encouraging me, and supporting me.
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ABSTRACT

ELIZABETH WILLIAMS DURBIN
INCLUSION, INSTRUCTION, AND EDUCATION OF OTHERS: A
PHENOMENOLOGICAL STUDY OF SIBLINGS WITH AND WITHOUT
DISABILITIES AND THEIR TEACHERS
Under the direction of SHERAH BETTS CARR, Ph.D.

Due to the increased push for inclusion in the United States, siblings with and without disabilities have been attending the same public schools. They share many of the same experiences. This study aimed to understand how the shared school experiences affected siblings and the teachers who work with these siblings. Through a phenomenological study design, the researcher conducted interviews with sibling groups comprised of siblings with disabilities and siblings without disabilities, general education teachers, and special education teachers to reveal the lived experiences of sibling groups and their effect on teacher involvement and instruction.

Three themes emerged from the data: valuing differences, responsibilities, and growth. The findings indicated that siblings without disabilities hold a unique position to influence and educate their peers about individuals with disabilities. Teachers also hold a unique position to create lessons and opportunities for siblings without disabilities that promote sharing their thoughts of, and experiences with, individuals with disabilities. This, in turn, influences the way other people interact with individuals with disabilities. These findings, consistent with current research in the area of school perception of disabilities, implicate the need for further study in the area of teachers and siblings
without disabilities working together to create more and better opportunities for inclusion of people with disabilities.
CHAPTER 1

INCLUSION, INSTRUCTION, AND EDUCATION OF OTHERS

When I was new to my doctoral program, I mustered the courage to give a presentation at a statewide conference for education. I decided to give a presentation on how my sister Donna, who is a woman with Down syndrome, and I have supported one another through our experiences growing up. I chose to give this presentation in conjunction with my sister because I felt that all too often people with disabilities are not asked how they feel or what they think, and her input was important to me. I wanted my audience to know how important it was to me, but to feel it as well.

As she and I worked on this presentation and discussed our experiences with one another, I realized that we never had the opportunity to share school. We shared so many events together—from special Olympics every summer to my soccer tournaments—but school was something that was separate. I began to imagine what that experience might have been like for us as sisters. I really questioned if our family dinner conversations would have been different. Would I have felt pressure at school to include my sister? These speculations would never lead me personally to an answer because we have both completed our secondary experiences, but I did wonder if I could answer these questions for my students in my classroom and their siblings in general education.

From that moment, I knew I needed to study the shared experiences of siblings with and without disabilities. Since there was a gap in my knowledge on this subject as a
teacher, I postulated there might be a gap in the literature that I could fill with these answers to give me an idea of what these experiences might be like for other siblings. The following pages use research to discover how being a sibling in school with a sibling with a disability might affect the experiences of both siblings. This research has brought me as close as I will come to answering my own personal questions about what could have made my sister’s time in school even more productive.

Background of the Problem

Education is a means of providing equality to all people and giving access to knowledge and privilege (Ferri & Connor, 2005). However, privilege and knowledge have not always been accessible to all people based on color, ability, and intellectual functioning (Nielsen, 2012). According to Ford and Whiting (2016), “systematic denial of education” (p. 121) was a way to keep people marginalized. People with disabilities have long been a group particularly marginalized because of their inability to fully participate in education (Kliewer, Biklen, & Kasa-Henrickson, 2006), since their perceived inabilities perpetuated their role in their societal marginalization.

The idea of disability being born of an inability to physically or mentally perform a useful societal function has shaped the way people view those with disabling impairments. Lightfoot (2015) contended that ableism “in the context of disability means that certain physical, cognitive, sensory, or other types of abilities are preferred, and people who have differing abilities are considered impaired” (p. 446). Ableism has marginalized groups of people with various disabilities and labeled them as incapable, suffering individuals who deserve pity and sympathy, rather than empathy,
understanding, and support to function like those without a disability (Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010; Nielsen, 2012). The desire to change the way people with disabilities function in society, alter societal perceptions, and improve the amount of support they receive has been the impetus for theoretical considerations and concrete actions that have evolved into disability theory. This theory ultimately aims its discourse around the description and betterment of life for people with disabilities. This discourse is both critical and post structural in nature, and both paradigms have proven effective in illuminating many of the issues that people with disabilities and their families face (Siebers, 2011).

Disability theory evolution notwithstanding, the historical (dis) abling of people with disabilities is still reflected in many parts of society in the United States (Sherry, 2010). School personnel, for example, still struggle with positive inclusion of students with disabilities. Shogren and colleagues (2015) credited the negative attitudes of some teachers involved in inclusion as an indirect influence of peer perception of students with disabilities.

Both school personnel and families hold unique positions of influence on how society views disability. Furthermore, siblings of an individual with disabilities often affect peer perceptions of that sibling (Cox, Marshall, Mandleco, & Olsen, 2003; Floyd, Purcell, Richardson, & Kupersmidt, 2009), thereby impacting the family and the school. The nature of the relationships they form with family and friends can influence the view of school members on disability by actively supporting (or not supporting) disability through their choice to be involved with their disabled sibling at school (Floyd et al.,
They can choose to educate their peers about their sibling, or they can choose to deny, or simply fail to acknowledge, that they have a sibling with a disability altogether. This type of influence can ultimately translate to their contacts throughout each stage of life, thereby influencing society as a whole.

Statement of the Problem

After completing a review of old and current literature in the area of sibling studies for families inclusive of a person with disabilities, I determined that much of the research focused on the family, specifically, the ideas of the parents or on the nondisabled sibling. Many of the researchers reported on the parents’ feelings of maladjustment of their children without a disability and concentrated on the lack of social skills and the potential societal problems faced by the nondisabled sibling (Findler & Vardi, 2009). Also discussed were the multifaceted challenges the nondisabled sibling faced because of the sibling with a disability. These studies placed the siblings at odds with one another or centered on the families’ difficulties in dealing with the child or sibling (Harris & Fong, 1985). The seemingly negative focus in this research area appeared to place blame on the siblings with disabilities for the problems of their nondisabled siblings. This negativity also translated to studies conducted on school personnel’s perceptions of how to work with the nondisabled siblings (Lobato et al., 2011).

The perceptions of secondary school personnel play an important role for most students (Shogren et al., 2015), possibly affecting their perceptions of self and peers across all grade levels, but particularly in the secondary setting. It gives them a sense of belonging and importance as they learn and grow into adults and challenges them to think
critically about many societal aspects within a safe space of learning. These perceptions also play a role within families, especially those with multiple children in the same school, by providing topics of conversation and debate when the siblings are together that lead to the development of a sense of togetherness shared by the siblings (Shogren et al., 2015). It is unclear how the perceptions of school personnel regarding disability affect the sibling groups consisting of siblings with disabilities and how their teachers’ perceptions could also play a role in their relationship.

While researchers have focused on the parents and the maladjustment of the siblings (Breslau, Weitzman, & Messenger, 1981; Cox et al., 2003; Hannah & Midlarsky, 1999; Harris & Fong, 1985), few have focused on the voice of disability from the perspective of the sibling with a disability. This voice and power could prove to be helpful in the continued discourse of disability theory and of research framed in a lens of support for families and siblings.

**Purpose of the Study**

Teachers’ perceptions of disability in the secondary setting play an important role in how students perceive themselves, their peers, and their siblings (Kugelmass, 2006). However, little is known about the perceptions of sibling groups inclusive of a person with a disability attending the same school and the effect their relationship may have on their teachers, classroom instruction, and their peers. Through the use of phenomenology, this study aimed to develop knowledge in that area by interviewing teachers, siblings with disabilities, and siblings without disabilities to determine their lived experiences within this phenomenon.
Research Questions

The following research questions guided this study:

1. How do students and teachers’ perception of disability inclusion in a secondary setting influence the school experience of siblings with and without disabilities?

2. When working with one member of a sibling group, how do teachers modify their instruction to support the siblings?

Methods

Researchers have utilized a variety of methodologies, both quantitative and qualitative, to investigate the family dynamic of those including a person with a disability (Findler & Vardi, 2009; Floyd et al., 2009; Hannah & Midlarsky, 1999; Kramer, Hall, & Heller, 2013; Lobato et al., 2011). However, a conclusive search of research determined that very little qualitative research exists regarding sibling studies in a school-based setting. Therefore, I designed a qualitative, phenomenological study to target the secondary high school setting because I sought to understand a phenomenon that occurs through the experiences of the participants (Creswell, 2013).

For the purposes of this study, to gain greater understanding of their experience with disability and to learn how these experiences affect the sibling relationship and school achievement when they are inclusive of a sibling with a disability, I interviewed students with significant intellectual delays or autism and their siblings without disabilities. I also investigated teacher perceptions of disability as well as the possible
influence on instruction due to knowledge of working with a sibling of an individual with a disability.

The data for this study was generated in two ways from three groups of siblings and five teachers in order to appropriately triangulate possible emergent themes (Hoyo-Oliver & Allen, 2006). The first method of collection was comprised of interviews with teachers to determine their perceptions of disability and how the relationship of siblings, when they are a part of a sibling group inclusive of a person with a disability, affects their classroom instruction and the possible achievement of the siblings. The second data collection derived from interviews with all of the siblings, with and without disabilities, to gain their perceptions of the phenomenon under study.

Significance of the Study

This study revisited much of the research already conducted on sibling groups with people with disabilities. However, it adds to the relevant literature by examining the sibling relationship at school and utilizing an educational point of view. Much of the research in the area of sibling studies within the disability perspective focused on the maladjustment of the siblings without a disability. Instead of using a “yours and mine” approach to analyzing the relational aspects of siblings, this study sought to determine if shared school experiences were available to all siblings, with and without disabilities.

A smaller, but significant, part of this study attempted to give a greater voice to the siblings with a disability in hopes of increasing better understanding between the siblings. This was accomplished by giving each sibling with a disability a more intimate one-on-one interview session using their form of alternative, augmentative
communication devices (AAC) so that they were better understood. These devices were both high technology devices, such as programs on tablets with vocal output and low technology devices that were in the form of yes, no, and stop pictures printed on paper. Due to difficulties with communication, some of the siblings with disabilities required a communication facilitator, such as a sibling or a parent. This led to the potential for surrogacy of thought or for a total change in answer because the presence of a family member might have swayed answers in hopes of pleasing or not offending the facilitator. Although research has been conducted on siblings with and without disabilities, there is a lack of research on the perspectives of the sibling with a disability (Meltzer & Kramer, 2016). This study helped fill that gap in the literature.

Assumptions

It is necessary to address three assumptions of this study regarding the sibling relationship that does not hold true for all sibling relationships. First, the sibling relationship is one that is life-long and often outlasts the relationship children have with their parents (Lohmann, 2014). Knowing this to be true about most sibling groups, the siblings at some point in their lives support one another. It may not be direct care or help within the timeframe or the context of school, but in some way, siblings will support each other. Second, due to the length of the sibling relationship and the nature of growing up together, I assumed that, regardless if the relationship is perceived as positive or negative, all siblings at some point have a shared experience that they can relate to other people, or an experience that causes them to feel an emotion towards their sibling. Finally, siblings who attend the same school are affected by the school personnel’s perception of
disability. This perception of disability shapes who they are and how they perceive the world as they grow. These perceptions also have an effect on how a student sees groups of people within their school, and this perception in turn affects their relationships with peers and with family members. In this study, I assumed that school personnel perceptions affected the sibling relationship in some manner.

Delimitations/Limitations

Some limiting factors potentially affected the outcome of this study. The study site choice, a suburban school in north Georgia, was a delimitation because it limited the diversity of thought of the participants who attended a single school. Furthermore, this possibly played a limiting role in my ability to find sibling groups who were diverse in race and socioeconomic status.

In addition, this study was delimited to ninth- through twelfth-grade students in high school, ranging in ages from 15-21 years, due to the legal right of people with disabilities to stay in school until their 21st birthday afforded by the Individuals with Disabilities Education Act (IDEA). Developmentally, teenagers often feel estranged from adults because they struggle in that difficult age of not being perceived as an adult, but desiring to be one. As a result, some of the siblings in this age range may have been hesitant to reveal their perceptions of disability and their siblings. Furthermore, they may have felt as if they were betraying their family or siblings to speak openly about their positive or negative experiences. In turn, this possibly made them feel protective of their feelings and protective of their sibling.
A limitation for the participants with disabilities may be their inability to answer the questions physically, either verbally or with access to an augmentative and alternative communication device (AAC) that can speak for them. The intent of these devices is to assist the person with a disability to speak and make clear their thoughts. However, depending on the cognitive or physical disability of the person, these devices may have limited abilities to assist as well. I provided these participants an alternative option for communication, or during the interview process, offered modified questions with limited answering options that would be in the same spirit of questions asked of others with the abilities to provide full explanation. This was noted when coding and reporting the interviews in order to give adequate power to that particular voiced opinion.

The last limitation was my personal experience with disability. I am a sibling of a sister with Down syndrome, and I greatly desire a world where my sister receives equal opportunity and rights to thrive. While I attended a private school, my sister attended a public school with adequate programs to meet her needs. Our high school career overlapped by a year or two, and given the opportunity, I would have liked to have shared that experience with my sister. I sometimes assume that all siblings who have a sibling with a disability should have positive relationships with that sibling. I bracketed this personal assumption (Husserl, 1931/2002), but it also provided a partial lens through which I conducted this research.

Definition of Terms

The following terms are provided to assist the reader:
Ableism is the discrimination of people with disabilities. It is the understanding that, because of their disability, individuals lack the perceived ability to participate in society; thus, they are largely excluded as worthless individuals (Linton, 1998; Neely-Barnes et al., 2010; Storey, 2007).

Augmentative and alternative communication device (AAC or Aug Com) is a device often used by people with disabilities to enhance or aid in communication with others.

Disability can be disaggregated into two parts: (dis) and (ability). According to the Merriam-Webster (2019) dictionary, (dis) means to do the opposite of and (ability) means competence in doing. In placing those two parts together, disability insinuates that a person lacks a competence in doing. Deconstructing the word can further imply that people with disabilities are not able to do within the setting of society. Sherry (2010) offered a definition in the social model of disability: “Impairment is defined as a biological, cognitive, sensory, or psychiatric difference . . . and disability is the negative social reaction to those differences” (p. 94). For the purposes of this study, I used a combination of the social definition of disability by Sherry (2010) and the one proffered by Freeman et al. (2006) that describes significant disabilities as cognitive, sensory, and motor impairments that make it difficult to communicate with adults or peers. This is apt since I conducted this study with students who exhibited multiple impairments and disabilities.

Nondisabled siblings or siblings without disabilities (SWO) are siblings without disabilities.
Others can be referred to in two ways. The first being the traditional definition found in the Merriam-Webster (2019) dictionary, the thing opposite to, different. The second definition is one used to describe a person on the margins of society or not included in the societal group. This dichotomy was found in many writings by Derrida (1973; 1976).

Shared experience, in this study, refers to any experience jointly witnessed or participated in by the sibling subjects.

Siblings/siblinghood refers to brothers or sisters, biological or adopted from the same family, who have a life-long relationship with the capacity to influence one another (Lohmann, 2014; Meltzer & Kramer, 2016).

Sibling with a disability (SW) is any sibling possessing impairment as defined by Sherry (2010) and Freeman et al. (2006) (refer to the definition of disability).

Summary

People with disabilities have been placed on the outskirts of society. In the past, little has been done to ensure that people with disabilities have opportunities to contribute to society in a meaningful way. Recently, however, people with disabilities have taken greater part in larger societal roles, such as attending schools, participating in the school community, and finding jobs with positions that leverage their strengths.

The purpose of this study was to examine the role of people with disabilities within the school personnel perception of disability and to determine if they have shared experiences with their siblings that directly affect their relationship. This study also sought to provide an equal voice for those participants who have a disability by
encouraging them to voice how they feel about their school and their relationships with their siblings. Finally, this study investigated teacher perceptions of disability and the influence of siblings in the school environment on teacher instructional practices. Despite limitations that potentially influenced the results, this study addressed a gap in the literature and furthered the research in disability theory and sibling studies. Chapter 2 provides detail on both of those subjects and reveals the gap in the literature.
Following *A Special Message to Congress on Mental Illness and Mental Retardation* by John F. Kennedy in 1963, a large number of people with disabilities moved from institutions to their homes and communities (Kennedy, 1964). Community members and families were ill equipped to deal with the needs of the individuals with disabilities (Nielsen, 2012). Although integrated into public schools, these individuals attended separate classrooms, and teachers received little training on how to educate these students (Dunn, 1968). Families and school personnel began working together to find ways to educate these students. Private family counseling outside of the school environment provided greater support of the needs of families, for it proffered much needed parental and sibling support.

The passage of the Education for all Handicapped Children Act in 1975, later renamed the Individuals with Disabilities Act (IDEA), mandated the provision of “a free and appropriate education for all children . . . in the least restrictive environment” (Torreno, 2010, para. 5). This requirement led to inclusion of disabled individuals in the general education classroom and spurred research on best practices to educate students with disabilities (National Council on Disabilities, 2018).

However, many studies focused on the maladjustment of the nondisabled sibling. It was not until the 1990s that researchers focused on supporting the siblings of people
with disabilities from the perspective of the siblings (Dyson, 1998). Researchers finally turned to the school setting for improving the sibling relationship.

The effects disability has on families, communities, and schools appear as a subject that requires extensive research to answer pertinent questions of how society deals with a person with a disability and their families. This study sought to determine how school culture affects disability. The following questions were posed to help ascertain what school personnel can do to help students with disabilities and their nondisabled siblings and create a space of support and inclusion:

1. How do students and teachers’ perception of disability inclusion in a secondary setting influence the school experience of siblings with and without disabilities?

2. When working with one member of a sibling group, how do teachers modify their instruction to support the siblings?

The following literature review addresses research pertinent to disability in schools, community, and family. The chapter begins with a description of the search strategy, followed by a discussion of inclusion into society and schools through the lens of disability theory. The review reveals the gap in the literature and showcases the entre of the study addressed in later sections.

Search Strategy

When deciding to pursue a study based on shared sibling experiences of groups of siblings that include a person with a disability, I determined the best search strategy that would provide the breadth of the literature’s history, along with the specificity and dearth
of literature on my specific topic. This project’s search strategy progressed from a simple search of single, relevant terms to a compilation of articles gained from subsequent combined-phrase searches, followed by a critical review of notionally relevant articles and a focused ascertainment of the appropriateness of inclusion or exclusion from my literature review. Relevant articles were examined for other relevant sources that may not have appeared in my rudimentary search. I refined my search strategies to accommodate the presence or lack of relevant results and created a summary of those searches.

Since this study is rooted in curriculum and instruction, I conducted a broad review of topics pertaining to education. Subsequently, I focused on school culture and its effects on the siblings (disabled and nondisabled) while in the same school. The following five search terms were the basis of initial searches with several combinations eventually used to compile a relevant compendium of extant research.

- Disability
- School culture
- Siblings
- Siblinghood
- Teachers

Utilization of the EBSCO tool on the Mercer University libraries site, and subsidiary searches on the broader Internet via Google Scholar, led to the discovery of the majority of the articles related to this topic. The original search was not limited to specific years of publication, although the relevant peer-reviewed publications ultimately
referenced in this review range from 1960 to the present. Also excluded from the final research were international articles due to the limited relevance of such research with regard to culture, educational systems, and public policies in the United States.

Some search terms yielded very few relevant articles, ultimately pointing to the dearth of published literature on this dissertation project. As an example, “siblinghood” searches with EBSCO returned few relevant citations, forcing a greater reliance on Google Scholar. Similarly, some word combinations, such as “disability + siblinghood,” also failed to return adequate results with EBSCO (e.g., one article), making Google Scholar the principal search engine for this combination (e.g., four subsequent articles).

In addition to the formal search of the literature via EBSCO and Google Scholar, I initially relied on reviews of seminal articles by Evelyn Deno and Lloyd Dunn, as recommended by Dr. Stramiello, a former professor at Mercer University. The curriculum and design of services of both researchers heavily influenced how students with special needs were viewed in schools, as evidenced in part of this literature review.

Search Indications

Siblings in any family have various types of relationships that shape the family dynamic (Kim, McHale, Wayne Osgood, & Crouter, 2006; McHale, Updegraff, & Whiteman, 2012). Since the deinstitutionalization of people with disabilities and their inclusion into education, researchers have been interested in the familial relationship and the effects of disability on the children in these families. They have also been interested in these relationships and their effects on many aspects of culture. The consort diagram displayed in Figure 1 demonstrates the search results flow from general terms to specific
combinations of terms, providing some evidence that researchers have an interest in the family and sibling relationships. The construction of this consort diagram and research review matrix serves to summarize my searches and demonstrates a paucity of published research involving the proposed study population and topic of interest. This gap in knowledge allowed this research to initiate a specific space in the useful literature.

Figure 1. Consort diagram of term.
After I narrowed the initial search terms, I used the following combinations of search terms to determine a possible gap in the literature on sibling relationships:

- Disability, siblings, and school
- School culture, teachers, and disability
- Siblinghood, disability, and school culture

As noted in Figure 1, the term combination, “sibling, disability, and school” was intended to encompass “school culture”. However, that search did not return any results. Omitting “culture” from the term and simply using “school” broadened that particular search.

I discovered 31 articles under the search term combination “disability, school, and siblings”. These articles all had a common theme of the familial relationship having some effect on the sibling relationship. Two of the articles were literature reviews that, while informative, were not actual studies. Twelve of the articles were studies conducted with parents, with five of those addressing single parenting as the subject and seven including the nondisabled siblings with the parent. The majority of the articles surveyed the nondisabled sibling only. Three articles were studies of the whole family, and three other articles addressed all siblings; although after reviewing those articles, the sibling with a disability was not given a voice, but were observation participants. It appeared rare to find an article that promoted conducting research on and with the sibling with a disability and giving them an actual voice in the research, as noted in Figure 2, which provides a visual delineation of all of the article participants. This figure excludes the two articles that were literature reviews, yielding 28 useful articles.
When analyzing the search results in Figure 2 for the search term combination, “teachers, disability, and school culture,” six articles had relevance to the topic of this dissertation. The final combination of search terms “siblinghood, disability, and school culture” returned only one article in EBSCO and many articles that had no direct relevance to the search terms in Google Scholar, but they contained a word within the article or abstract. Two of the articles discovered in this search had overlap with the first set of search terms. The most recent and most relevant article by Meltzer and Kramer (2016) appeared in both the first and the last set of search terms, as well as on Google Scholar. When again analyzing Figure 2, Meltzer and Kramer (2016) authored the single article in which the researchers discussed giving voice to people with disabilities within research of that population.
Final Analysis of Pertinent Literature

A final analysis of the entirety of the articles, excluding the literature reviews and articles meant to be informative, brought the total to 37 articles analyzed. During the analysis, “family” was defined as inclusive of the parents as well as the siblings. “Clinical” was defined as the use of the word in the setting or observations being made in and isolated manner by the researchers. “Education” was defined as teachers and other school personnel who participated in the study through questionnaires or observations. *Figure 3* depicts a visual analysis.

*Figure 3*. Article settings.

When analyzing all the articles and the participants of the studies or the subject of the article, it became apparent that most of the articles regarding disability focused on the families and the effects the disability had on the family members. Only a few articles were purely clinical or entirely in the educational setting. When reading through the
articles based on the families, I identified the common theme was the effect the person with a disability had on the family dynamic. No articles included a discussion of the dynamic of the siblings in schools together. This gap of knowledge is the entre for needed formal research represented in this study.

Amendment of Initial Search Term

Since the initial searches were completed for this project, one of the major search terms was changed. “School culture” was difficult to define and apply appropriate parameters. This term was changed to “school perceptions” to gain a better understanding of the lived and shared experiences of the siblings with and without disabilities and their peers. This also changed one of the search combinations. The combination of “school culture, teachers, and disability” did not yield many articles that fit within the boundaries of this study; therefore, that search combination became “school perceptions and disability”. This yielded results for teachers, students, administration, and parents. It also addressed the needs of all of the stakeholders. However, upon reading the articles and applying them to the previous graphs, I decided that the most beneficial articles were those from the teachers and the students because they are the main stakeholders in the school who are seemingly most influenced by cultural changes and changes of perceptions.

Furthermore, the initial search left out the international articles because of potential cultural differences. However, during the literature review writing process, some international articles were necessary to support the various claims made. They also
supported the idea of disability culture and added to the body of knowledge of disability studies, while still leaving a gap in which to situate this study.

Following the search strategy previously delineated, the remainder of this chapter aims to address the theoretical framework of the study by aligning it within the discipline of disabilities studies, as well as providing a lens through which I viewed all research, literature, and explanation of data. This study relies heavily on the influence school can have on how students within their peer groups and their siblings (with and without disabilities) perceive disability. In addition, this study addressed indirect connections to how the perceptions of teachers may influence student views. These ideas establish school personnel perceptions of disability, as well as how those perceptions play a role in the shared experiences of sibling groups inclusive of a person with a disability. The following theoretical framework and literature review will address the aforementioned points.

Theoretical Framework: Disability Theory

In the colonial United States, if a person was born with a disability, that person became the problem of the town citizens. Disabled individuals who wandered from municipality to municipality were cared for, but they lacked the rights afforded to citizens of the colonies (Nielsen, 2012). Due to the hardships faced by the members of the fledgling nation, little time was available to engage in appropriate discourse on disability.

Later in history, those with disabilities were taken from their families and placed in institutions, isolated from society, where they were left to live unseen and unheard; they were no longer viewed as the problem of the town or colony, but they were still seen
as the shameful family secret (Nielsen, 2012). The medical community viewed disability as something lacking, usually as the inability to work and contribute to the community physically and/or cognitively (Nielsen, 2012). Wong (2010) asserted that justice and personhood should not be contingent upon one’s cognitive ability because people with disabilities are humans who inherently deserve justice and personhood.

These assertions are main tenets in the disability theoretical framework, formed as a way to address ableism and the deficits it created for people with disabilities. Ableism is the idea that a person’s disability keeps him or her from being able to achieve or to be as successful as a person without a disability (Linton, 1998; Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010; Storey, 2007). This thought places people with disabilities in a space outside of normalized society, or others them. Ableism employs language that places the deficits of a person before the expression of the person’s identity. Disability theorists aim to change the thoughts of society by granting people with disabilities the opportunity to show their gifts and talents, express their identity separate from their disability, and reverse the language used to place them on the margins of society, thus allowing them to become a part of the discourse on their lives.

The disability theory framework, which follows a similar timeline to those political movements that include people with disabilities in normalized society, is contained within a larger continuum of theories. Many philosophers, who likely did not anticipate that their ideas would be applied to this field, informed it. From the origins through the future of this new ideology, discussion of ideas and research of disability advocacy may seemingly have some significant overlap across various theorists. When
looking to determine its U.S. identity, the influence of international ideas of thought is apparent. Examples include Jacque Derrida (1973, 1976) and Michele Foucault (1977), writers whose thoughts on linguistics of deconstruction and resistance to power of docile bodies have been ascribed to this theory. Derrida and Foucault both became more concerned with ethics as their writing and ideas progressed through poststructuralist and postmodernist movements (Corker & Shakespeare, 2002)

Much of what is written about disability occurred since the passage of the Americans with Disabilities Act (U.S. Department of Justice, Civil Rights Division, 1990), which gave people with disabilities access to buildings and public spaces by including items to support people with varying disabilities in this sphere. This law, cited as one of the single most important laws in the disability rights movement, held many implications for future laws passed (Concannon, 2012).

Most recently, the U.S. Congress passed the Achieving a Better Life Experience Act (ABLE) in order to allow people with disabilities to maintain a savings account free from government tampering, thus providing better monetary support for their independence (Crenshaw, 2014). These acts were only possible because of the union of disability theory and politics in the advocacy movement. Hall (1992) wrote, “I don’t believe that knowledge is closed, but I do believe that politics is impossible without what I have called ‘the arbitrary closure’” (p. 278). This means that some political policies create an end to certain conversations within a movement, but by expanding knowledge and revisiting the previous dialogue, a movement can advance forward for better possibilities in the future. By utilizing expanding knowledge, disability supporters and
politicians have been able to keep pace and continue to advocate for a place of power for people with disabilities in a normalized society, thus utilizing deconstruction and power structures discussed by Derrida and Foucault.

Disability Theory through Power and Discourse

As previously mentioned, in the past, persons with disabilities did not receive voice or power. Liberation from institutions led to the inclusion of people with disabilities in family life and eventually in schools where they received an education (Barnes, 2010). Born from this history was a theoretical construct that would help bring people with disabilities from the margins to the center, thus decentering normalized society and forcing people to acknowledge the innate worth of people with disabilities (Siebers, 2011).

Differences through a Derridian lens. Individuals in society perceive differences, and these differences often define the individuals. Derrida (1973) contended that language reflects this construct in society. It is possible to define difference in terms of the presence and the absence of, or to differ and defer (Derrida, 1973). Disability is the absence of ability, but also the presence of a lacking societal construct. Individuals in society see the difference in persons in how they look, act, or exist, and they often seek to normalize these differences by exclusion of these divergent persons. People with disabilities differ from the norm in many ways.

Individuals with disabilities have been called Mongol, idiots, and more recently, retarded—all degrading terms used to denote the absence of ability or something less than what societal norms deem appropriate or valuable (Simpson, 2011). Simpson (2011)
discussed the idea of intellectual disability being referred to as *idiocy*. She used the term, *otherness*, in language and applied it to idiocy because the “backward child, however, poses a threat of interruption into the system” (p. 544). Applying ideas of Derrida to her argument, she stated, “Idiocy can be seen as the suppressed other term” (p. 543). Any talk of normalcy relies on the need for there to be an opposing factor to *normal* (Simpson, 2011). The silent *other* does not allow intellectual disability to assume a *normal* status (Simpson, 2011).

Due to this persistent idea, people with disabilities rarely receive basic rights that encourage contributions as productive societal members. It has been difficult to allow people with a disability—who are so different—the chance to voice who they are as individuals, or as individual members of a larger group. Derrida (1973) discussed the idea of voice and the signifier, “I” (p. 70), as a means of inner talk. It is not until this “I” is understood to another person that it actually becomes speech. Derrida (1973) elaborated, “On the other hand, the subject can hear or speak to himself and be affected by the signifier he produces, without passing through an external detour, the world, the sphere of what is not ‘his own’” (p. 78). People with disabilities can communicate with their own language and be understood by each other. In a sense they are using Derrida’s “I” (p. 70), but until they receive a voice outside their own space, they are only giving meaning to each other and not coherence to those outside.

The voice of the disability “I” might be heard by society so that affected individuals can be given voice and be universally understood. The difficulty in allowing the “I” voice of disability to be heard is that it may not express what is expected. Many
presume competence in all people, but when they do not find that competence, they often summarily discount the person with a disability (Berube, 2012). Others often assume that persons with disabilities are not capable of making decisions or participating in the discourse of their own lives and seek to strip the power and the “I” from the people with disabilities. It begs the question about whether the inability to express competence actually connotes *incompetence*.

Disability voice and power. Nussbaum (2010) introduced the discussion of capabilities and how society should help people with disabilities to be independent, based on their capabilities. For example, she explained that voting and serving on a jury were actions that make a person essentially American; therefore, she postulated that society can provide support and surrogacy for people with disabilities to participate in such essential American events. However, it is not obvious whether this guardian or surrogate allows the disabled individual appropriate agency and acts in accord with the disabled individual’s desires versus using that person’s status as a proxy for personal desires.

Individuals in society have found it difficult to allow people with disabilities to express their thoughts and feelings, possibly for fear of exposure of society’s inadequacies in providing for these different needs. Everelles (2002) used Foucault’s ideas on power structures as a way to discuss how people with autism and cognitive disabilities can communicate. Everelles (2002) related Foucault’s discussion of the trial of Pierre Riviere as an example of the injustices dealt by medical and judicial professions on individuals with disabilities. Using this idea and passage by Foucault, Everelles (2002) asserted that when people with autism and cognitive disabilities used augmentative
communication devices, many physicians discounted the idea that people with disabilities could authentically communicate with the world. In other words, alternative and augmentative communication devices (AAC)—programs and machines given to people with disabilities to aid in communication—give them the ability to express their thoughts and feelings. According to Everelles (2002), our society hardly accepts that communication because it comes from a different place, meaning the device and the person are not one, when in reality they are together. However, power is not given because of that societal separation from the device. Many perceive an otherness in the use of the device. The medical field plays a part in making sure that a diagnosis provides us with an explanation for the device instead of a way for society to hear individuals with disabilities (Everelles, 2002). Yet only by allowing people with disabilities to express all of their ideas and receive the space within the normal can they maximize their opportunities to be productive contributors to society.

Society can give voice and power to those who not only have bodies that look different, but also do not resonate from a place of normalized intelligence (Foucault, 1977). To disallow a person with a disability the forum for active participation because they look, speak, and communicate in different ways is an overt form of control. Kudlick (2005) asserted that Foucault’s power structures have played an integral part in assisting marginalized groups in the United States to destroy existing power structures for the betterment of the minority. She placed disability into the marginalized other, but further claimed that disability plays a larger role in western cultures. For Kudlick (2005), disability seems to be the other that has gained status for power resistance last, but it is
the fastest growing. Furthermore, it has the most implications for improving the status of all others because it has inadvertently seeped its way into our language, due, in large part, to the need of the medical field to express an inability to work and contribute. Because of the need to define the other, individuals in society harshly exert control, since it is difficult to allow such differences to participate in society, lest they say and do things that would break apart the social structures that people cling to so tightly (Kliewer, Biklen, & Kasa-Henrickson, 2006).

The hegemonic powers that often strip people with disabilities of their rights as individuals are also frequently afraid of what is unknown; the anomaly of disability presents ambiguity for those who strive for a perfect society. Danforth (2000) noted that Foucault discussed this idea in his book *Madness and Civilization: A History of Insanity in the Age of Reason* (1961), pointing out that people were considered mad when they did not conform to social norms through attitude, behavior, or appearance. This led to the formation of the profession of psychiatry, the major power and knowledge constructor on madness during the 17th and 18th centuries (Danforth, 2000). This knowledge has followed people with disabilities through time, leading them to be silenced by those in power. Danforth (2000) used Foucault’s power constructs to emphasize how the psychologists sought to prove deficiencies in people with disabilities as a means of stripping their agency and employing the use of institutions and eugenics to control their culture. Barnes (2010) even suggested that the eugenic ideals of Nazism are still in a place of power over disability today, as demonstrated by some people through use of
descriptors that often refer to an individual’s inherent functioning level in terms of animalistic traits (O’Brien, 2003).

Eugenics in today’s society aims to oppress people with disabilities by not even allowing their lives to count or by preventing their very existence. Saxton (2010) posited that today unborn babies with presumed genetic or developmental disabilities are aborted under the assumption that these humans will experience a lesser life and cause an unnecessary burden for their families and society. It deems women with a disability to be unworthy mothers. However, when given the chance to advocate for themselves and for the selectively aborted children, these women are able to make the case that babies with disabilities could likely turn out to be the next voice in an oppressed culture (Saxton, 2010).

Disability in Society through Multiple Philosophical Ideations

Historically, even the economics of societies did not support people with disabilities (Barnes, 2010). As societies became more permanent, people perceived disabilities as an evil to be avoided (Nielsen, 2012) and viewed children with disabilities as punishment for their family’s generational sins (Lowe, 2012). Lowe (2012) discussed the representation of disability as a manner of atonement for sin and the associated shame. However, she also stated that sin supports a societal structure of limits that are helpful and harmful to different groups of people. These limits are imposed upon people with disabilities to explain their differences or limitations in accordance with the normalcy sought by society (Lowe, 2012). The idea that sin creates disability further limits the ability of people with disabilities to participate in society, since normalized
societies tend to view sins as an evil to evade. Hoping to empower people with disabilities in their plight to gain control of their lives and control of a place in society, Lowe (2012) ended her discussion through an assertion that knowing about sin and disability can only lead people to realize the sins of different theories towards disability.

In the 1930s, eugenics was a prominent factor in pushing those with a disability outside the mainstream, inciting new fears of differences (Danforth, 2000). Infanticide and experiments on people with disabilities took place in an effort to eliminate what was undesirable. When research revealed that genetics did not play a large role in the determination of disability, IQ testing in schools further characterized and excluded people with disabilities from normalized culture (Barnes, 2010). Society provided minimal care of people with disabilities by appointing places for them to work, but conditions were universally atrocious (Barnes, 2010).

By the early 1960s, the idea of disability was slowly losing its taboo, and society began moving to push for the betterment of life for people with disabilities. Children with disabilities were being served in school and more inclusive settings (Barnes, 2010). During this transition, a medical diagnosis was typically necessary to gain a child access to the realm of disability (Danforth, 2008), and IQ measurement played a key role in the inclusion or exclusion of children in schools.

Language was also important in placing disability on the outskirts of acceptance. The simple prefix, “dis-,” meaning “apart,” ultimately placed people with disabilities apart from those with normalized abilities. It categorically placed dis-ability away from acceptance into a normalized society simply because the word associated with the
disability culture would evoke negative thoughts from those in the normal society. Discourse surrounding disability was nonexistent, because society thought it was too sensitive a subject to address. Foucault (1976) often addressed similar discourse in sexuality, explaining the need for discourse in sex and sexuality can similarly be applied to bring disability to the forefront of society by tracing its roots and determining where society made the choice to exclude those who were different. Foucault (1976) stated, “It may well be that we talk about sex more than anything” (p. 1512). In the case of disability, application of Foucault’s (1976) conclusion may lead to the inference that people in society could also talk about disability more than they talk about anything else, without actually attempting to construct a different meaning or value than the one that currently exists. As such, society may not give agency to those in the disability culture, but through deconstruction of language, disability may be able to gain voice or power.

Derrida (1976) related the idea of deconstruction of language as he addressed the contradictions in language. He posited that binary opposition was the contradiction of one another (Danforth & Rhodes, 1997). Using Derrida’s theory to discuss the need for inclusion in schools, Danforth and Rhodes (1997) claimed special education is creating a binary between ability and disability by giving a diagnosis as a means to address the learning needs of students and using those supposed needs as a way to place them in (or out) of the school culture. Therefore, the diagnostic process itself is detrimental to individuals with disabilities. Unfortunately, the binary disability label given to children in schools often follows them for the rest of their lives, especially those who fall in the lower cognitive functioning range. By simply breaking from labeling students,
individuals can view disability differently insofar as changing the semantics might serve to return power and agency to those with disabilities (Danforth & Rhodes, 1997).

Binaries notwithstanding, disability can best be explained by a continuum of abilities. At different points of development, a person can be placed within a definition of disability and therefore be placed within such an identity group, which itself is very diverse. Even so, since disability is signified by a lack of ability, which often is a transient status versus a lifelong identification, persons could naturally slip outside the clinical definition while they continue to be labeled as disabled. However, using Derrida’s (1976) logo centrism concept, disability can be deconstructed into something different, or seen as a term that does not suggest a deficit. A person can enter disability by various avenues along the continuum from birth to old age. Because a person can be born or become disabled, the binary idea of absolute permanent ability (or dis-ability) cannot wholly exist (Danforth & Rhodes, 1997).

Deconstruction of any component of society necessarily leads to disruption or disorder, but when the push for an egalitarian society settles, people with disabilities could realize greater rights and a more appropriate match of their power to the societal hegemony (Derrida, 1976). Thus, these individuals will be allowed space in society where they can experience a full life that may have historically been denied through antiquated societal constructs.

Although Derrida’s (1976) deconstruction of society’s language towards disability is important, it is necessary to note that, in some ways, persons with a disability may not have the capacity for understanding how to project their power and their words, thereby
advocating for themselves. In this matter, the disability theory shows limited research and knowledge. Because this is a newer field of thought pursued through a newer political push for inclusion, it lacks adequate exploration of all avenues of disability.

As a societal group, those with disabilities have been forced into their own culture. Hall (1992) noted that cultural studies were not always comprehensive or consistent. As an example, feminism is one of the most prominent recent additions. Hall (1992) also related that the field is open to even more additions, allowing for the addition of cultural disability dynamics and application of its overarching ideals. Couser (2010) explained, “Although it is as fundamental an aspect of human diversity as race, ethnicity, gender, and sexuality, it [disability] is rarely acknowledged as such” (p. 456). In other words, Couser (2010) maintained identification as a person with a disability is just as important and inescapable as identification by race, ethnicity, and gender.

Disability and identity. Sherry (2010) suggested two definitions of disability. One needs the other, but they can be difficult to reconcile. The first definition addresses a social model of disability defined as impairment or lack of and the disability itself as a negative social reaction. The second definition is disability as an identity. Individuals in society need disability to be an impairment or lack of something because that is easy to see. In an introduction to one of his chapters, Siebers (2011) told the story of a man experiencing difficulty boarding a crowded plane due to the lingering effects of polio. When the gate agent wants this man to use a wheelchair in order to prove his disability, the man refuses, and eventually, the agent allows him to board the plane. The point of the story was that this man was not born into disability; it happened to him. However, he
is not ready to identify completely with the acquired disability. It is not until the man in
the story falls and needs crutches later that this visible sign of disability causes him to
take on this identity.

Siebers (2011) then discussed the dichotomy of visible and invisible disability,
stating that disability is not obvious in a person’s self-identification. The presence of a
limp for the man in the story might give him agency when talking with the gate agent, but
the man would still rather identify himself as nondisabled if given such a choice. Siebers
(2011) posited that if an individual identifies with disability and can make that known to
society, that person would gain enough agency within the broader culture, thereby being
accepted as a legitimate part of the normative culture and minimizing his or her
marginality.

Currently, social structures exist to limit the rights of a person with a cognitive
disability. However, rebuilding of those structures thoughtfully with disability at the
forefront would result in enrichment of the lives of people within disability because they
received the means to better experience the world. Danforth (2008) stated, “Individual
students enjoy the satisfaction as a result of their own roles within the larger project” (p. 62).
The same concept can be applied outside of schools to the lives of the adults with
disabilities. They also would enjoy being a part of a larger project in society if asked
how they could contribute to the world because they are human beings. Soliciting their
input would bestow dignity upon them.

Geisinger (2012) highlighted the philosophies of Immanuel Kant, who wrote
about the ideals of dignity in education and children, relating that Kant believed all
humans had a right to be given dignity, and all people had the right to realize their own
dignity. Geisinger (2012) suggested it is a human duty to realize one’s dignity and to act
against one’s duty would be to lose that very dignity. Disability culture has the capability
to follow through with this human duty and to gain its own dignity, but it requires a
societal advocate to do so, especially in the case of those with cognitive disabilities.
Persons with disabilities may not realize that they have dignity because others do not give
them the freedom to experience dignity (Geisinger, 2012).

As stated earlier, disability identity can be as fundamental to a person as their
race, gender, or sexuality (Couser, 2010); however, it is often overlooked or added as a
secondary characteristic. A blind person may be a man, but his disability often becomes
his primary identity. While disability is a marginalized culture, it is very widely
represented in popular culture, although this representation is rarely a positive one
(Couser, 2010). Despite this negativity towards people with disabilities, a growing
impetus to begin the conversation to understand their differences exists. Couser (2010)
discussed the idea of life narrative giving rise to further awareness of disability and all it
entails. This is not the end of what can be learned about people with disabilities or their
culture, which they created out of necessity, but a start and middle to the dialogue that is
fundamental to the advancement of people with disabilities.

The hope for the study of disabilities as a culture is to continue to bring awareness
to the plight of the disabled human, and to hopefully drop the dis- from disability in order
to assume that these individuals are not the lesser to anyone else in society—to instead
focus on their abilities. Bérubé (2010) stated, “The margins are in fact the center” (p.
Working to bring the margins to the center is difficult but may provide more fulfillment and happiness to many people with disabilities.

Literature Review: Disability and Education

In the early years of the United States, all people were expected to work in order to support their families and communities. If an individual was not able to work, others often perceived that individual as having a disability, thus, as a societal burden. As the country matured, such individuals were institutionalized. It did not matter if a blind or a deaf person was able to work despite their perceived sensory defect; they were institutionalized and then treated as if a burden to their family was lifted (Nielsen, 2012). Their lives were judged to have less value to the community because of their inability to perform according to societal norms at that time. It was a harsh reality for many people, and especially for those who were of sound mind, but not sound physicality.

Members of the new nation had many problems as they sought independence from Great Britain. Despite the wording of the Declaration of Independence, most Americans inferred that the ideas of the pursuit of life, liberty, and happiness were only applicable to the privileged few (Nielsen, 2012). Everyone else, including women, children, African slaves, and people with disabilities were unable to participate in the politics of this new country, because they were not considered privileged (Nielsen, 2012).

Education was not an option for everyone in the colonial era. When the rise of public education for citizens took place, only those with economic advantage received considerable educations. Even those who were blind or deaf had to possess wealth in order to attend schools that would serve to make them more independent. These schools
were more likely located in the northern part of the country. Affluent families in the South would often send their children to the institutionalized boarding schools in the North to receive the best education possible. However, even those schools were limited in the types of people with disabilities allowed to enroll (Nielsen, 2012). Persons with cognitive or mental health disabilities were not accepted simply because they were not able to participate in that society in a meaningful way.

As the country aged, ideals of superior mind and body continued to emerge. The Civil War highlighted the need to keep slaves in their place and women at home while men fought in the war (Nielsen, 2012). In the early 19th century, the gap between those who were of sound mind and body and those who were not became more apparent. Disability remained shameful to the family and community (Simpson, 2011). Often mothers of children with disabilities explained away the behavior or lack of social couth of their child (Neely-Barnes et al., 2010). Other mothers would stand up for their children and try to create an environment where the child would flourish and possibly gain ground in the community as part of the center instead of the margin. Both actions derived from the notion that the child with a disability should be perceived and accepted as normal. Even medical terms of the Civil War era were derogatory. For example, Dr. John Down, who characterized Down syndrome in the 1860s, used the terms, deviant and feebleminded when describing people with Down syndrome (Simpson, 2011).

Many early medical advances did not permit an individual’s disability to be defined by his or her ability to grow and be human. The view of disability was as a biological dysfunction, and few sought to determine if it was a naturally occurring
genetic anomaly or the result of environmental factors (Hansen, 2014). Rarely would the medical community seek to adapt to life with the disability; instead, they would focus on preventing and curing the disability prior to or shortly after birth (Nielsen, 2012). The prognosis for disability was usually poor, often based on racist ideals to promote or compare the perceived shortcomings of people of color, or out of ableism, to determine how one was going to be able to contribute meaningfully to community and society (Stubblefield, 2010). Ableism and racism seemed to run parallel and intersecting paths through the lens of social justice, for ableism eventually became a prominent notion in schools, as well as society.

Ableism, a term used to describe one’s abilities to perform labor or the functioning status of mind and body, was widely applied to all people with some form of disability (McLean, 2011). As Siebers (2011) noted, “Ability appears unmarked and invisible because it is the norm, while disability, as an affront to ability, feels the full and persistent force of an ideological impulse to erase from view any exception to ability” (pp. 102-103). Storey (2007) described it as “the belief that it is better or superior not to have a disability than it is to have one” (p. 56). Ableism claims a superior body or mind, which a person who has a disability would never realize, and therefore, never be able to participate in society, despite the need to portray normativity to fill a social role. In a way, ableism defines disability’s apparent inability to function as normal or as close to the norm.

Therefore, it is not surprising to learn that people with disabilities were typically not allowed to attend school, and compulsory school laws did not apply to them. Many
states passed laws that prohibited individuals with disabilities from attending school because the perception was they were uneducable and unable to learn because their minds lacked the capacity to gain and use new information or skills (Yell, Rogers, & Rogers, 1998).

These ideas remained fixed with Americans as the country entered the turbulent times of the civil rights movement, which sought to liberate all those who were victims of oppression, especially people of color. Ableism and racism intersected to gain more freedoms and services. When the Black community filed suit in Brown v. the Board of Education in 1954, claiming a win for the desegregation of schools, the disability community knew it would not be long before they were able to integrate into schools as well (Yell et al., 1998).

This suit created an opportunity for the disability rights movement to gain access to normal society through the education of people with disabilities in public schools. Using the language of Brown v. the Board of Education, the Pennsylvania Association for Retarded Citizens claimed that several secretaries of education in Pennsylvania were systematically excluding people with disabilities from receiving an equal education under the laws. This 1971 suit resulted in lawmakers stating that people with disabilities were entitled to a free and appropriate education (Yell et al., 1998). This victory was the beginning of free and appropriate public education (FAPE) laws, later defined in the Individuals with Disabilities Education Act (IDEA) (Johnson, 2012).

Despite the progress gained towards more inclusion for people with disabilities, they still did not receive the same educational opportunities as their normal peers.
1975, the U.S. Congress passed the Education for All Handicapped Children Act, which mandated that students with any kind of disability should be allowed to attend school and further solidified disability in education with the implementation of the Individualized Education Program (IEP) for every student with a disability (U.S. Department of Education [USDOE], 2010).

However, because many of the school buildings were physically inaccessible for people in wheelchairs or people who had significant vision impairments, more legislation was necessary. It came in the form of the Americans with Disabilities Act, which required all public buildings, including schools, to create physical access for all people with disabilities (U.S. Department of Justice, Civil Rights Division, 1990). The 1990 Individuals with Disabilities Education Act (IDEA) renamed and amended the Education for All Handicapped Children Act by requiring the addition of transition plans for postsecondary opportunities in the IEPs for students with disabilities (USDOE, 2010). This law receives reinstatement and improvements every time the law reaches its expiration date, for it is meant to be a living document that will continue to influence education, community, and society, (USDOE, 2010). The following sections provide an in-depth discussion of the impact of these legislative acts on the education of students with disabilities.

Special Education in Public Schools

After the passage of the Education for All Handicapped Children of 1975, students with disabilities were included in education (Yell et al., 1998). They received a place in the schools, but they were still separate from their peers. Many questions arose
regarding the quality of education and the methodology for addressing equality of education for these students (Deno, 1970). How were teachers going to meet their needs? What was the school setting expected to look like? What type of specialized training for teachers was necessary? What was the role of education to play in the lives of these students? Although many researchers wrote extensively on education of students with the *retarded* label, the challenge became more complicated as the institutions began placing their residents in their family homes (Yell, Shriner, & Katsiyannis, 2006). Disability varies so much from person to person that each student had individual needs to meet. In addition, there were many who engaged in what Valencia (1997) referred to as deficit thinking, an idea that students fail in school because of internal deficits.

**Deficit Thinking and Disability**

Deficit thinking has defined school failures of students within minority groups. It is an idea that students fail in school because of internal deficits; however, some argue that failure is due to external factors that many school improvement teams fail to recognize as valid reasons for poor performance of marginalized groups (Valencia, 1997). These groups often include those of low socioeconomic status, race, gender, and disability. In the introduction to edited works by various experts in the field of deficit thinking, Valencia (1997) introduced six characteristics of deficit thinking: blaming the victim, oppression, pseudoscience, temporal changes, educability, and heterodoxy.

Valencia (1997) wrote that victim blaming removes the need to identify social problems, such as low socioeconomic status or intellectual delay, and serves as a venue to determine how advantaged or disadvantaged one could be based on these issues.
Oppression seems much more straightforward in the sense that it is a simple power play. People in power wish to keep those who are not in their place by denying they could be capable of the same as those in power (Valencia, 1997). Educability is a way to determine who holds the deficit and who does not. Most schools are teacher centered, elitist, and hesitant to address the problems of failure. Valencia (1997) claimed school personnel blame the students for school failure and attribute the success to the teachers. Deficit thinking addresses a lopsided power arrangement that leaves the marginalized students little to no possibility of school success (Valencia, 1997).

When pondering deficit thinking in regard to schools and disability, professionals in the field of education often think of disability as a lacking of ability. Due to their preconceived notion of disability that a student cannot perform, they fail to recognize the potential of every student (Dudley-Marling & Burns, 2014). The laws of special education address this through the provision of the least-restrictive environment (LRE) to students with disabilities. This deficit thinking becomes problematic when one thinks that disability is inherent to the child and as something that requires fixing (Dudley-Marling & Burns, 2014).

Varying Perspectives among Educators

To exacerbate the problem, teachers often feel that the students with disabilities have to conform to the current type of education system (Deno, 1977). However, special educators seem to believe that the education system should change “drastically from its present forms if the precious uniqueness of each child’s humanity is to be cherished” (Deno, 1970, pp. 229). The next step following the passing of inclusion laws was better
training for teachers as they learned how to meet the unique needs of students with varying disabilities and how to, at least tacitly, support the families of those students to ensure that all educational needs were being met (Yell et al., 2006).

Dunn and Educability

Dunn (1968), believing students with mild mental retardation would be better served in the general education classroom, recommended their removal from self-contained classes specifically designed to meet the needs of students unable to participate in the general education classroom. Dunn (1970) asserted these classes had become a catchall for undesirable students, placed there by general education teachers who claimed there was nothing they could do to better serve them. However, Dunn (1968) realized, with support from special education teachers via resource rooms, those students were educable in the general classes. As one of the pioneers of a continuum of special education services, Dunn (1968) felt students could receive remediation in special schools and then return to their neighborhood schools. By moving many of the students out of self-contained classes and into the general education classrooms, special education would promote the elimination of discrimination in education based on race and class (Dunn, 1968).

Deno and Cascade of Services

Shortly after Dunn published his ideas for the betterment of education for the mentally retarded, Deno (1970) designed her cascade of services to serve all students in the special education system. In her seminal article, *Special Education as Developmental Capital*, she first discussed the idea that students with disabilities were expected to adjust
to schooling instead of adjusting school norms to match their learning needs. To explain her design, she utilized two pyramids (see Figure 4).

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The size of each level displayed in Figure 4 indicated the size of the disability group, as well as the corresponding number of teachers needed to meet the needs of those students. Deno (1994) explained that the design reflected the intention of having the majority of students in the mainstream setting with accommodations, supports, and a special education teacher supporting the mainstream teacher. This system of placement in special education allows the teachers to play a key role in the decisions made about the
students they teach. It also provides students more flexibility to move in and out of the mainstream setting within the cascade as deemed fit (Deno, 1970, 1994).

Deno’s (1970) cascade of services still holds great implications for how school personnel should address the needs of students with disabilities. Originally, Deno (1970) designed the cascade for Minnesota schools to better serve their students with disabilities, but as the legislature became involved with piecemeal laws that attempted to diminish the service design, Deno (1970) published the cascade to address issues not covered in the existing laws. In a later article, Deno (1994) stated how she designed the cascade to not only better place the students with disabilities in school settings, but also to provide descriptions of the necessary services and corresponding staffing. Deno (1970) wrote the job descriptions for teachers in consultative teaching and coteaching classes. These descriptions are similar to current standards in special education, although there is a continuum of training refinement to match the needs of the students in special education (Billingsley, 2004; Deno, 1994; Major, 2012).

The Debate over Inclusion

Despite the logic of Dunn’s arguments and Deno’s model, many major stakeholders opposed inclusion. In a qualitative study of general education teachers, Giangreco, Dennis, Cloninger, Edelman, and Schattman (1993) reported that most teachers felt unsure of the abilities of students with severe disabilities and uncertain of how to meet their needs within the general education setting; thus, they were an inherently intimidating group. Nineteen general education teachers volunteered to place students with multiple physical and cognitive disabilities in their classrooms to “try” to
see how the students would do. Each teacher participated in private interviews as well as member checks during the coding process. After the initial worries of these teachers subsided, many reported positive reactions. Their perceptions changed from unwillingness to view anything more than the student as disabled to viewing them as a student in the classroom (Giangreco et al., 1993). One teacher reported that she felt a responsibility to have an impact on her student’s life. Giangreco et al. (1993) concluded that teacher perceptions greatly influence how inclusion works in the classroom.

Fuchs and Fuchs (1994) also found this to be true in their in-depth comparison study of the inclusive schools movement and the regular education initiative. General education teachers felt they were not responsible for the education of students with disabilities and viewed special education as a separate program from general education, despite attempts made by numerous special education teachers to gain access to the general education. A large number of U.S. special educators felt students with disabilities had a place in the general education classrooms, yet it remained a struggle to enroll students into the mainstream classroom. Many special educators believed that the best way to help special education students flourish was to place them in a challenging environment and provide support in reaching higher educational goals; whereas others were territorial and opposed to inclusion. Fuchs and Fuchs (1994) concluded that inclusion was inevitable, and to facilitate the transition, they recommended compromise, respect for the law and special educators, avoidance of extremism by leaders of the inclusion movement, and solicitation of the opinions of parents and professionals.
Change in the Roles of Special Educators

Inclusion was inevitable, as the role of special educators and the requirements for student achievement changed per the No Child Left Behind (NCLB) Act of 2001, which mandated that all students become proficient in math and reading. To align with NCLB, the 2004 reauthorization of the Individual with Disabilities Education Act (IDEA) included the following requirements: highly qualified status of special education teachers, like their general education counterparts; participation of all students with disabilities in state or alternate assessments; implementation of peer-reviewed and research-based services for special education students; and enrollment of special education students in the least restrictive environment (USDOE, 2004). Yell et al. (2006) contended that the laws mandated special education teachers focus less on paperwork and compliance and more on results and progress for the students (Yell et al., 2006). This change blended service lines for students and effectively changed the job roles of the special educators.

The change in the roles and placement of special education teachers in the general education classroom often resulted in uncertainty of special educators in regard to their identity (Jones, 2004). For example, in a study of special educators, Jones (2004) described the educators’ need to be identified as professionals who were equal to the general education teachers, social justice advocates for students with disabilities, and possessors of a specialized skill set for educating for students with disabilities. These identities can be embodied in one teacher and denied by another (Jones, 2004), but either way, the need for supporting better models of special education is key to the success of teachers who work with special education students. Schlichte, Yssel, and Merbler (2005)
found that administrators’ lack of understanding of the appropriate structure of special education, and therefore a lack of attention to the needs of the job, created uncertainty in special education teachers’ roles in schools. Their professional identities as teachers depend on the positive support and attitude for inclusion in the school culture (Jones, 2004).

Ultimately, the variability of quality and high attrition rates of special educators can lead to a destabilizing culture for students and their families because of additional stresses that are not easy to anticipate or measure (Billingsley, 2004b). This stress is often felt in transitional phases for the students—morning and afternoon routines, weekends away from school, and school breaks, in addition to those within a school day. Therefore, appropriate training and retention of dedicated special educators may have a strong, if indirect, effect on the attitudes of students with disabilities and their families toward education (Billingsley, 2004a).

Change in the Roles of General Educators

The higher accountability requirements and creation of more inclusion classes also changed the role and responsibilities of general educators (Blanton, Pugach, & Florian, 2011). Many teachers in the general education setting expressed concern that students with disabilities would decrease test scores as accountability and state testing became a prominent idea in education (Hardman & Dawson, 2008). Furthermore, the efficacy of general educators suffered because most did not possess the knowledge of how to educate students with disabilities (Blanton et al., 2011). In a policy brief for the American Association of Colleges for Teacher Education and National Center for
Learning Disabilities, Blanton and colleagues (2011) outlined recommendations for federal and state policy makers, as well as designers of teacher education programs. Their suggestions included professional learning for established teachers, holistic preparation programs for teacher candidates, partnerships between colleges and public K-12 schools, collaboration between educators and stakeholders, and federal/state funding for dual certification. Blanton et al. (2011) concluded such measures would promote positive change in the attitudes of general educators toward students with disabilities, which were necessary for the success of inclusion, students, and teachers because “an important part of teacher professionalism includes an ethic of persistence and a belief in the learning capacity of every student in their classroom” (p. 9).

Inclusive Teaching

Blanton et al. (2011) advised, “To realize high expectations for all students, including students with disabilities, teachers must be prepared to work collaboratively to utilize specific, evidence-based teaching practices that both challenge and motivate all of their students” (p. 5). This requires effort and knowledge of the special and general educator working collaboratively with all students. Musiowsky-Borneman (2016) compared coteaching to a marriage in the classroom, where the teachers have to work through their pedagogical differences to meet the needs of the students. Scanlon and Baker (2012) interviewed special and general education teachers in focus groups to discuss how they work together to inform the IEPs of the special education students in their classes, as well as guide their own teaching practices, to ensure all students work to their full potential. Instead of utilizing a theme-based process of coding,
Scanlon and Baker (2012) sought to avoid limiting what the data might reveal; therefore, they reported results of member checking at the third focus group to ensure they appropriately represented the teachers’ thoughts and ideas.

Scanlon and Baker (2012) determined that when teachers communicate and work together on meeting the needs of their special needs students in the general education setting, all students in the classes perform at a higher rate as a result. One teacher stated, “Providing class-wide accommodations for the benefit of all students is not only pragmatic but also desirable because it benefits all learners” (Scanlon & Baker, 2012, p. 222). Inclusion into general education classes could be a model considered for use by all students with disabilities in some capacity or another (Blanton et al., 2011; Scanlon & Baker, 2012).

However, successful inclusion within schools requires a team of people to meet the needs of all students in the inclusive environment. In a review of three schools in which staff implemented schoolwide positive behavior supports (SWPBS) to address the needs of students with significant disabilities in the general education classes, Freeman et al. (2006) discovered students with significant disabilities and behaviors were not isolated to special classes; instead, they were included in the general education classrooms. Whole school or whole classroom supports were in place to address the difficult needs of students. In one instance, in order to decrease the incidence of a student who skipped class, the coteachers required all of the students to sign in and sign out as they came and went from the classroom. This decreased the truancy of the student while making him a part of the class because the teachers did not implicate him by implementing a single-
person plan for this student. This became part of the classroom routine (Freeman et al., 2006). However, this would not have been successful if a team comprised of administrators, parents, and the classroom teachers had not taken the time to meet in a collaborative effort to decide how best to help and include this student. This type of inclusion limits the ability for other students to single out their friends experiencing difficulties and makes behavior interventions part of the norm and the culture of that classroom (Freeman et al., 2006). It promotes the social model of disability (Peters, 2007).

Effects of Inclusion on Stakeholders

Philosophically and idealistically, inclusion derives from social equity, thus providing students with disabilities the education that will further lead them to have the full benefits, rights, and life experiences in a socially supportive society (Peters, 2007). This means that students with disabilities receive opportunities to participate with their general education peers, quality and equal education, and respect of their human dignity in the process. Peters (2007) postulated that policy that works towards these ends are of good practice. However, many schools still work in the medical model of disability and actually limit the growth, education, and abilities of students with disabilities. Peters (2007) also speculated that the number of people with disabilities will grow in the coming years and contended that a movement towards social model of disability will mean better outcomes.

The social model of disability encompasses societal acceptance of and relationships with people with disabilities (Peters, 2007). Simpican, Leader, Kosciulek,
and Leahy (2015) researched social inclusion of people with disabilities in various settings throughout their lives. They discovered that people with profound intellectual disabilities were likely to form relationships with their caregivers, whereas people with moderate disabilities were likely to form relationships with other people with moderate intellectual disabilities because they felt more supported by people like themselves. However, people with mild and severe intellectual disabilities were most likely to feel socially isolated because they fell into a group that does not quite fit into regular society (Simplican et al., 2015). When applying this concept to inclusion, it is important to consider how the feelings of people with disabilities might affect their ability to be included. Many individuals with disabilities place a high level of importance upon the opportunity to increase their friendships and involvement in schools (Simplican et al., 2015), and the school setting offers numerous opportunities for those relationships to form. The attitudes of others can impact the opportunities a person with a disability receives in the school (Westling, Kelley, Cain, & Prohn, 2013), but inclusion in general classes, and in the school as a whole, is important to the growth of a person with a disability.

The influence of a positive culture of inclusion was the topic of investigation by Kugelmass in 2006. Using a comparative analysis of one elementary school in the United States, one primary school in the United Kingdom, and one school that served students of ages 10 to 16 in Portugal, Kugelmass (2006) found that all three schools shared a positive culture of inclusion, regardless of their apparent differences and the uniqueness of each school. The way in which teachers dealt with various subjects in their
classrooms greatly shaped student thought. For example, teachers supported having students with disabilities in their classrooms and in the school; therefore, their students without disabilities were more likely to accept their peers with disabilities because they had only seen these students supported (Kugelmass, 2006). The principals shared a similar view that teachers had to be open to inclusion in order for it to work in their school.

From the analysis, the following themes related to inclusion emerged: (a) success; (b) uncompromising commitment and belief in inclusion; (c) difference among students and staff perceived as a resource; (d) teaming and collaborative interaction style among staff and children; (e) willingness of staff to struggle to sustain practice; (f) inclusion understood as a social/political issue; and (g) commitment to inclusive ideals communicated across the school and into the community (Kugelmass, 2006). The researcher noted that regardless of race, gender, and ability, all students were included in their educational process, and each school built a culture of inclusion for all students as one of their key tenets. The collaborative nature of the teachers in all the schools made it apparent that they focused on plans for each student’s success. The teachers supported each other in the implementation of curriculum and in their own teaching differences. Kugelmass (2006) also noted that, in order to continue acceptance of inclusion, school personnel would have to develop plans that addressed the needs of the schools, the requirements of the education systems, and the politics of the 21st century in the various communities. Kugelmass (2006) highlighted that the community and the general perceptions of the families served by the school also played an important role in
promoting inclusion for all. The adults in the schools seem to be great influencers of the lens through which students perceived each other.

An individual’s perceptions of others often influence the way a person will interact or form relationships. This is also the case when thinking about how students with disabilities are labeled in school. Often the labels can influence how a person perceives the competence or incompetence of the other (Johnson, Sigelman, & Falkenberg, 1986). Johnson et al. (1986) noted that perceiving a person with a disability seemed to garner more sympathy as the perceiver aged. Elementary students seemed less likely to perceive their peer with a disability positively if they knew that they were labeled with a disability; however, they were more likely to interact with the person if they were unaware of any label (Johnson et al., 1986). As the years have progressed, more studies have shown a more positive outlook on disability from people of all ages (Bunch & Valeo, 2004; Galván, Spatzier, & Juvonen, 2010; Grutter, Gasser, & Malti, 2017; Westling et al., 2013), but factors in schools that may influence the perception of people with disabilities by their peers remain (Dudley-Marling & Burns, 2014).

One influential factor is the inclusion model implemented in a school. Dudley-Marling and Burns (2014) conducted a comparison of two models of inclusion of disability into schools. The first was the least-restrictive environment (LRE), which approaches disability as something to be fixed, and the second was social constructivism, which acknowledges differences in disability not as a deficit inherent to the student, but rather a construct of the culture. Dudley-Marling and Burns (2014) highlighted that both models had the best interest of the students at the core of the thought process, but the
social constructivist view allowed for student differences and sought methods for adapting the already existing environment to the student, as opposed to removal to a specialized environment found in the LRE. The way in which school or school system personnel try to address the needs of the students with disabilities could have a direct effect on how they view themselves, how they are viewed by peers, and how they are included in the major events of a school that occur outside the classroom learning environment.

Student Interactions

Student interactions also have an effect on the overall inclusivity of the school and the perceptions of the roles of students with disability within each school. Peck, Donaldson, and Pezzoli (1990) conducted a study on two schools—one school that was inclusive of students with disabilities and another school that housed those students in special classes—and discovered that nondisabled students within schools that contained special classes and those that were inclusive of students with disabilities harbored very different attitudes towards their peers with disabilities. Peck et al. (1990) interviewed 21 students total in both schools in grades ranging from elementary to high school. The researchers selected student without disabilities based on characteristics exhibited by initiating interactions with students with disabilities, participating in peer programs, or participating in recreational events. The selection of students with disabilities derived from the relationships formed with their nondisabled peers (Peck et al., 2006).

In the school with special classrooms, students had various physical impairments or intellectual disabilities, and nonverbal students selected from this classroom used
communication boards to participate in the interview process. The students in the inclusive school setting all had moderate intellectual disabilities. Teachers aided in the conducting of interviews by assisting with communication for students with severe intellectual disabilities (Peck et al., 2006).

The transcription and coding of the interviews led to the discovery of six perceived benefits of interactions with peers with disabilities: (a) self-concept, (b) social cognition, (c) reduced fear of human differences, (d) tolerance of others, (e) development of personal principles, and (f) relaxed and accepting friendships (Peck et al., 2006). One student who was struggling with dropping out of school said that working with his peers with disabilities allowed him to be seen as “someone who was valued as himself” (p. 246). He also reported never feeling alienated from this classroom and always receiving the opportunity to participate in a positive way (Peck et al., 1990). This was the consensus for most of the students in the study.

While most benefits were positive, there were instances of reported discomfort because of behaviors and physical appearances of students with disabilities (Peck et al., 1990). Most of the older participants noted that after a while, the relationships they formed became more important than the worry of any sense of discomfort. One student stated, “Once you see they’re human, you know, you don’t see it” (p. 246).

While the age of the study may make it dated, the data are still relevant to inclusion, relationships, and friendships formed between peers with and without disabilities. This research spurred further study into the area of inclusion, but Peck and colleagues (1990) encouraged others to conduct further study to broaden the concept of
social policy as it relates to inclusion and relationships of people with disabilities to those without disabilities.

Student Perceptions of Peers

Hendrickson, Shokoohi-Yekta, Hambre-Nietupski, and Gable (1996) offered an indirect exploration of social policy. They discussed the idea that the perceptions of forming friendships with peers with disabilities held by students in middle school and high school settings greatly affect social interaction. They noted that prior to conducting their study, many other studies focused on elementary students, but rarely focused on students in the middle and upper grades, who suffer from many of the same feelings of isolation expressed by students with severe disabilities in other studies (Hendrickson et al., 1996). Therefore, they could mutually benefit from a relationship that helped to quell loneliness.

Hendrickson et al. (1996) defined friendship as “a social relationship between two people that is reciprocal, rewarding, and fun for both parties and is characterized by multiple, voluntary contracts and shared experiences across weeks, months, or years” (p. 20). When asked about students with disabilities in their classes, 37.9% of the 1,137 middle and high school students without disabilities reported having class or a friendship in class in the past and currently with a peer with a disability. The researchers conducted an ANOVA on the likelihood of these students developing friendships with peers with disabilities, and it revealed a significant effect related to friend development due to the type of educational setting, $F(3, 1113) = 70.535, p < .0001$ (Hendrickson et al., 1996). Student completion of a ranking for reasons they could be friends revealed the highest
ranking was the idea that students with disabilities needed friends, too; the next highest ranking was that the students liked to help people. Hendrickson et al. (1996) reported that students felt that teachers could facilitate these friendships by allowing them to work in teams with their peers with disabilities or by becoming peer buddies. Students who felt that it would be difficult to be friends rated the statement of “I wouldn’t know what to say or do” the highest, with “I would be nervous or uncomfortable” as the next highest (Hendrickson et al., 1996).

In their closing discussion, Hendrickson et al. (1996) noted a few key points indicated by the results. The first was that these student perceptions are complementary to more inclusion into secondary programs and community-based programs for people with disabilities; the second point was that 55% to 65% of the students who took the survey indicated a benefit to themselves for being friends with peers with disabilities (Hendrickson et al., 1996). Inclusion in schools and communities is important for the formation of strong and beneficial friendships and relationships for people with and without disabilities. Even though this research was conducted in the late 1990s, the sentiments expressed by these older students still holds true 20 years later, and the researchers recommended further research of shared experiences that various relationships within schools might provide to all students.

One such research study, conducted by Bunch and Valeo in 2004, addressed the effects of isolating students with severe or significant cognitive disabilities in special classes or schools. Students in special education schools and classes often receive fewer opportunities to interact with their peer than students with disabilities in inclusive settings.
receive (Bunch & Valeo, 2004). Many argue that these students lack positive social role models because they are only offered the opportunity to emulate students with other disabilities and not their nondisabled peers to gain an understanding of socially acceptable behavior (Bunch & Valeo, 2004). This argument supports inclusion of students with severe or significant cognitive disabilities into general education settings.

Bunch and Valeo (2004) posited that the peers of students with severe or significant cognitive disabilities accepted them better if those students were not isolated in special classes or schools. To investigate this, Bunch and Valeo (2004) conducted qualitative research in two settings: inclusive and special schools. They interviewed students without disabilities of all ages in both settings regarding their interactions with peers with disabilities. Major differences existed between the settings in regard to the formation of friendships. Elementary students in the inclusive schools claimed to have friendships with students with disabilities, while those in special schools noted that they knew who their peers with disabilities were, but felt they really only had friends within the special classes (Bunch & Valeo, 2004). Interestingly, no secondary student in either setting claimed to be friends with students with disabilities, but they defended their peers with disabilities when questioned about inclusion into the general population—they felt they had a space to be included even though they did not always receive the opportunity (Bunch & Valeo, 2004).

The secondary students interviewed by Bunch and Valeo (2004) were the primary speakers of advocacy among the student participants. These statements of advocacy came in the form of defense of their peers with disabilities when they performed strange
or socially awkward behaviors. Elementary students did not feel the need to advocate for their peers because they just automatically included them if they felt there was a mutual friendship.

The researchers noted that a salient find of this study was students in inclusive settings claimed to have friendships with students with disabilities (Bunch & Valeo, 2004). This claim is likely because they have the opportunity to form relationships with each other due to the safety of the setting for all. This study also seemingly supported the need for inclusion in the general population because it affected the perceptions students without disabilities have towards peers with disabilities and could affect the school population’s overall perceptions of disability (Bunch & Valeo, 2004).

Students’ perceptions of each other can largely influence relationships and friendships. For instance, if something is “cool” (Galván et al., 2010, p. 346), other students may participate just to achieve the same level of coolness or social status. Galván and colleagues (2010) applied this concept when they conducted a study with general education students at two elementary and one middle school to investigate the idea of social influence on student perception at school and determine how students establish a social norm for themselves. The research suggested the behaviors changed as the students got older to possibly establish dominance and social status. These behaviors, classified as academic engagement, academic disengagement, and antisocial conduct, differed significantly from grades 4 to 8 because students were less likely to try to please adults and more likely to try to please each other as they age (Galván et al., 2010). The Tukey post hoc analysis utilized by Galván et al. (2010) revealed “academic engagement
was rated more prevalent at 4th and 5th grades” (p. 348) compared to those of the middles school grades; sixth graders reported higher academic engagement compared to seventh and eighth graders, whereas seventh and eighth graders reported consistent academic engagement by their peers. All grades showed a proportion of their peers had higher academic engagement in the spring than in the fall. The same post hoc analysis conducted on academic disengagement showed that fourth and fifth graders felt that antisocial behavior was less prevalent than it was in the middle school grades. Sixth and seventh graders felt that same about the grade higher (Galván et al., 2010).

Galván et al. (2010) also performed a correlational analysis of peer coolness in relation to academic engagement, academic disengagement, and antisocial behavior. The elementary students showed positive correlations between coolness and academic engagement, but the middle school grades did not. Sixth and seventh graders showed positive correlations with coolness and academic disengagement. Eighth grade showed this same correlation, but only in the spring semester. All students in the middle school grades had positive correlations between coolness and antisocial behavior, but the students in elementary school grades had a negative correlation between these. The behaviors that show status differed drastically in elementary and middle school (Galván et al., 2010).

The increase of antisocial behavior as considered cool in middle school could come as a determent to both social and academic behaviors. Galván et al. (2010) noted that larger class sizes possibly create a less intimate setting for positive student interaction. It begs the question of whether students feel that they need to stand out more
in larger groups by soliciting negative attention. All of these finding suggest that the establishment of social norms among students has a great impact on how they view and treat others, which in turn may influence how they view and treat difference in groups.

Other factors could potentially affect social norms, student perceptions, and student perceptions and treatment of one another. Brown, Higgins, Pierce, Hong, and Thomas (2003) noted disability, gender, and race played a role in the formation of alienation. The researchers deconstructed feelings of alienation into four dimensions: normlessness, powerlessness, estrangement, and meaninglessness. To test their hypotheses, Brown and colleagues (2003) distributed a Likert scale questionnaire to 222 students at two high schools. Sixty-eight of those students, identified as having a disability, received services in the special education setting.

When conducting a MANOVA, Brown et al. (2003) found students with disabilities reported statistically significant difference in all four dimensions $F(4.216) = 10.31, \ p<.001$. ANOVAs conducted on the individual dimensions and three of four dimensions showed a statistical significance: normlessness $F(1.219) = 9.98, \ p<.005$, powerlessness $F(1.220) = 13.36, \ p<.001$, and estrangement $F(1.220) = 21.27, \ p<.001$. The mean scores indicated that special education students scored higher than did general education students in all dimensions. Brown et al.’s (2003) findings indicated that special education students were more likely to feel alienated, possible due to placement and/or enrollment in other classes to address remedial academics and social skills. Brown et al. (2003) concluded that students with disabilities desire to have the same school experience as their peers and perception as a part of the school body, but further
research is necessary to determine how to improve inclusion of students with disabilities in the student body.

In an investigation of peer attitudes toward students with disabilities, Grutter and colleagues (2017) conducted a study on adolescent students without disabilities in Switzerland to gauge how their cross-group friendships and emotions might affect their views of having students with disabilities in class. Grutter et al. (2017) found that females reported higher rates of cross-group friendships than did males ($t(1028.11) = 17.89, p<.001, d = 0.82$) and higher positive emotion attributes ($t(1150.06) = 2.84, p<.005, d = 0.13$), thus leading to more inclusive attitudes for girls. Those students who emigrated to Switzerland held less inclusive attitudes than those who were native to the country ($t(1000.95) = -2.51, p = .01, d = -0.12$). Slope tests indicated that cross-group friendships were significantly related to positive attitudes towards inclusion (Grutter et al., 2017). The researchers concluded that if students are placed in an environment that fosters cross-group friendships and models positive peer interactions with students with disabilities, students will interact positively with their peers with disabilities and accept them as part of their class. Grutter and colleagues (2017) also noted exposure to inclusion prior to adulthood can greatly shape adult attitude because adolescents are more flexible in their views of self and ideas. Providing social situations could prove beneficial to students with and without disabilities by giving them the opportunity to understand each other and interact in positive ways. Doing this makes students with disabilities part of the community, instead of pushing them to the margins of the school (Grutter et al., 2017).
On some college campuses, inclusion has helped to create relationships and provide a positive space for people with disabilities to flourish. In a study completed by Westling and colleagues (2013), 572 undergraduate college students without disabilities answered questions regarding their perceptions of the inclusive college experience offered at their campus. Analysis of each 11, forced-choice items on the questionnaire involved a simple percentage of the highest answer. The researchers concluded that responses to the most important items (numbers 4-9) showed that most students felt that classes should include people with disabilities and peers personally benefited from the experience.

Westling et al. (2013) also conducted a t-test on the data and determined that people who had family members or friends with intellectual delay (ID) had more positive attitudes than did students without prior contact ($M = 4.33, SE = .04$). This was significant given that $t(507.88) = 3.38, p < .001, r = .16$. Women reported more significantly positive attitudes than their male peers: $t(246.48) = 6.50, p < .001, r = .37$. The results indicated that many of the students felt that they benefited from having a friend in the program. Other students reported that if they had not previously had experiences with people with ID, but attended with them, the class was improved due to the presence of the person with ID. However, female students tended to view the program and people with ID more positively than did their male peers and accounted for 14% in the variance of attitude (Westling et al., 2013). None of the students reported a loss of time with the professor due to having a person with ID in the class. As a parting thought, the researchers posited that their findings in the study indirectly suggested the
importance of having inclusion and an inclusive culture in high schools. Inclusion seems to positively affect the attitudes of the students towards disability (Westling et al., 2013).

Self-Perceptions

Self-perceptions also play a part in schools for people with and without disabilities. School-aged children tend to hold a positive self-perception when they are successful in school (Begley, 1999). People with disabilities are the same in the sense of holding positive or negative self-perceptions as they relate to varying competencies commonly monitored for people with disabilities.

For example, Down syndrome is often a disability subject to the stereotype that one of its traits is a positive outlook on all things in life. A study conducted by Begley (1999) aimed to demonstrate that people with Down syndrome may have varying self-perceptions based on three competencies: academic, physical, and social acceptance. The educational placement of students with Down syndrome varies from special classes and schools to inclusion in the general education process (Begley, 1999). Begley visited each of the 64 student participants, ages 8 to 16 years old, two to four times. On each occasion, the researcher introduced herself and clarified to the students that she was not a teacher; instead, she simply wanted to know what they were thinking.

Begley (1999) utilized the Pictorial Scale of Perceived Competence and Social Acceptance due to its relevance to school aged children, but adapted the scale to include pictures in order to serve the research participants in a better capacity. Begley reported the results in comparison to students in first or second grade. The mean score for social acceptance was 3.42 for people with Down syndrome. This score was higher in self-
perception than that of the first or second graders, and the researcher felt the comparison was not a valid comparison. However, when placing the research subjects into age groups and comparing the mean scores of those groups, the scores were close, giving a much better picture of their self-perceptions according to their ages; the older the subjects, the higher the positive self-perception scores (Begley, 1999).

Begley (1999) also compared the scores across genders and found that females scored higher than males in positive self-perception; however, Mann Whitney U testing revealed that the higher scores were not statistically significant. Students in the general education classes scored higher on academic and social acceptance self-perception domains than their peers with Down syndrome in special classes, but the students in special classes scored higher in the physical competence self-perception domain than did their peers in the general education classes (Begley, 1999). These results indicated that students with Down syndrome, regardless of age, gender, and class placement, generally possess positive self-perceptions and feel accepted by their peers (Begley, 1999). This positivity is possibly due to the need to be accepted and the desire to have a place in the various school settings.

Students with other disabilities could possibly feel that same, but this exact study has not been replicated with other subgroups of disabilities in schools, such as students with autism, cerebral palsy, and other possible developmental disorders (Begley, 1999). Because this study was conducted in the late 1990s, its implications may be dated no longer applicable to the inclusion settings. However, the idea that students with
disabilities have self-perceptions could be explored to address their needs and the importance of peer acceptance within the current school settings.

Begley’s (1999) study revealed the importance of helping students with disabilities find their voice and soliciting their opinions about being included in school. Begley indicated that further research needed to be done to see if self-perceptions changed when their siblings attended the same school. It also left a gap for discovering how a teacher might react to a sibling group inclusive of a person with a disability when a sibling is in their classroom and how that might influence their instruction or interactions with the students.

Peer and Sibling Perceptions

To examine perceptions of siblings with and without disabilities, Fellner and Comesañas conducted and authored a study with two female siblings, Laritza and Yarotza Duperoy in (2017). This qualitative study utilized narratives and videos of the two sisters presenting their perspectives on special education and its impact on their education, lives, and relationships. The two sisters, Laritza and Yaritza were born only a year apart. Upon immigrating to the United States from Puerto Rico with their family, the two sisters participated in bilingual classes until Laritza was identified as a student with a learning disability in the fifth grade. She attended math class in the general education class, but she received instruction in her other subjects in the special education setting (Fellner et al., 2017).

When Yaritza entered college, she suggested the creation of a poetry workshop to her professor. When Laritza attended a session, the professor asked the two siblings to
discuss the impact of special education on their lives in his special education class for
preservice teachers. This experience led to the idea of conducting a study that allowed
the siblings to voice their perspectives to a wider audience.

The researchers worked closely with the sisters to analyze the themes in their
discussions of schooling and the effect on their view of themselves and each other.
Yaritza reported feeling that she had to take care of her sister, Laritza, because she was
disabled. Laritza felt that placement in a special classroom isolated her from the rest of
the school. She reported feeling dumb and unable to go to college like her sister. In the
discussion, Fellner et al. (2017) described how Laritza could advocate for herself and
might have done better in school had she had the adult encouragement to do so.

School personnel’s perception of her as a student with a disability might have
influenced how she viewed herself. If the school had taken on a more inclusive attitude
towards disability, then she might have felt she had the ability to advocate for herself, and
her sister might have had a greater voice in defense of her sister as well. The researchers
felt that teachers viewed Laritza’s disability as a deficit to her abilities (Fellner et al.,
2017). Laritza unknowingly placed herself in the deficit thoughts of others in her school
due to the great influence her disability had on her as a student and person. This idea
could affect other students in a similar situation, leading overall school perspectives to
fall into the deficit camp as well.

Perceptions of Family Roles and Support for Siblings

Often, the longest relationship a person has is that of the sibling relationship
(Lohmann, 2014). Siblings of people with disabilities will often share many of the same
responsibilities as their parents as they age (Conway & Meyer, 2008). Research has focused a great deal on the best method for making a person with a disability feel included in school; however, consultation of siblings of people with disabilities rarely occurs when making decisions that could change the family dynamic or affect their school environment (Conway & Meyer, 2008). Furthermore, siblings of people with disabilities often feel isolated because they may not meet someone in a similar situation until it is their turn to care for their sibling (Conway & Meyer, 2008).

Conway and Meyer (2008) wrote about sibling shops, or sib shops, where individuals work with the family to help the sibling without a disability feel supported. In the Sunfield sib shop, personnel work with siblings of people with disabilities to include them in the planning process for their sibling with a disability (Conway & Meyer, 2008). They provide them with the opportunity to meet other siblings, listen to their feelings, and carefully consider their thoughts on how to continue to help other siblings of people with disabilities. Giving agency to the siblings of people with disabilities helps them to cope with the difficulties they might experience and educates them on their sibling’s disability so that they might find a way to advocate for their sibling in other places. Overall, siblings have experienced positive outcomes in their program (Conway & Meyer, 2008).

Not all siblings have positive experience when thinking about how their sibling with a disability makes them feel, as Ward, Tanner, Mandeleco, Dyches, and Freeborn (2016) discovered in their interviews of school-aged siblings of people with autism from 25 different families. Ward et al. found that the main theme from all of the participants
was contradiction. Many of the participants would say that they had up and downs but mostly happy memories and times with their siblings, but then they would report how difficult their siblings could be a good bit of the time.

When the siblings talked positively of their sibling with autism, it was often their personality attributes that they liked and felt made their siblings unique. When they discussed differences, the older siblings noted the difference from their peers’ families, but the younger ones seemed to do a better job taking the differences in stride and often did not report really noticing a difference (Ward et al., 2016). The majority of the siblings felt positive about their experiences with their siblings and reported a positive impact on their life, such as being kinder and more patient with others. Most of the older siblings noted being in a position of caregiving, and the younger siblings noted being playmates and friends with their sibling with autism (Ward et al., 2016). This could have an effect on how they deal with sharing school experiences and how they advocate for their siblings as they mature.

Typically, thoughts of inclusion center on the idea of inclusion in school; however, siblings with and without disabilities have to work to learn how to include and accommodate each other in order to grow their relationship. Often the sibling is the first friend and first relationship for the sibling with a disability (Ali & Sarullah, 2010). Ali and Sarullah (2010) addressed the relationship between typical siblings and siblings with a disability. They interviewed five siblings without a disability and asked them questions about how their relationship with their sibling with disabilities changed over time.
Because they felt that they would be able to engage in mature reflection on the growth of their relationship, Ali and Sarullah (2010) selected siblings between 22 and 24 years old.

Many of the siblings reported that their growth occurred through having to help care for their siblings with disabilities (Ali & Sarullah, 2010). They liked when their friends acknowledged how wonderful it was that they were able to help their sibling with a disability in a meaningful way. The siblings reported that their relationships changed for the better as the nature of their caregiving tasks changed. Ali and Sarullah (2010) noted that for the most part, the siblings without disabilities reported having only positive ideation towards their sibling with a disability, and only one sibling reported any negative feelings due to perceived neglect of the parents. When the parents shared information about the disability of their child with the siblings and how to help care for their sibling, the siblings typically reacted positively, and they were willing to help (Ali & Sarullah, 2010). Inclusion in the family life appears to be positive if the siblings will help with inclusion of their siblings with disabilities in other aspects of their shared experiences.

Oftentimes when a student with a significant cognitive disability is included in school, it is because the parents of that child have pressured school personnel to include their child. Gallagher et al. (2000) conducted qualitative phone interviews with parents and siblings without disabilities to determine how the families felt about the inclusion of their child with a disability in school. To encourage honesty, Gallagher and colleagues (2000) assured the siblings that they would not share their answers with their parents. They first asked parents who broached the idea of including their child with a disability in school, and the majority of the parents responded they had asked; only a few stated the
school had suggested it. When asked the same question, most of the siblings were not sure, but a few responded that their family had asked because they wanted their sibling to be treated equally by the school (Gallagher et al., 2000).

Many siblings reported that they felt their sibling with a disability was included enough in school and in the community, while parents wanted more for their children (Gallagher et al., 2000). Both the parents and the siblings stated that the child with a disability wanted to participate in many of the same activities as their sibling. The siblings liked that their sibling with a disability wanted to do the same things they did. Finally, when asked if they saw their siblings during the school day, most of the siblings without disabilities reported going to a different school than their sibling with a disability, and only two, who attended the same school, said they saw their sibling in the hall and in electives. The parent participants reported that their child without a disability played a valuable role in the inclusion of their other child, while the siblings did not really know what inclusion was (Gallagher et al., 2000).

Siblings without disabilities may have different feelings about their siblings with disabilities at different times during their lives. Pompeo (2009) conducted a qualitative study on five women in college who were sisters to brothers with varying disabilities. She talked with them during interviews about how they felt during their later childhood years about their brothers and the reaction of their friends and community. A few of the sisters reported they really did not notice the difference in their sibling until school, when someone pointed out that their sibling was different. Some would question them about what it was like to have a brother with a disability, and they would respond that it was
normal because they had known nothing different. The sisters noted that when they had friends coming over to their houses, they would often tell their friends ahead of time about their brother as a way of coping with the noticeable differences in their family and protecting the brother and parents from any offhanded comments (Pompeo, 2009).

They often worried about other students bullying their brothers in school and wanted to do what they could to protect them (Pompeo, 2009). Many times, they felt glad they did not have to witness some of the bullying because they did not want to know more than what they did on the subject because it made them sad and angry.

Pompeo (2009) also found that having a brother with a disability affected the participants’ career choices. All five were in caregiving industries, and three of the sisters reported they were planning to become special education teachers because they wanted to make school better for children like their brothers. Pompeo (2009) concluded that it is necessary to inform teachers of the family situation to better support the siblings of people with disabilities.

Summary

This study aimed to discover peer and sibling perceptions of disability, as well as how those perceptions influence the sibling relationship. Through the lens of disability theory, I gave voice and power to the participants with disabilities and their siblings without disabilities. Furthermore, students who are peers of individuals with disabilities were allowed the voice to explain their positive and negative perceptions of inclusion of these individuals in school events.
This literature review focused heavily on the historical underpinning of school and its effects on the perceptions of disability throughout its inclusion into the educational sphere. It provided a discussion of the teacher’s influence or needs on the conducting of special education. Inclusion of people with disabilities has both positive and negative impacts on the classroom and instruction. Deficit thinking also plays a role in the perceptions of all stakeholders involved in the education process. However, a gap in the literature exists regarding the influence of attendance in the same school on the relationship of siblings with a disability and siblings without a disability. Additionally, a gap in the literature exists on how teachers may or may not change their instruction when they know they are working with a student from a sibling group inclusive of a person with a disability. This study sought to fill that gap by soliciting answers about teacher and sibling perceptions and giving special attention to the participants with disabilities. Chapter 3 offers a detailed description of the methodology to accomplish this.
CHAPTER 3

METHODOLOGY

In recent U.S. educational history, students with disabilities have been included in the classrooms and school activities. Many of these students attend the same schools as their siblings. The purpose of this phenomenological study was to determine whether the relationships and experiences among siblings with and without disabilities influence their school performance and the instruction of these students. This chapter addresses the study methods of phenomenology as they pertain to answering the following research questions:

1. How do students and teachers’ perception of disability inclusion in a secondary setting influence the school experience of siblings with and without disabilities?

2. When working with one member of a sibling group, how do teachers modify their instruction to support the siblings?

Research Design

The purpose of this study was to understand the perceptions of disability inclusion in schools from the viewpoint of siblings with and without disability who attend the same school. I also sought to discover how those perceptions might influence the shared experiences and if it impacted the performance of siblings and teacher instruction of those siblings. Due to the nature of discovering relationships, this study lends itself to a
qualitative paradigm. In qualitative study, “the inquirer and respondent are acknowledged to interact and influence each other” (Brotherson, 1994, p. 103).

Phenomenology provided the method to gather, analyze, and discuss data pertaining to the questions. The inclusion of people with disability into schools and the inclusion of disability in daily discourse are recent phenomena that allowed me to learn more about their influence on life in school and on siblings. This provided an opening as a researcher to uncover more about the phenomenon of shared experiences of siblings with and without disability as they relate to each other in the school setting.

Perceptions are often a way for people to categorize or find meaning in their experiences. Perceptions can be found in the description of these experiences and in interpretation of the descriptions. Phenomenology is the study of the lived experiences and how the perceptions inform or create a phenomenon (Creswell, 2013). These perceptions are formed by lived experiences, and that is the essence of phenomenological study (Husserl, 1931/2002). Because I sought to understand the perceptions of disability from a group of students and those of siblings with and without disability who attend the same school, phenomenology allowed me understand disability from the viewpoint of the students as they have experienced it. It also allowed me to gain understanding of how the siblings experienced disability and how they viewed the perceptions of their peers.

Unique to phenomenology is the idea that participants who have common individual experiences when grouped together create a phenomenon. Those experiences compose the essence of the what, how, and who of that phenomenon (Moustakas, 1994). van Manen (2016) wrote about phenomenology as being conscious experiences or
trials—almost like experiments. He described all experiences as ordinary and extraordinary based on the participants’ perceptions. I wanted to discover how the ordinary and extraordinary experiences with disability influence sibling perceptions of the world and how those perceptions might alter the worldview of the sibling groups. These perceptions are similar to interpretations of the reality of the event or time (Merleau-Ponty, 1962; Romdenh-Romluc, 2011). Heidegger (1927/2013) viewed interpretation as a precondition for our understanding of the world. In order for us to understand experiences, we must be able to interpret them.

Heidegger (1927/2013) and Husserl (1931/2002) held opposing ideas on how a researcher should include, or not include, his/her own informed experience while conducting research on a phenomenon. Heidegger believed that the researchers should include his/her own experience when interpreting that of the participants, whereas Husserl believed that the researcher should put aside personal experience and simply describe the experience of the participants as the reality of what they thought they experienced, rather than interpret them. Romdenh-Romluc (2011) described Husserl’s idea through the use of a dog, stating that if a person imagined a dog as brown and then changed the color of the dog, the dog would still be a dog and the color change perceptions do not destroy that which makes a dog a dog. However, if one were to change the paws to hooves, then the dog would cease to be a dog. The color of the dog is unessential, but the paws of a dog are. Romdenh-Romluc (2011) elaborated,

One imagines the thing one experiences as having different features to find out whether changing a particular property destroys its identity as a thing of that type.
If it does not, then that particular property is not essential to it. If it does, then that particular feature is part of the thing’s essence. (p. 8)

When looking into the phenomenology of disability as it pertains to the students’ perceptions of it, I tried to understand how it may be essential to, or unessential to, the events of a school, as well as how it may influence siblings. I adopted a Husserlian stance on perceptions and described them as they were when documenting data. However, I also applied the philosophies of Heidegger and Merleau-Ponty to interpret this phenomenon as a way to add to the body of knowledge of schooling and disability. They both believed that understanding one’s perceptions is a means of interpreting the phenomenon (Moja-Strasser, 2016). I attempted to give power and voice to people with disabilities in this study, understanding that their perceptions required interpretation if they were unable to completely describe their feelings, perceptions, and relationships, while staying true to their identities as people.

Also important is the idea of intentionality. This concept is discussed by Diedrich (2001) in her review of three books on disability. She stated, “Although illness and disability cause a shift in the character of one’s intentionality, they are not conditions in which there is simply a lack of intentionality” (p. 215). When thinking about how disability plays a part in this study, I pondered on the choices that the siblings with, and without, disability make due to peer pressure or due to personal choice. These intentions informed the phenomena in the study, but left room for some interpretation on my part as the researcher, although I had to bracket my previous thoughts on the sibling relationship due to my own bias in that area (Husserl, 1931/2002). Despite Husserl saying that a
description is sufficient in phenomenology, I aimed to use the ideas of interpretation according to Heidegger (Moja-Strasser, 2016) to answer the following question: How do students and teachers’ perception of disability inclusion in a secondary setting influence the school experience of siblings with and without disabilities?

Research Participants

I selected students from the secondary education setting because I felt that they were old enough to understand that their school experience could affect their sibling relationships. All of the sibling participants were teenagers or young adults between 17 and 22 years old, with the exception of a sibling without disabilities who was 25 years old and taught at the school where her sister attended. The age disparity is due to IDEA laws that allow a person with a disability to attend school until the day before their 22nd birthday (U.S. Department of Education, 2010). All students were school-eligible with the exception of one group of siblings where the sibling with a disability recently aged out of school because he turned 22, thus, he was no longer eligible for services. However, he had only been out of school a few months at the time of this study, and he attended the same school for six years, overlapping both of his siblings. This sibling group provided a good sense of the phenomenon in retrospect. Despite Hycner’s (1985) caution about interviewing being retrospective in nature, this family was a wealth of knowledge because of the amount of time they spent in the same school.

I chose the sibling groups based on a prior relationship with me, and this helped me understand the phenomenon because I have been a part of the culture in which the phenomenon is based. One of the students with a disability was previously in my class.
She and I had a great relationship, which proved beneficial when interviewing her because I understand her mode of communication. I chose the other sibling group based on a professional relationship I have with the mother of the participant. The final group chosen was from the Mild Intellectual Delay (MID) classroom. While I knew the students, I did not have a relationship with them like I do with the other students, but because they were in the MID class, I was able to communicate well with the student. All groups had one sibling in the group at the same school or a sibling that had overlapped their school secondary school career recently. One group had an older sibling who attended the school the year prior but overlapped his brother with a disability longer than the younger sibling did. All siblings with a disability received services in special classes for students with significant developmental delay.

During the identification of participants, all siblings without disabilities identified a teacher with whom they enjoyed a great relationship. Unfortunately, some of those teachers declined to participate, and I selected general education teachers who were willing. The five teacher participants worked at the same school the student participants attended. Three of the teachers were special education teachers. Of those three, two worked directly with the participants who were siblings with disabilities as teachers in their classroom, and one teacher was in a leadership position at the time of the interview, but had a previous relationship with one participant with a disability. Two of the teachers were general education teachers. One teacher was also a sibling without a disability, and the other was a teacher who had a previous relationship with the other general education teacher and her sister with a disability.
The school in which all participants attended was in an affluent suburban area, and the student population of 2900 students made it one of the largest in the state. A large majority of the students was ineligible for free and reduced lunch. Males and females constituted an equal proportion at the school. The majority of the students were White (69.9%), Asian (18.7%), or Hispanic (5.5%). Less than 1% of the students were African American. Fifty percent of the students were enrolled in advanced placement classes. Only 8% of the students were considered to have a disability.

While I no longer worked at the school that served as the study site, I found it beneficial that I still had professional and personal relationships that allowed me appropriate entre into the culture of the school. I already understood these students with disabilities, having previously known all participants, and I was able to gain rapport with the students without disabilities because I was able to relate to them based on the school culture and because of our shared uniqueness in being siblings of people with disabilities.

Description of Participants

The sibling participants in this study were from three sibling groups that consisted of two to three siblings, with one sibling having a significant cognitive disability or autism. The ages of the siblings ranged from 17-25 years. All siblings were of school age minus three.

The teacher participants were five teachers in the same school. Three were special education teachers, two who worked specifically with the SWs, and one who worked indirectly with one SW, but had a special connection with the student and often supported her when she was in crisis. Table 1 depicts the pseudonyms, ages, gender, and
roles for the sibling groups, which are numbered arbitrarily Group One, Group Two, and Group Three. Table 2 displays the pseudonyms and roles of the teacher participants.

Table 1

*Description of Sibling Participants*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age (in years)</th>
<th>Role</th>
<th>Group Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logan</td>
<td>Male</td>
<td>22</td>
<td>SW</td>
<td>One</td>
</tr>
<tr>
<td>Andrew</td>
<td>Male</td>
<td>20</td>
<td>SWO</td>
<td>One</td>
</tr>
<tr>
<td>Cathy</td>
<td>Female</td>
<td>17</td>
<td>SWO</td>
<td>One</td>
</tr>
<tr>
<td>Linda S</td>
<td>Female</td>
<td>25</td>
<td>SWO/General Education Teacher</td>
<td>Two</td>
</tr>
<tr>
<td>Alexandra</td>
<td>Female</td>
<td>17</td>
<td>SW</td>
<td>Two</td>
</tr>
<tr>
<td>Hallie</td>
<td>Female</td>
<td>19</td>
<td>SW</td>
<td>Three</td>
</tr>
<tr>
<td>Noel</td>
<td>Male</td>
<td>17</td>
<td>SWO</td>
<td>Three</td>
</tr>
</tbody>
</table>

*Note.* SW=sibling with disability; SWO= sibling without disability

Table 2

*Description of Teacher Participants*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Betsy</td>
<td>General Education Teacher</td>
<td></td>
</tr>
<tr>
<td>Carl</td>
<td>Special Education Teacher</td>
<td></td>
</tr>
<tr>
<td>Linda T</td>
<td>General Education Teacher/SWO</td>
<td></td>
</tr>
<tr>
<td>Megan</td>
<td>Special Education Teacher</td>
<td></td>
</tr>
<tr>
<td>Regina</td>
<td>Special Education Teacher</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* SWO= sibling without disability
Sibling Group One: The Triad

This sibling group consisted of three siblings: Logan, Andrew, and Cathy. Logan was a 22-year-old young man with Down syndrome and the oldest of the three siblings. It is important to note that Logan was very shy with people with whom he was unfamiliar. While he knew me and said he remembered who I was (the researcher, I used to be a teacher at his school), a significant amount of time had elapsed since our last interaction, so he was hesitant in answering my questions without the presence of a sibling. Cathy, his sibling without a disability, assisted him in answering. We gave him and answer sheet with pictures for “yes” and “no,” and he also shook his head to answer, “yes” and “no”. Occasionally, he would utter “uh huh” for “yes” or say “no”. This began toward the end of the interview, presumably become his comfort level increased.

In addition, Logan used a communication program on an iPad, but he did not appear interested in using it during the interview. I wanted to ask Logan to use the iPad program, but I also did not want to take away his power and communication preferences during the interview with him.

His mother asked him to participate with me, which is likely why he agreed, but I gave him a “stop” picture, which we practiced using, and asked him to sign his own consent form just to make sure he really wanted to participate. I also interviewed him at his home so that he was in a familiar environment. I provided these accommodations to allow him to have a voice during his interview. Logan had aged out of school, but it was a few months prior to the collection of data for this study, so he was able to remember what it was like to go to school with his brother, Andrew, and his sister, Cathy.
Andrew, the middle sibling of Cathy and Logan, was a 20-year-old young man without a disability. He was in college when the data collection started, but he had good recollection of his experience of sharing school with his brother, Logan. Andrew spent more time in school with Logan than did Cathy. Logan started high school just before Andrew, but due to Logan’s learning differences and the requirements of the Individuals with Disabilities Act (IDEA), Logan was able to stay in schools six years or the day before his 22nd birthday. This spanned the entire time Andrew was in high school.

While in school with his brother, Andrew was active on the football team and the basketball team. He reported that sports were a big part of his life and Logan was often present at his events. Every morning, they would ride to school together, and Andrew would either walk Logan to class or leave him with Logan’s paraprofessional at the bus ramp. When Andrew broke his ankle and could not participate in sports, he would pick Logan up in the afternoons, and they would walk together to their mother’s car.

Andrew appeared to be a very relaxed and quiet person. He did not seem overly excitable, even when discussing things about which he obviously felt passionate. It was clear that he adored his older brother by the way he spoke highly of him. He did say that he did not like to talk badly about his brother or complain about his frustrations because he did not feel it was right to do so because Logan was not always able to understand or control some of the choices he made. Andrew was willing to answer all questions and quickly responded to the follow-up email I sent during the analysis process.

Cathy was the youngest sister of both Logan and Andrew. At the time of this study, she was a sophomore in high school, and she spent her ninth-grade year sharing
her school experiences with her brother, Logan. Cathy also seemed very calm and relaxed. She spent her first year at school sharing her time there with her brother Logan as he prepared to age out of the public-school system. When Andrew, graduated from high school, Cathy assumed the responsibility of walking with Logan to classroom in the mornings and from his classroom in the afternoons to meet their mother in the parking lot. She was a competitive swimmer for their high school. Logan often attended her swim meets, and she attended his Special Olympics meetings. In addition, Cathy volunteered to help with Logan’s swim team.

In the afternoons, Cathy stayed at home with Logan until her mother arrived, which was a new arrangement because of mother’s work schedule. I was able to interview Cathy at her home and observe some of her interactions with Logan. For the most part, they had their own activities at home with only a little bit of interaction. When they interacted, it appeared Cathy assumed a caregiving role until their mother got home. It was clear how much she cared for her brother and how willing he was to allow her to help him. This was even more apparent the day I interviewed Logan because he wanted Cathy to be there with him for moral support.

Despite the distance that college and other programs naturally created for the siblings as they matured, this triad appeared to be very close group. Both Andrew and Cathy talked about how much they really liked having a brother with Down syndrome. While Andrew shared that he sometimes imagined what life without a big brother with Down syndrome might have been like, he said that he would not change it because he felt that the experience had shaped him into a better and stronger person. Cathy echoed those
sentiments, although she never questioned having a sibling without Down syndrome.

When I asked Logan if he liked having his younger siblings go to school with him, he shook his head “yes” and pointed to “yes” on his answer sheet.

Sibling Group Two: Sister/Sister Pair

Group Two consisted of two sisters: Linda S, also referred to as Linda T for a teacher vignette, and Alexandra. Linda was the oldest sibling of Alexandra. They had a sister in college who did not participate in this study because she did not meet the criteria for participation due to never sharing time with Alexandra in the secondary setting.

Linda was a teacher and former student at the same school where Alexandra was a student. Linda, only in her second year of teaching, was very knowledgeable and passionate about the subject she taught in general education classes that were inclusive of people with disabilities, such as attention deficit hyperactivity disorder, dyslexia, and Tourette syndrome. The students with special needs in her class received services in settings that ranged from a collaborative setting with a special education teacher and a general education teacher to consultative services, where the student checks in periodically with a special education teacher to make sure their needs are met, but otherwise participate in a general education setting.

At the time of the study, Linda S was a 25-year-old teacher at the school that served as the study site. She was also the oldest of three siblings. Her youngest sister, Alexandra, attended the high school where she worked. Linda’s classroom was not far from Alexandra, and she often assisted if Alexandra needed help with anything. They saw each other at school several times a week. Although they were not in school together
in a traditional sense, they still shared a great deal of Alexandra’s high school experience. They did not live together, but sometimes they saw each other on the weekends as well as through the week at school.

Linda presented as a very open and outgoing person. She reported that she knew from a young age that she wanted to be a teacher, although she had never felt a desire to be a special education teacher: “That’s just never been on my radar . . . and I have been fine without it.” She also reported that, because she is an SWO, she defined disability differently. She thought of people with disabilities as more like her sister, or as she phrased it, the more “extreme cases.” Linda believed this thought might have played a small part in how she envisioned herself teaching.

Alexandra, the youngest of three sisters, had Down syndrome. She was in a classroom of other students with Down syndrome and other similar disabilities. Alexandra was very social, and she reported that she loved hanging out with her friends at school. As part of the cheerleading squad at her school, she had the opportunity to cheer at six varsity basketball games this year. She was also part of a cheer squad for teens with disabilities. Alexandra said she had a lot of spirit to share and loved to cheer as loud as she could. She attended the school where her sister, Linda, was a teacher, and she really enjoyed getting to see her sister throughout the week at school.

It was very easy to engage in conversation with Alexandra. She appeared very aware of herself and others. She was able to answer all questions without assistance, but she did need the question repeated at times or time to think about what I asked her. She answered “yes” and “no” questions with ease and responded to the majority of the “why”
questions or the open-ended questions that required more thought on her part. I repeated
some of her answers back to her to clarify her responses because, while she was able to
answer all the questions, her speech at times was harder to understand, and I wanted to
ensure accuracy for transcription purposes and avoid presuppositions. I felt that doing
this gave her more voice and power in the interview.

Sibling Group Three: Brother/Sister Pair

Sibling Group Three was the brother-sister pair of Noel and Hallie. Noel, the
younger and only sibling of Hallie, was a 17-year-old young man without disabilities. A
talented musician, he played the French horn for the school orchestra and played the
megaphone in the marching band. He also participated in the school’s musical theater
and community theaters. In addition, Noel sang and played piano and guitar.

I had the opportunity to get to know Noel his freshman year of high school
because I taught his sister, Hallie. If he forgot things at home, Hallie would bring them
into school, and Noel would come and get them from my classroom. He was always very
polite and thankful. Over the course of the year, I was able to get him to stay and talk for
a couple of minutes, which allowed me to get to know him better.

When I was recruiting families for this study, Noel and Hallie’s mother was very
candid when talking about her children. I was able to reconnect with Noel, and we were
able to have conversations about his sister that he may have not been as open to having
with someone he did not know. He revealed that the most important thing for him and
his family was for people to accept Hallie for who she was and the gifts she had. Since I
was able to get to know Hallie as a student and I was knowledgeable about her gifts and talents, Noel seemed willing to discuss with me the nuances of being her brother.

Hallie was an 18-year-old female with autism and a developmental disability. She was very energetic, and she expressed numerous opinions and emotions. Communication was difficult for her at times, often leading to meltdowns that could be difficult to manage. Due to her breakdowns, Hallie had a shortened day at school, which helped her stay calm and settled. However, she appeared very happy, and she loved to be around people with whom she was familiar. She knew many people at school, remembered them from year to year, and possessed a unique way of bonding with people. Her relationship with her mother was special, and she loved spending time with her mom. Like her Brother, Noel, Hallie expressed the same love for all things musical. She became really excited when her favorite songs play on the radio. One of her favorite musicals was *The Sound of Music* with Julie Andrews.

My observations conducted at school and her home revealed that Hallie requires a fair amount of mobile sensory input. Opportunities to get out of her seat and move around during work times helped her to remain calm. She also needed to work in short timeframes to keep her from reaching her fatigue threshold. Aware of her needs, I modified the interview methodology accommodate her and retrieve answers to the questions. For example, I provided her with visual options for the “yes” and “no” questions. I made a “stop” sign that she could touch just in case she decided that she did not wish to continue with the interview. I also told her she should request a break if she needed one, and she wanted to continue the interview after resting. Her mother was
present for the interview just in case she reached her fatigue level and could not communicate that to me. Hallie had a hard time communicating with people with whom she was unfamiliar; however, I was her former teacher, and she seemed comfortable talking with me. Her mother served as her communication facilitator. We talked in small timeframes led by Hallie so she could communicate and feel like she had voice and power in the interview process.

Teacher Participants

Five teachers participated in this study. Two were general education teachers and three were special education teachers. All of the teacher participants worked at the high school that served as the study site. The following sections provide a description of the teachers, who are referred to by their pseudonyms: Megan, Carl, Regina, Linda T, and Betsy.

Megan. Megan was a veteran teacher of 25 years. A special education teacher for a number of years, she had worked with students with cognitive disabilities for the last six years. She was the classroom teacher of Alexandra. She taught a class where the students were with her for most of the day, and she adapted and modified core subjects as necessary. Megan also worked with students on life skills, job skill, and social skills. Most of the students in her class fell in the mild to moderate range of abilities. All were verbal and able to do many things independently. Megan reported using general education peer facilitators to help the students in the areas in which they struggled. These students also accompanied Megan’s students into electives and worked with students individually in her classroom during academics. She felt very strongly about the
importance of her students being included with the whole school, and she worked hard to encourage her students to do many things outside her classroom, such as, clubs, teams, and dances.

As a huge proponent of inclusion, Megan worked with her students to be a part of the general education classes for many of the electives and some of the core subject areas where it was appropriate. She also led the peer facilitator program or the reverse inclusion program, as she referred to it, which was a program at the school where the general education students sign up to be helpers and friends in the specialized instructions classrooms. Megan felt this program singlehandedly raised awareness of people with disabilities within the school and helped her students to gain confidence and friendships with the general education students.

Carl. Carl was a special education teacher who had been working with students in the general classrooms for a number of years. He had also been a behavioral support in the classroom where needed. He knew many of the students in all settings and expended extra effort to ensure he met certain students on a daily basis because he helped to support them behaviorally when they needed his help. In addition, he held a coaching position at the school. His roles in the school setting and in extracurricular activities made him well-known part of the community.

Carl reported that he felt very strongly that inclusion served an important role in creating awareness of students without disabilities and challenging teachers to improve their instruction and classroom climate to meet the needs of all their students. A very student-oriented- individual, Carl enjoyed working with students of all types of
disabilities. He reported feeling that he was a good leader and supporter of his teachers and students. However, Carl noted that many of his decisions were based on the needs of the students because he felt their needs were very important.

Carl had a very positive relationship with Hallie, one of the sibling students with disabilities. Every day, he was certain to visit her classroom and check on her to make sure she was okay. He was often around to help deescalate Hallie’s meltdowns at school because she trusted him very much. While he did not specifically teach in Hallie’s classroom, Carl felt that he had a good amount of knowledge about the students in that classroom; therefore, he was able to support the classroom teacher to help her meet the needs of all the students in Hallie’s class. He appeared very passionate when he related that special education students brought life and diversity into the educational environment.

Regina. Regina, a relatively new special education teacher, was Hallie’s classroom teacher. She had experience in working with people with disabilities from various volunteering opportunities and teacher program clinicals. At the time of data collection, Regina had only been in the classroom one month, but she reported completing her student teaching in a similar classroom environment. Regina was an athletic coach at the school as well, and she stated she liked to try to include people with disabilities on her team.

Regina stated that it was important for students with significant cognitive disabilities to get to know students in other classrooms, and she used general education peer facilitators to help her students with the skills they needed to master. She reported
this was her first year working with a sibling group where the siblings attend the same school and enjoy some of the same things. While she admitted that she was still learning about her new students, Regina reported that she felt like she had plenty of experience to talk about her feelings of inclusion and the relationship that she observed between Hallie and her brother, Noel, a student without disabilities. It was easy to converse with Regina because she was very open about her feeling and experiences with Hallie and Noel.

Linda T. Linda T was another relatively new teacher. She taught several sections of classes that also include students with disabilities, such as dyslexia, attention deficit hyperactive disorder (ADHD), Asperger, and Tourette syndrome. When asked about how many students with disabilities she taught, she replied that she really did not consider an individual as disabled unless he or she closely mirrored her sister, who has Down syndrome. Linda T reported that many people asked her why she chose to teach general education versus special education; she responded that the family members of general education students do not have a heavy influence on her daily planning as they do in a special education classroom. She appreciated the autonomy that she has a teacher in that sense. Linda T was also known as Linda S in Sibling Group Two.

Betsy. Betsy was a general education teacher who had been teaching for 13 years. Originally, she was a scientist. While pursuing a graduate degree, she decided to become a teacher’s assistant and fell in love with the idea of teaching. She pursued a teaching certificate and landed in the secondary level where she has taught different sections of various scientific subjects ever since. She related how much she loves the sciences and feels that all students should have access to science in any way possible. She talked at
length about how science “shouldn’t be viewed as some elitist thing” and that it is a subject that everyone should experience at some point in school. Betsy expressed her great desire to build a generation of students who view science as a tool for the betterment of life for all people.

Betsy was passionate about all students having access to the sciences. She taught advanced placement and gifted classes, but she also volunteered her planning to work with students with significant cognitive disabilities in her subject area. A few times a month during her lunch and planning time, Betsy created and implemented science labs with students with significant cognitive disabilities. She conducted these labs with the help of general education students she referred to as her “lab aides”. These students volunteered to create and implement these labs on lessons based on the standards that Betsy and the special education teachers agreed were important scientific aspects for these students. Betsy oversaw their creation of the curriculum and lessons, making sure that they are meeting the needs of these students. She stated, “You can find elementary labs, but you can’t find lab work for high school age students that modifies accordingly. There is not science work for them. So, we’re having to make it all.” She worked hard to make sure these lessons occurred no matter the schedule changes occurred due to various events in the school. While her daily class schedule did not include working with people with disabilities, she wanted to make sure that people with disabilities had access to the information she had to share because she believed that it could change how they viewed the world. Betsy believed these labs were some of the most important lessons that she
taught, and she reported really loving the opportunities and challenges these students bring to her classroom.

The two teacher participants, Betsy and Linda T, had known each other for years. Betsy was Linda’s science teacher, and she related that Linda T had very a positive influence on the other students in her class. Linda T was willing to talk about her relationship with her sister, who had Down syndrome, and share that experience with her class. In a small way, Linda T’s experience influenced Betsy to create and continue some of her class projects because she realized they were valuable for all students—with and without disabilities.

Data Collection

The purpose of this phenomenological study was to discover how the perceptions of inclusion within the school setting affect the relationship and achievement of siblings with and without disabilities, as well as discovering how the relationships might affect teachers and their instruction of these students. According to van Manen (2016), phenomenology aims to find the essence of experiences of a person or group of people. In this case, I collected interview data from three different sibling groups and five teachers of the students’ choosing. The teachers participated in individual interviews, and I conducted individual interviews with the siblings. This allowed me to be flexible with the schedules of the siblings and the teachers. Teachers were more willing to participate because of this flexibility, rather than trying to work them into a larger group at a certain time and possibly taking up more of their valuable time.
Interviews

Interviews are a common in many types of qualitative data collection. They can be an integral part of any study, for they provide data that can explain, disprove, or add to a time, place, or phenomenon under study (Dilley, 2004). I conducted individual interviews with all of the siblings because I felt that their input would be particularly important to the study. During my research process, I discovered that many studies conducted in the field of disability are often conducted on people with disabilities as the research subjects rather than participants. Munger and Mertens (2011) supported this finding by stating a similar sentiment. While my study focused on the perspectives of all the participants as important, I specifically wanted to give my participants with disability a platform to express their thoughts and ideas. Anyan (2013) discussed how power shifts in interviews can change the dynamics of the interview itself, as well as the reactions and answers of the interviewee. Therefore, it is important to enter an interview as equal to the person who one interviews (Anyan, 2013). With this in mind, I sought to ensure that the people with disabilities whom I interviewed were seen as equal in order to have the data reflect the power in their responses. Table 3. illustrates the location and the length of time spent with each participant.

In order to adequately give voice and allow the students with disabilities to maintain power, I considered special ways to interview these students in order to accommodate communication needs, such as providing visuals during the interview to aid in understanding and communication. Two students involved in this study had limited, effectual verbal communication and used alternative, augmentative communication
(AAC) devices. Through a longitudinal study that sought to include people with disabilities in their community planning, Cambridge and Forrester-Jones (2003) conducted a study on how to conduct effective interview with people with AAC needs. Cambridge and Forrester-Jones (2003) found that it was important to establish a prior understanding of the person’s AAC needs and to understand how they used AAC. This way the participant and the researcher would both be comfortable during the interview.

Fortunately, I had the opportunity to work two years with both students who used AAC devices. One participant was in my class for two years and the other was in another classroom that I worked closely with, thus providing me the opportunity to get to know that participant. Both participants had communication facilitators and devices that allowed them to answer my questions. Although facilitated communication can be a misunderstood and controversial way of assisting a person with a disability to communicate with others, Simpson and Myles (1995) asserted that it is an effective and scientifically proven way of communicating with those who struggle to communicate. In the event that facilitated communication did not work for the participant, I planned to formulate answers in the form of “yes” or “no” and included those on visual answer sheets so they could point to them, just in case they struggled with the open-ended questions. I also utilized a stop sign visual aid to allow the participants to stop the interview if they chose. The third student with a disability was a completely verbal student who required no communication device for facilitation. I conducted the interview with that student in a more similar manner as one of the siblings without a disability.
The siblings without a disability were also part of the individual interviews because I wanted a better sense of how they felt about their sibling with a disability. I believed a one-on-one setting would encourage the relating of their experiences better. I wanted to have a standard set of questions for all of the siblings in order to ask clarifying questions of each as needed. I asked the following questions of the siblings:

1. Do you like going to the same school as your brother/sister?
2. What do you like best about going to the same school?
3. What do you dislike about going to the same school?
4. How does it make you feel to go to the same school as your sibling?
5. Do you get to see your sibling during the day? What settings do you see them in?
6. Does your sibling help you with your school work? How do they help?
7. When you see your sibling at school how do you react?
8. Do you talk about school at home? What are some of the things you talk about? Why do you keep your school life separate from your sibling’s?
9. Do you feel supported by your brother/sister? What are some of the things they do to make you feel that way?
10. How do your teachers react when they find out you have a sibling at the school?
11. How does your teacher change their language when they learn you have a sibling with a disability?
12. When thinking about your sibling at school, how do you think they feel about sharing their school experience?

13. How do you think your teachers might change instruction to gear it towards your needs or your sibling’s needs?

14. What is your favorite subject to talk about with your sibling?

Interviews can be structured or completely naturalistic, allowing the conductor to ask questions as they arise organically from the discussion (Dilley, 2004). My teacher interviews were structured, but allowed for flexibility as the conversation developed. I started with a basic series of questions, while allowing the flexibility to ask other questions as they arose. I addressed the following questions, allowing for school subject matter specificity between the teachers to address their individual classrooms appropriately:

1. What is your understanding of the definition of disability?

2. How does inclusion affect the dynamics in your classroom?

3. How many classes do you teach that include students with disabilities? Any with significant cognitive disabilities?

4. How do you feel that students with disabilities are included in the school population and where do you notice them the most?

5. How does having a student with a disability impact your classroom?

6. When working with students who tell you they have a sibling with a disability in other classes, how does this impact your instruction for that student?
7. Have you ever felt the need to change your instruction for those students and how do you do that?

8. How does having a sibling affect their performance in your class?

9. What differences have you noticed in their responses to other students in your class and do you alter your instruction to illicit those responses?

10. Knowing that you have a student who has a sibling in the school, how do you encourage the other sibling to interact? How do you incorporate them into your classroom?

11. How do you think your language about disability might change if you knew you had a sibling of a person with disability in your class?

12. How would your language change with a person with a disability if you knew they had a sibling in other classes?

13. How would you change your instruction of a student with a disability to encourage interaction among the siblings? How do you encourage the sibling without a disability to engage in your classroom?

Data Recording

The interviews were structured but informal, so it was important that I record all sessions to help me remember the discussions for all questions asked, as well as any additional questions that organically arose. To do this, I used a voice recording application on my iPad Pro, as well as a small back-up digital recorder. Following the interviews, I transcribed the data collected through the use of a denaturalized transcription process (Oliver, Serovich, & Mason, 2005), hoping to capture the exact
words spoken without the extras of accent and body language. I then examined the transcripts for common themes to gain understanding of the participants’ perspectives. I made anecdotal notes in a research notebook to record ideas and questions in case I needed to revisit with the participants and to provide my analysis some context to keep from reducing the data too much (Hycner, 1985). On an as-needed basis, I reconvened the interviews to clarify any questions I had and review analyzed data for a validity check (Hycner, 1985). I did this with Andrew and Cathy for clarification during the analysis process, but I also did this will all of the SWO to establish trustworthiness.

During interviews with all participants, I was able to conduct a 15- to 45-minute interview, depending on how much the participant was able to participate or how long he or she was able to stay engaged with the interview. See to Table 3. for a description of each interview.

Table 3

*Interview Participants and Process*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Durationa</th>
<th>Role</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logan</td>
<td>Male</td>
<td>10</td>
<td>SW</td>
<td>Home</td>
</tr>
<tr>
<td>Andrew</td>
<td>Male</td>
<td>24</td>
<td>SWO</td>
<td>Home</td>
</tr>
<tr>
<td>Cathy</td>
<td>Female</td>
<td>28</td>
<td>SWO</td>
<td>Home</td>
</tr>
<tr>
<td>Linda S/T</td>
<td>Female</td>
<td>50</td>
<td>SWO/General Education Teacher</td>
<td>School</td>
</tr>
<tr>
<td>Alexandra</td>
<td>Female</td>
<td>15</td>
<td>SW</td>
<td>School</td>
</tr>
<tr>
<td>Hallie</td>
<td>Female</td>
<td>21</td>
<td>SW</td>
<td>Home</td>
</tr>
<tr>
<td>Noel</td>
<td>Male</td>
<td>38</td>
<td>SWO</td>
<td>Home</td>
</tr>
<tr>
<td>Regina</td>
<td>Female</td>
<td>22</td>
<td>Special Education Teacher</td>
<td>School</td>
</tr>
<tr>
<td>Megan</td>
<td>Female</td>
<td>33</td>
<td>Special Education Teacher</td>
<td>School</td>
</tr>
<tr>
<td>Carl</td>
<td>Male</td>
<td>25</td>
<td>Special Education Teacher</td>
<td>School</td>
</tr>
<tr>
<td>Betsy</td>
<td>Female</td>
<td>32</td>
<td>General Education Teacher</td>
<td>School</td>
</tr>
</tbody>
</table>

*Note.* a refers to minutes. SW=sibling with disability; SWO= sibling without disability
When working with a few of the siblings with disabilities, I had to provide breaks because they needed time to process questions, or they needed time to do something other than talk with me. I allowed the participants to guide the time and length of the interview. After the completion of the interviews and subsequent transcription, I created analytic voice memos that allowed me to record my thoughts of the moment and any questions I had. I sent follow up email interviews to for any questions that arose during the coding process. I entered interviews, follow-ups, and memos into Nvivo, data analysis software, and coded.

Data Analysis

Through phenomenology, data are analyzed to understand how the participants perceive the phenomenon they are living. Hycner (1985) delineated steps that can be applied to analyze this type of data, but cautioned that being formulaic with the data analysis in phenomenology can lead to too much reduction of data and not enough broad sweeping strokes to paint a good picture of the phenomenon and what can be learned from it. However, Hycner (1985) described a part to a whole method where the researcher starts with the broad transcription and strips it down to barest minimum without reducing the data to meaninglessness with little to no description of the phenomenon.

First, Hycner (1985) recommended transcription while noting as much nonverbal action as possible. For the nonverbal notation, I used field notes as recommended by Groenewald (2004), which, during transcription, helped me perceive how the participant
reacted to questions. For example, when working with Logan, He shook his head quite a bit and pointed to the answers. As I was asking questions I would note on the question list, shook head and pointed to yes. I would sometimes as for verbal clarification just to make sure that what he pointed to was what he wanted to answer. Second, Hycner (1985) recommended that the researcher bracket personal perceptions of the phenomenon in order to reduce the data by finding the smallest units of meaning while retaining openness to what the data might tell the researcher. I did this after listening to the interview for the first time before transcription. I felt this was an important part for me personally, because I had to work to separate my thoughts about what it meant to be a sibling and what the perceptions of the SWO were. I did not want to mix up my perceptions with theirs. Third, I listened to the interview recording several times and read the transcription several times. This provided a context for the data when finding units of meaning. Fourth, the researcher should find general units of meaning that “express unique and coherent meaning clearly differentiated from that which precedes and follows” (Hycner, 1985, p. 282). I did this on first quick first pass through all of the interviews right after transcription. Then I made more in depth passes to find all of the units of meaning. The fifth step was to find units of meaning that were relevant to the research questions. These units of meaning derive from the previous units of meaning. The sixth step was to have independent judges verify the units of meaning. For this step, I utilized the computer software of Nvivo to help me check my units of meaning in a meaningful way to provide me with a visual of my codes. Seventh, Hycner (1985) recommended the elimination of redundancies in the units of meaning, while noting how many times that unit of meaning
was listed because that could mean that unit is significant in some way. In the eighth step, Hycner (1985) recommended clustering the units of meaning and making sure to remember the context in which these units were found. The units of meaning can be found in more than one cluster, and the clusters can overlap because it is impossible to completely delineate human meanings. Once the clusters have been determined, the researcher can move onto the ninth step of determining themes from the clusters. The final step was to write a summary of each interview, making sure to include themes and to check with the original interview so that every piece of analysis is included (Hycner, 1985).

Groenewald (2004) related five steps as a way of “transforming the data through interpretation” (p. 17). His steps are broader than Hycner’s; however, he cited many of Hycner’s techniques. The first step Groenewald (2004) discusses is bracketing and phenomenological reduction, where the researcher is open to what the data might say without adding personal perceptions to avoid over analysis of the phenomenon. The second step is delineating units of meaning where the researcher finds statements that illustrate the phenomenon. These units are the smallest bits of meaning that a researcher could discover within a transcript. The third step is to cluster the units of meaning to find the essences of the meanings and to identify the significant topics within the data. The fourth step is to summarize each interview, validate, and modify the data. This is where all of themes come together to shape and inform the researched phenomenon. Here the researcher might want to check with the participants to ensure the researcher has understood what the participants meant. This gives the researcher the opportunity to
modify the summary to state the truest essence of the phenomenon. The final step is to summarize all the themes to extract their meaning and discuss the phenomenon in order to accurately and adequately report the data to fully understand the phenomenon (Groenewald, 2004).

The primary data source for this study included the transcripts the interviews. I used a combination of the data analysis methods recommended by Hycner (1985) and Groenewald (2004) when completing the data analysis steps. Hycner (1985) provided a descriptive step-by-step procedure for analysis that was helpful to me because it was easy to follow. Groenewald (2004) was not as prescriptive as Hycner (1985), even though I previously stated Hycner’s caution against prescriptiveness, but for the purposes of this study, following Hycner’s steps proved most beneficial. I also utilized field notes in the manner in which Groenewald (2004) used them because he seemed to rely a little more heavily on notes than did Hycner (1985). My field notes were generally in the form of questions I had during the interviews. They were also some body language of the SW so that I was able to capture what they were really telling me. Also, they were my initial thoughts right after completion of the interview. I kept field notes as a way to organize the data to provide a stepping stone towards analysis, as suggested by both Hycner (1985) and Groenewald (2004). I applied the preceding steps to the transcripts on an ongoing basis, as I constantly compared the data from one interview to the next to make sure that I found commonality among all of the data sources (Glaser & Strauss, 1967).

During analysis, one important part to remember was to listen to the interview recordings multiple times to familiarize myself with the words and the persons
interviewed (Hycner, 1985). Moustakas (1994) referred to this as “horizontalization” (p. 96), where each part of the transcription is considered important prior to forming the final themes and codes used to make in depth analysis. This method proved to be very helpful during analysis because I felt like I intimately knew each interview and was able to refer to exact spots while analyzing and putting my thoughts together.

Through the use of constant comparative analysis (Glaser & Strauss, 1967), I coded and segmented data into meaningful chunks, eventually leading to more code changes in order to find the most obvious themes. I made several passes on each piece of datum to find all the meaningful units. Anytime I coded a new piece and new node appeared I went back to all the previous pieces and coded for that new node. Bazeley and Jackson (2007) stated that codes should change from broad to narrow as the researcher progresses further into the research project. Through the use of the steps described by Groenewald (2004) and Hycner (1985), I conducted this broad to narrow analysis in a very succinct, meaningful way to provide the best possible outcome in discovering findings that describe the essence of the phenomenon in this study. At first I was coding very broadly by looking for any units of meaning, upon subsequent passes through the data, I was really looking to answer my questions while allowing the data to speak to the truth of my participants.

While analyzing the data according to the steps of Hycner (1985) and Groenewald (2004), I clustered the data into meaningful units that described the participants’ experiences with the phenomenon, as described by Moustakas (1994). I did this step with the interview transcripts and common codes in those transcripts. I made mind maps in
Nvivo that allowed me to get a good visual of the clusters. While looking at all of the transcripts, I found common themes to describe the phenomenon of disability in school and to describe how it might have an effect on the siblings and their teachers’ instruction. Doing this helped me to discover the essence of the phenomenon and, according to Heidegger (1927/2013), interpret it as well. Chapter 4 provides in-depth descriptions of the siblings’ shared experiences and relates how their peers’ perceptions influenced those experiences.

After I transcribed the data collected from the interviews, I uploaded them into Nvivo. I used this data analysis software by following the five guiding questions asked by Creswell (2013). I had enough transcript data that the use of computer software enhanced my codes and themes and provided great visual mapping of the data. While Nvivo does not analyze data, it is a useful tool in data storage and provides visualization and comparison, which assisted in providing adequate discussion. It also allowed the replacement of Hycner’s (1985) sixth step with computer software analysis. This opportunity was not available at the time Hycner authored his 1985 article on the steps of phenomenological data analysis.

**Bracketing and Researcher Bias**

When discussing researcher bias in phenomenology, the researcher must be able to disconnect his/her personal experiences in order to better discern the truth connected to the studied phenomenon (Husserl, 1931/2002). Husserl (1931/2002) suggested bracketing to achieve this disconnection. He stated that a researcher imagines a bracket where he/she places personal experiences with a phenomenon in a “box” in order to
expand his/her understanding or to discover new ideas within a phenomenon. I employed this technique in this research of siblings with disabilities and how the perceptions of their peers could influence their relationships.

I worked previously in the school that served as the study site. I still hold professional and personal ties there. I enjoyed my time at the school and felt very supported by my administration and my colleagues. I felt like this school did a decent job of addressing issues within special education and was happy to be able to use it as my study site. While, this may not have a direct effect on the collection and interpretation of data, it is a potential source of bias insofar as I already know the school culture and its effect on my language regarding the school.

As a sibling of a sister with Down syndrome, I also directly understand how wonderful and difficult having a sibling with a disability can be. I have experienced the joy and challenges that can occur as one grows up with a sibling with a disability. Knowing these things so intimately definitely presented a challenge to me when completing this study. I have a very positive relationship with my sister, who is now 28 years old and thriving because of the support of my family. While there are several years between my brother, sister, and me, due to my sister’s IEP and her right to stay in school until 21, she overlapped both of our high school experiences. However, the three of us went to two different schools. My brother and I received the private education rarely afforded to people with disabilities at the time we were in school. We did not have the opportunity to participate in school events and activities together. I find myself
wondering what that would have been like for my brother and me, and for my sister to have had that opportunity and joint experience; thus, my curiosity in this topic of study.

When completing the study, I put aside the fact that my relationship and experiences with my sister were positive. I aimed to enter each interview with an open mind as to the type of relationship each sibling group had, and I was accepting if the relationship was not positive. All families have different dynamics that influence how siblings view each other, and it is possible that school dynamics also affect that view.

The other challenge I had to accept is that not all people have direct experience with disability and therefore may not know how to approach it. This inexperience could lead to some negative views or views of ignorance. As a researcher, I had to accept those views openly, despite my desire to advocate for those students to have an opportunity to understand and appreciate disability.

I also recognized my own tendency to correct things that I feel that are “wrong”. I had to adopt a more neutral stance when examining each influencer of those thoughts as if that influencer was acceptable in its own right. I recognized that my own lack of inclusive school perceptions, but having a positive sibling relationship, led me to ask the questions that I addressed in this study.

Ethical Issues

This study has some ethical issues necessary for me to address. In my submission of my proposal for this study to the internal review board (IRB) at Mercer University, I fully explained my intended procedures and processes for collecting data and described the measures I would use to protect the participants and help them to understand that they
could discontinue participation in the study at any time. My own knowledge of the school and the type of students I worked with assisted in the location of students with experience of the phenomenon under study. Having worked at the school prior to completing this study helped me to gain participation, but also created some overlap professionally and academically. I selected some students with whom I was familiar and some whom I was not. My hope was that those students I knew would help me to establish rapport quickly with those I did not know, so they would be more willing to openly discuss ideas during the interview process. My experience as a teacher has been that rapport with teenagers is important to achieve their openness and candidness on various subjects.

For the sibling groups, I chose groups based on the previous relationship that I had the opportunity to form with the students with disabilities prior to the start of the study. This helped me to comprehend their speech patterns better and understand how they might use their AAC devices or a communication facilitator. Nussbaum (2010) discussed the idea of having a surrogate or a facilitator to assist a person with a disability to communicate or to navigate their community and the world. Everelles (2002) noted the importance of viewing the AAC devices as the voice of the user. Allowing them to use their devices provided the participating students with disabilities the power of voice, as well as a physical voice. These ideas were important for me to consider because I want to ensure that the students with disability received the opportunity to express their thoughts adequately, in addition to the opportunity to opt out of participation if they wanted. The communication facilitators were there to help them maintain a level of
comfort while talking and to help clear up any misunderstandings of speech or use of the AAC.

When transcribing and analyzing data, I used a computer software program to check my work. While the software of Nvivo does not analyze data, it provides much-needed visuals to ensure I discovered and analyzed all units of meaning to find themes. Within the analysis and coding, I kept participants’ identities confidential. According to Individuals with Disabilities Education Act (IDEA) (Yell, Shriner, & Katsiyannis, 2006), it is important to maintain the confidentiality of a person with a disability; however, having attained guardian permission to speak with those individuals, I was be able to report the types of disabilities of the participants. I used pseudonyms throughout the study and reporting, as also noted by Creswell (2013), to maintain confidentiality.

The final ethical issue I needed to address was the time each participant spent to adequately complete the interview. I ensured all participants understood that I respected them, their thoughts, and their time. For the general education students, I supplied pizza as a token of thanks for their participation, and for the sibling groups, I engaged in a rewarding activity of choice. These actions played an important role in helping to maintain mutual respect and continued interest in this study.

Trustworthiness

This phenomenological study was designed to produce results of the small group of participants involved. This study solely encompassed the phenomenon pertinent to them. Since it is not easily transferable to another study of this type, it is important to establish trustworthiness to ensure the credibility of this study in other ways (Lincoln &
Guba, 1985). It was important to philosophers such as Husserl, Heidegger, van Manen, and Moustakas to report the truth in the experience of the phenomenon (Moja-Strasser, 2016). Therefore, I employed the use of qualitative study methods to gain credibility and to reduce the possibility of the results inaccurately reflecting the truth of the phenomenon (Shenton, 2004).

I referenced these same authors in the research design, data collection, and analysis sections of this paper while I recruited participants, collected data, and analyzed data. In the preceding sections of this chapter, I discussed a clear and concise plan for the research. I did this to paint a picture of exactly how I conducted my research, so the reader would be able to understand each step of the process. I kept all of the data collected and the steps I used in a data manager to not only help me to organize my thoughts and actions, but also to be able to analyze the data quickly.

Shenton (2004) discussed the concept of learning the culture of the participants, stating it is important to either observe culture prior to starting the study or already be a part of the culture. Prior to this study, I was part of the culture of the school, since I worked there for two years. I am also part of the disability culture discussed in the literature review, and I have extensive knowledge of how to work with participants with disabilities. Because I am able to claim to be a part of these cultures, I was able to work around schedules and needed breaks to work well with participants. I shared appropriate information with all participants to ensure quality communication and understanding of the study.
When conceptualizing this study, I felt that focus groups with the teachers would be beneficial because I did not need to speak with them individually, since garnering a collective idea of the phenomenon would be sufficient. However, scheduling became an issue, so I conducted individual interviews with the teachers. When choosing the sibling groups, I was more purposeful in my sampling. I chose the sibling groups because I already had an established relationship with the sibling with a disability. It made them more comfortable to talk with and open up to someone they already know. It also leveled the playing field between the interviewer and interviewee to allow them to have the power to guide the interview. Anyan (2013) discussed the idea of power in interviews as being something equal so that all parties could participate. This way I was able to ensure they were an actual part of the experience of the phenomenon I was studying, as opposed to simply being the subject of the study.

Because of the nature of this study, it was difficult to employ the use of member checking as a way to establish trustworthiness and validity of the data. However, I was able to follow up with the SWO to make sure that I had accurately represented them and their siblings. Hycner (1985) stated that it would be a good idea to allow the participants to review the data after analysis and before writing a summary in order to better check the units of meaning, codes, and themes within the context. The participants were living or had lived the experience under investigation, so they were able to intimately understand the data and help to determine correctness of the analysis. Shenton (2004) stated this as being an important way to determine new ideas and perspectives and reframe or discard old ones that no longer served the researcher and study in a meaningful way. I also
discussed the emerging themes with my dissertation chair and my methodologist at length for further validation of the findings. Hycner (1985), Groenewald (2004), and Shenton (2004) cited this was a valid way to ensure the trustworthiness of the project.

Summary

This chapter related the purpose of the research, reiterated the research questions, and described the methodology of this project. The purpose of this phenomenological study was to describe the shared experiences of siblings with and without disability and how their peers’ perceptions might play a role in the formation of their relationship. To gain a reasonable cross section of teachers for the interviews and to determine which sibling groups should be selected to participate, I utilized purposeful selection of participants. Participants in the study were three groups of students with disabilities and their siblings without disabilities and five teachers chosen by the students. Through interviews with study participants who are AAC users, I sought to provide power and voice to students with disability and show they can be active participants in a study on disability. Each teacher engaged in a one-on-one interview with me. Data analysis focused on identifying themes and discovering the shared experiences of the siblings, the effect their relationship may have on their classroom achievement, and how teachers create instruction based on having these siblings in class.

As a researcher with a sibling with a disability, I bracketed my own perceptions and experiences to truly understand those of my participants. I discussed the ethical issues that arise from conducting research in a school with people with disabilities, as well as using people with disabilities who were AAC users. I used all research processes
to discover the true essence of the phenomenon of disability in a school and with sibling
groups. I researched and described multiple angles according to the methods and theories
of phenomenology by Moustakas (1994), van Manen (2016), Merleau-Ponty (1962),
Husserl (1931/2002), and Heidegger (Moja-Strasser, 2016). These methods provided
analysis and anticipated answers to the questions stated for this study. Chapter 4 presents
the findings of this study.
CHAPTER 4

FINDINGS

The purpose of this phenomenological study was to explore the perspectives of teachers, siblings with disabilities (SW), and siblings without disabilities (SWO) regarding inclusion in the secondary setting. An additional purpose was to determine if the teachers changed their instruction to meet the needs of both types of siblings. Finally, this study attempted to give voice to all siblings, but especially to the SW.

This chapter offers insight into the perspectives of the participants as revealed from the data collection. The participants were siblings from three sibling groups who overlapped years in school in some way, and five teachers, who were either current or former teachers and coaches of the siblings in the groups. Following the participant interviews, I transcribed and coded the results to provide the following analyzed data. The chapter begins with the reiteration of the research questions, followed by a description of the participants and subsequent discussion of three thematic units: valuing disability; responsibilities of teachers and siblings; and growth through the value of disability and responsibility. These themes provide evidence to support the answering of the research questions and the lived experiences of the participants in this phenomenon.

Research Questions Reiterated

The data for this study were analyzed using codes derived from the individual interviews and subsequent member checks for each participant in order to obtain their
perspectives on the phenomenon under study. The following research questions guided all interviews, thoughts, and analysis:

1. How do students’ and teacher’ perception of disability inclusion in a secondary setting influence the school experience of siblings with and without disabilities?

2. When working with on member of a sibling group, how do teachers modify their instruction to support the siblings?

Thematic Findings

During the data collection phase of this project, I worked first with the sibling groups to set up individual interviews with each participating member. I then transcribed and coded the data line by line to find the units of meaning for each interview. Through constant comparison, I coded and reviewed each transcript after adding new codes to new transcripts to ensure I captured all units of meaning from each participant (Hycner, 1985). Next, I followed the same procedure when working with the teachers.

During initial analysis of all data, categories began to emerge that showed relationship among the codes and the ideas expressed by the participants. I was able to make several analytic passes through the codes to create the categories of attitudes, roles, needs, and personal growth and map those in Nvivo to provide me with a constant visual of where my data were leading. Once I established the strength of these categories apparent in all interviews, I analyzed the data case-by-case, looking for how these categories affected the lived experiences of each participant. On final passes through the data, the following themes emerged: valuing differences, responsibilities, and growth,
which led to the same idea of the education of individuals through social interactions.

*Figure 5* illustrates the relationship.

*Figure 5.* Thematic relationships among teachers and siblings.
The top and bottom bubbles of the diagram are representative of the labeled teacher and sibling groups. Each group experienced the idea laid out in the themes. The participants’ value for disabilities influenced the responsibilities they felt they had, which influenced the amount of growth the students or the siblings experienced. Those three influences played a role in the education of individuals through social interaction. The following sections present the themes as defined by all of the participants and provide detailed insight into the lived experiences of each sibling group and teacher in order to give the participants a voice in the phenomenon.

Theme 1: Valuing Differences

Valuing differences is defined as the level of importance the participants of this study placed on people with disabilities participating in school. The SWO placed a high importance on people with disabilities in school because they reported wanting their siblings to be able to participate more and better in various school activities, such as classes, electives, and extracurricular events like drama and sports. They felt like it was important for their teachers and friends to have an awareness and understanding of people with disabilities so that their siblings were more included.

Alexandra and Linda S both talked about Alexandra’s differences. Alexandra, who knew she had Down syndrome, was in a classroom designed to help her to become more independent and gain work skills. She talked about her friends also having differences. She also talked about how she had different goals in school than her friends. She said that sometimes she liked being different and other times she did not. Alexandra enjoyed being on the cheerleading squad, and she reported that she had friends on the
team. She also liked that her friends on the football cheerleading team allowed her and all of her friends to cheer. She said that she felt as if she was part of the school and that was important to her.

Linda, as a teacher and former student, echoed her sister’s sentiments stating,

I am super glad she is here and having been a student here . . . it makes me proud that throughout the entire program here, be it typical students or special needs, the school is really supportive. Overall, I couldn’t ask for better things for her.

Linda felt the school personnel were very supportive and helpful. She liked Alexandra’s teacher and acknowledged that Alexandra had some really great opportunities at the school.

However, she did wish she could have more. For example, Alexandra was on the junior varsity (JV) cheer squad for basketball last year, and she cheered at every JV game, but this year they did not have enough cheerleaders to make a JV squad, so they moved everyone on the varsity squad and allowed Alexandra and her friends the opportunity to cheer at only six games. Linda expressed how she wished Alexandra could cheer at every game like last year and participate in every practice. Last year, Alexandra and her friends went to Linda’s classroom after school to change and wait for cheer practice to start, but because of the change this year, they practiced every other week. Linda stated that she missed her sister and friends coming in her room every day because it was an opportunity to spend time with her sister at school while not disrupting her day. She valued the time they spent together.
Linda S and Alexandra both desired greater inclusion for Alexandra and for other people to get to know her, as well as for others to see that Alexandra and her friends were worth being a part of the school. Linda felt that her presence in school with Alexandra might help other realize Alexandra’s worth and abilities as a person. Linda also felt it important to protect her sister and others like her sister because they deserved a chance of being a part of the school in a positive way.

Sibling statements of value. During the interviews with the sibling participants without disabilities, many made value statements of how they viewed people with disabilities and the differences they presented. These statements generally expressed participants’ feelings that people with disabilities were important and related how the differences played a part in their classroom or in their lives. During the interviews, the SWOs often refrained from using derogatory language, such as the word “retarded,” commonly referred to as the “r-word,” either in the common phrase “that’s so retarded” or in referring to people as “retarded”. They reported using phrases of “that’s so dumb” or “that’s so stupid” to express that they did not like something or felt that it was silly to act a certain way.

Linda S noted that she was not as offended by the phrase “that’s so gay,” but was enraged by the phrase “that’s so retarded.” She reflected upon the double standard in that situation and said she might feel differently if her siblings were gay instead of having a disability. She really did not want to interact with people who used the “r-word” unless they were willing to make a change in language. Many SWOs also reported correcting their peers for using the phrase “that’s so retarded” and would offer alternate phrases to
use. Some SWOs felt these corrections were made by their peers when they were together, but when they were not part of the activity, those phrases would find their way back into the colloquial language of their peers. The SWO reported not appreciating the “r-word” no matter who said it and felt that it was personally hurtful to their sibling.

In high school, Linda S discussed how she would correct her peers. Now that she was a teacher (Linda T), she really did not tolerate students using the word “retarded” in any form:

As a teacher on my platform, I don’t like people to use hurtful language in class, but if you used the ‘r-word’, I would throw you out of class; you’d leave class; you’d owe me an apology and serve detention. Because in my mind, it’s a group of people who can’t defend themselves, and you are using a slur against those people, and that’s not okay. So, that’s my stance.

Another teacher questioned Linda T on a day where she stood her ground with a student. She told the other teacher that she had a sister with special needs, and she would not ever tolerate such language in her classroom. The other teacher immediately stopped questioning her on why she got so upset. Linda said, “I just don’t think they had put the 2 dots together.” In that moment, Linda felt that she had raised some awareness of people with disabilities to the student and the teacher. She wanted them both to know the value that people with disabilities bring to everyone.

Cathy and Andrew expressed similar sentiments. Having a brother with Down syndrome affected Andrew and Cathy differently, but they held some commonalities in the way they spoke about their brother. However, they both provided statements of value
that showed how much they respected their brother, Logan and admired all that he had to offer. Andrew and Cathy referred to the “r-word” as being almost like a cuss word in their family. They refused to say the phrase “that’s so retarded” or refer to anyone with a disability as a “retarded person.” They both disliked it so much that they would correct a person who said it. Andrew said,

I just feel like there are a lot of people that use the ‘r-word’ at my age and stuff. I would never say that, and if someone world say it around me I would tell them afterwards that that’s not the best thing to say.

Andrew was confident in correcting people and felt like it was a way for him to advocate for his brother.

Cathy would also correct people but felt more comfortable doing it if there were friends to back her up. She stated,

One of my friends, her brother also has Down syndrome. We would talk about like things, like how some people don’t understand, like the situation and using words and stuff. Like, we’d over hear people use words, you know, we probably wouldn’t agree with just because we have brothers with Down syndrome. Sometimes it’s hard to stick up for someone and like, like I said, my friend, who also had a brother with Down syndrome. We were in the same class and like some kid was like, saying something. And we would be there to take up for each other.”

Andrew and Cathy believed it was important for people to use language that was kinder and not so degrading to people with disabilities. They took statements like that to
heart because they felt people were not taking the time to understand that people with disabilities might be slower than others, but they were not stupid. They never wanted anyone to think Logan was stupid.

Noel was the only SWO who did not talk about people using the “r-word” in conjunction with his sister or in conjunction with people with disabilities. However, he did discuss that he did not want people to have negative misconceptions about autism. Often people would try to interact with his sister, Hallie and not get the response they would expect. Noel explained,

It’s harder for them because they don’t understand the disability that she has and when they try to talk to her she doesn’t talk back immediately, and they are like, “Huh, that’s weird, that’s interesting, what’s wrong with her?” People will ask “What’s wrong with her?,” you know. That’s a hard question to answer because its . . . I don’t see it as something that’s wrong with her; I see it as her being really special.

Noel did not want people to look at Hallie’s communication deficit as something wrong; instead, he wanted them to realize it as something that made Hallie who she is. He wanted people to take the time to get to know her and understand how autism changes the way the brain functions. Hallie also noted that she felt special and unique because she “thinks differently” than other people.

Noel would make sure that his friends and some of his peers in class were not saying mean or hurtful things about people with autism:
I mean I don’t lash out at them [like] “You’re wrong, this is what autism is and how dare you say something like that.” I just put a hand on their shoulder and just say, “Hey, I think you’re seeing this the wrong way; I think you should see it from the perspective that I do because I live with it.” I just give them the rundown about what it is, and they’re like, “Oh, huh, that’s interesting.” That helps me to understand it too.

Noel always wanted people to see his sister as he did, but he understood that he had a unique perspective because not many people are SWOs. When talking with others, he really just wanted them to value the differences people with disabilities brought to the table in a similar way that he valued the communication struggle of his sister, Hallie. His focus differed from that held by the other siblings. He did not worry as much about people using the “r-word” as much as he just wanted people to think positively about his sister.

Difficulties of having a sibling with a disability. Most of the SWOs expressed positive feeling towards their SW with a few negative comments usually made about the difficulties presented by having an SW. The positive comments were usually stated in tones of gratitude, happiness, and general feelings about their sibling. For example, phrases like, “it makes me happy to see him during the day” or “she is a jewel” or “I am thankful she is nearby” were a part of the positive comments made to demonstrate that they valued having an SW at school with them. The positive comments were also expressed as a way to demonstrate that they were happy to have their siblings included in their lives and happy to be a part of their sibling’s life.
Some of the negative comments expressing the difficulties of being a sibling were “she doesn’t communicate well, and it’s hard to know what she is thinking or feeling sometimes,” or “sometimes I have to change my plans to accommodate her needs and I don’t like that.” The SWOs made negative comments usually asserted when talking of times when taking care of their siblings meant having to sacrifice a portion of their identities or desires.

At times, Noel felt that it was difficult for him to have a sister with autism. He said, “I wish that she didn’t have the disability that she does” because he really wanted to be able to fully communicate with her and understand how she was feeling all the time. He discussed how if she could talk and communicate better, she would likely be an interesting and exciting person because he knew she had such a strong personality, but because she cannot communicate with words as others do, he felt that she could be difficult at times. Noel revealed that her meltdowns were the biggest hindrance to her full participation in school. Noel felt if he could help her with those more, their relationship would be stronger, and they would be closer as siblings.

Andrew acknowledged that there were positives and negatives of having a sibling with a disability:

It has its positives and negatives, but I have enjoyed it all because it gives you a different perspective on life. It makes you realize that not everyone has it as well as you do. I have thought about what it would be like to grow up with a normal bigger brother, but I don’t think about it that often, but I have thought about what
it would be like. I feel like I try to do things that he can’t exactly do, and I try to live life for me and him.

While Andrew did not state any specific negatives about having Logan at school, his statement of wanting his brother to be normal at times is profound in that he really wanted his brother to have all the experiences that he felt he was privileged to have as a person without a disability. He reminisced about playing football when he was little and coming to the realization that Logan did not play because of his inability to move like his brother. In these statements, Andrew showed the most emotion, clearly touched by the thought that his brother was limited. However, Andrew pointed out that Logan’s limitations also led to him to be a stellar Special Olympian.

Happy to be a sibling. All of the SWOs in this study talked of only sharing their positive thoughts with their friends. A few of them reported being willing to share their negative thoughts, but only with close confidantes because they did not want others to think negatively of their sibling due to the nature of their disabilities. They felt it was wrong in some ways to be negative about a person with a disability because it felt like they were unaccepting of their sibling. The triad group of Andrew and Cathy often noted a vastly different way of talking about their SW, Logan. Neither sibling wanted to “bring down” their SW.

Andrew and Cathy expressed value for their brother, Logan, by talking about how happy they were to see him during the day. While neither of them used a special route to class that would pass by Logan’s classroom, if they saw him, neither hesitated to greet their brother and say hello. In fact, Andrew said that it was almost impossible to not say
hello because whenever Logan saw him, he would “run up to me and give me a hug”. He reported that these moments “always brought a smile to my face, and it was a happy moment throughout the day”. It became routine for Logan to see Andrew at school.

When Cathy started school, she reported that Logan’s schedule was initially disrupted when she got in the car, but once it happened for a few days in a row, she felt like Logan was okay with her being at school. Cathy was excited about being in school with Logan, stating,

I was actually kind of excited about it, just to be able to see him in the hallways and stuff and at the school. I got to see how happy he was at school with his friends. I got to meet some of his friends.

She discussed sentiments like this multiple times. Logan’s overall happiness at school was important to her.

Cathy reported that there were really no negatives to having Logan at school. She said,

I wouldn’t say that there was anything I disliked about it. I felt like I got closer to him just because since . . . we were going to different schools; I wouldn’t see him during the day. So, I didn’t know what he was doing. I could sometimes see him in the hallway.

Overall, both siblings felt their brother’s presence enhanced their school experience. Furthermore, Logan’s differences made them feel unique as siblings, although Andrew’s laid-back personality led him to downplay his uniqueness: “My mom
worked at the school, so they all kind of knew our family. It probably wasn’t that big of a deal.”

Whereas, Cathy felt that she was in a unique position: “You don’t find a lot of people that you can relate to with siblings with Down syndrome. It’s just not very common.” They both highly valued the lessons and ideals their brother gave them.

Linda talked a great deal about the opportunities she had to spend time with her sister at school. On Fridays, her sister’s class would go to science lab with one of the science teachers, and they would walk down the hall where Linda served lunch duty. Linda would walk with them to the science lab just to spend a few moments with her sister and also because Betsy, the teacher of the lab, happened to be Linda’s favorite teacher in high school. Linda reported,

I’ll ask what they did in that lab because I’ll try to lead her with questions because you know you’re always trying to push them and make them think further. “So, today we worked on weather.” I’ll say, “What did you do with weather?” I’ll make her explain to me what they did.

Linda liked how they were able to talk about lab because she had done many of the same labs in high school, and it was important to her to cultivate her relationship with her sister.

Like some of the other siblings, Noel and Hallie liked to see each other at school and both talked about positive interactions in the rare instances that they saw one another. Hallie stated, “Hug Noel and say hi” when questioned about what she did when she saw her brother. When asked how it makes her feel, she said, “I feel happy.”
Noel felt much the same way, stating,

I’m usually hanging out in the hallway doing some online stuff, and I’ll see her walking down, and I’ll say, “Hi Hallie.” You know, we’ll spend some time together. She puts a smile on her face—on both of our faces.

Noel felt it was important for Hallie to know that he was there just in case she ever needed him. He talked about how his family wanted him to stay focused on school instead of worrying about his sister, but he knew that she had difficult moments and just wanted her to be happy. It was important to him for her to be happy.

When they were at school, they were not able to see each other as often as they liked. Noel explained,

I can go to her class and visit her, and when we see each other in the hallway, we will sort of spend time together. But often times I don’t really see her that much in school because, you know, she is in this part of ed., while I am in general ed.

We are sort of really separated. We don’t seem to see each other that much.

He mentioned several times that he really enjoyed seeing Hallie at school. When I asked Hallie if she liked seeing her brother at school, she said, “Yes, brother is Noel.” When asked that question again later in the interview she said, “Yes”. She also liked to see her brother. Noel felt it was important to see his sister during the day. He noted that it helped them stay connected and made their relationship stronger. As he put it, “It sort of really reinforces our relationship that we get to see each other,” but it was just not always possible to see her because they were in different classes, and he was always busy with band or shows.
Teacher statements of value. Teachers also valued differences in the school setting, expressing that students with disabilities offered a challenge that general education students did not always offer. They spoke of having a duty to make sure they met the needs of these students within their rooms and in their lessons. Many of the teachers talked about different ways they differentiated their instruction for students. This came in the form of traditional differentiation, different levels of work within their lesson that addressed the same information, or modification of the lesson so a student could participate at their ability level, while experiencing a challenge to learn more. Linda T mentioned that she differentiated all of her lessons to accommodate the differences of her students in the classroom:

I am in a school that is really looking at differentiation in your lessons anyways. It is something I do consider to make sure that they have what’s best for them in class, but it’s not just them, it’s every student. So, when I design one lesson it has a total of three to four ways to get through it, depending on what the student needs. So, yes, I do make sure there are options, but it’s not necessarily any different than what I do anyways [when planning a lesson]. It’s been fine because it doesn’t change their face time because I’ll be up anyways, but their notes might be different—like they will have extra things written down just to make sure they get all the information they need, or if they are doing group things, I will group them differently. I will make sure they are all on task, and I will make sure that they all know what they are doing.
Linda T ensured that she met all of her students’ individual learning needs met because she did not want anyone in her class to feel left out or left behind. She also did not want them to feel like they stood out in her classes because she felt that not all students with learning differences want their differences to be obvious. She expressed,

I do try and make sure that they will never have to worry about being accommodated in my class or that their needs aren’t met in my class. From the student side of it, I try to make sure that it’s never an obvious thing because I don’t want them to feel like they are standing out or are ostracized because I know that it can make anyone uncomfortable at any age, but because it’s that way, I don’t want to make them stand out any more than they have to.

Linda T felt like she understood that school could potentially be hard enough for students with disabilities, and she never wanted their differences to be a reason for not wanting to come to her class and work hard every day. Betsy felt the same way as Linda T, noting the importance of making everyone feel comfortable in class and making sure they had what they needed to be successful.

When it came to meeting the needs of their students, all three special education teachers discussed the IEP process and that it took a team to determine needs and goals of the students. Carl’s statement of how IEPs worked in favor of the students’ needs best reflected the feelings of the three special education teacher participants:

It is really what the committee feels is the best for that student. It is a question of what can we do to best meet those social goals, those life skills goals, and in a lot
of ways, their transition goals as well, because you need those interpersonal skills to hopefully transition to some level of independence.

Megan and Regina both mentioned that their students often required a lot of accommodations or modification in lessons, whether it was extra time on tasks, easier tasks that address the same skills, or a shorten lesson to meet the attention needs of the students. The team discussed such accommodations during IEP meetings; therefore, it required a whole team of people with different approaches of working with students with disabilities to develop the best ways to meet the needs of students. This process was not only mandated by law, but also a process the teachers felt was important to understanding the differences that the students had.

Carl, Megan, and Regina discussed the idea that it is best to use “outside of the box thinking” to address the needs of the students as well. Regina noted that many of her students had difficult behaviors they exhibited at different points in the day. She spent a large part of her day looking for ways to help her students cope with their emotions and express their needs. She often created solutions to problems spontaneously, but she felt that the challenge was mentally stimulating and a reason she chose to work in the special education field. Carl felt that each student had unique differences with needs that had to be addressed in unique ways, but he felt those challenges were what kept many of the special education teachers motivated:

Sometimes simply the variety in the different point of view and the different learning styles and different perspectives that those children bring into the
classroom can wake up and engage teacher. We can wake up and engage other students in the room too.

Carl felt very strongly that including students with disabilities as much as possible would engage not only special education teachers, but also general education teachers and raise awareness for the advantages of having difference in students in all classrooms.

Teachers value differences. Teachers also made statements of valuing differences. These statements were often in the form of a definition of disability. For example, Megan stated people with disabilities had “academics needs, social skills, and life skills that had to be met in order for them to succeed in an inclusive setting or the least restrictive environment”. She elaborated, saying that inclusion in other classes or reverse inclusion of peer facilitators into the special education classrooms was important to make people aware of the existence and role of individuals with disabilities in the school. Megan delineated some advantages to inclusion:

- Inclusion had affected the dynamics of the social component of being included.
- The biggest way is through the peer facilitation with the push in and reverse inclusion. I think overall it’s had a great impact on my students and their interactions are [with others] are more comfortable.

She personally enjoyed working in tandem with peers and SW. She felt that this type of inclusion helped to improve the learning needs of her students in various aspects of their day.

Regina felt that the peer facilitation or the reverse inclusion also played a role in her class as far as her students’ ability to relate to their peers and learning to rely on their
peers more than relying on the adults. In Regina’s class, the peers “helped with whatever they are working on”. She further stated that she incorporated the peers into her daily lessons to by giving them a list of jobs:

They will help with their IEP goals throughout the day. We do a lot of jobs, so the peers know what our job list is and who is working on what job that day. They help them sweep or do laundry; all the jobs we have. They do a lot of social interaction, which is great for these students with autism because they need that exchange with communication, so they really just work on saying their names and saying hello and just really trying to build a relationship as much as they can.

Teachers in the specialized instruction classrooms placed the biggest value on inclusion because it was such an integral part of learning for their students with significant cognitive disabilities, and they purposefully planned lessons around the best ways to utilize the peers in their classrooms. They all felt that these students were unique, and the exposure to other people in the school only aided in raising the awareness for people to take time to understand and appreciate the differences of people with disabilities.

The general education teachers expressed similar thoughts on the inclusion of people with disabilities in class. Betsy felt similarly as did the other teachers. However, when it came to her regular classes, she had a slightly different view because of the differences her students presented:

Inclusion for me is gifted students, and so, it’s modifying to make sure that their needs are being met and that they are being challenged appropriately and that they
are being asked to do things that they’re capable of doing because the problem with gifted student is that they generally understand things so easily and quickly, they’re not getting the challenges that they need to get the stimulation that they need.

In order to meet that challenge for some of her students, Betsy created the lab aide program, where these gifted students can volunteer to work with students with significant cognitive disabilities on sciences labs to provide them access to the same science information as students in the general science classes, but in ways that meet their goals and needs. This program was a huge part of why Betsy placed such a high value on science being for everyone. She recognized how scientific principles impact daily life, and everyone should have the opportunity to understand how they work. Betsy stated, “All students, regardless of disability, should be given access to science.” She added, “Science was not meant to be an elitist thing; all people should have access to it.”

When talking further with Betsy on the lab aide program, she mentioned the program getting its start because the teachers of the specialized instruction classes simply needed a space to do some of their science projects for state-mandated testing. The program grew in part due to the teachers’ desire for more help in teaching science and Betsy’s belief that these students deserved a true opportunity to access sciences. These students were not in general education core subject classes. Betsy emphasized the importance of planning with the students’ specialized teachers:

So what we have found has been really interesting for us is like designing for MI/MO (specialized instruction); it’s hugely different, what we can do for one
group to the next for us. I’ve done that for I guess it’s been seven years now, the students have been coming in, um, and it started out as, you know, “Can we use this space? Absolutely”. Then it sort of blossomed into this thing that we really work hard to protect and build into our schedule. So, I sit down with the teachers at the beginning of the year, and we coordinate our calendars to make sure that it happens. Again, even taking the same content and adjusting for MI vs. MO, especially when I’m training new lab aides and they’re getting a feel for what that looks like, it’s very different.

Betsy really learned to value what each different class needed and what each different student needed. When she and her aides landed on a modification for one student, she generally felt like it could work for other students as well pointing out:

For a while, we had a student that was blind. So, every lab that we created needed to make sure that there was something that he could do, as well, that would speak to him. We found a lot of times that modifying for one, it was beautiful, it works really nicely, like it spoke well to a lot of students. It just makes you happy you’re helping someone, and you see like a spark of understanding, that spark of recognition, and seeing, you know, kids like they’re a part of something. So, we are really careful to not ever cancel lab, even when school schedule gets crazy. They look forward to it. I’ll run into students in other parts of campus, and they’ll go, ‘Betsy, do we have lab today?’”

It was important to her that all these students continue to look forward to lab and science as something they wanted to do and could find success. She knew that it was vital to be
able to access science in a way that was meaningful; therefore, she valued the differences that they brought to the lessons.

Statements such as those made by Betsy often influenced how teachers and SWO interacted with SW. They would create lessons or take time to mentor the siblings. Carl reported using SWO to help with the SW because their relationship was such that it helped to put the SW at ease in tough behavioral situations. Betsy emphasized how beneficial her lessons were to one sibling pair because they both received the opportunity to have Betsy as a teacher. Despite the modifications in the lessons, Betsy believed the lessons provided the siblings a bond through the opportunity to be in the same classroom and experience the subject. She really felt that it was a way for them to talk about school and the things they had done that day. She also said that any form of communication about that lesson was a way of showing that the SW learned about that topic.

Linda S, who was an SWO as well, felt like her life experiences provided a platform for her to support her students with their own relationship or struggles with an SW. She related that one student in her class had written a piece about her sibling but was unwilling to share it with the class. However, the student was willing to talk to her about the subject of the paper even if she did not share with her peers. Later, that teacher realized the she had provided an outlet for the student in a manner that was safe and encouraging. She stated that the SWO benefitted from releasing her emotions through a therapeutic medium; thus, she had done her job in supporting that SWO.

Comparing the mutual value placed on people with disabilities. Both teachers and siblings desired to change the way people viewed people with disabilities and felt if they
could be positive role models for their peers and students, then maybe they would actually see change. Betsy, for example, not only felt passionate about working with the lab aide program she created, but also passionate about making sure other students had the opportunity to learn to value differences as well. She found herself recruiting her gifted students to the lab aide program, but sometimes some students would come to her and ask to volunteer for the program. Those students likely felt similarly to those who often signed up for peer facilitation classes, but the biggest difference was that the lab aides gave up their personal time during lunch to be a part of the labs. Betsy realized she was in a unique position to influence the perceptions toward people with disabilities and raise their awareness and the awareness of their peers.

Through a lesson a Betsy created about genetic disabilities, students received the opportunity to talk with an SWO, which considerably helped her students conceptualize how family members helped or dealt with their members with a disability. Betsy stated the lesson provided the chance to “put a face to” the needs and markers of that particular disability, making it no longer an abstract thought, but something concrete the other students could experience. She believed such lessons were beneficial in changing the way other students thought about people with disabilities.

One such change occurred when Cathy’s friend wanted to be a peer facilitator in the special education classrooms because she had the opportunity to get to know Cathy’s brother, Logan. Cathy knew that friend had become friends with her SW and that she enjoyed the resulting relationship. Similarly, Noel noted that his friend, Miguel, got to know his sister and enjoyed spending time with her when he was over visiting Noel.
Noel felt like his personal positivity towards his sister set an example for his friend. His friend would often greet Hallie in passing. This made Hallie happy because she knew someone else in school, which made Noel understand it was important for Hallie.

*Figure 6* shows the relationship between the teachers, siblings, and others. The triangle demonstrates the values of each group and the impact on individual valuing differences groups. The teachers’ values were often present in their lessons or actions in supporting students that provided SWO the opportunities to share about the SW, which in turn gave others the opportunity to learn about disabilities. Siblings and teachers helped others learn how they value disability.

*Figure 6*. Uniqueness of teachers and sibling groups for valuing differences.
The perspective of others was based on what the siblings and teachers felt happened when they expressed how they valued disabilities. The teachers and siblings felt their job was to talk about people with disabilities as much as possible to help others find the value in the differences of people with disabilities.

Theme 2: Responsibilities of Teachers and Siblings

The needs of other people were so ingrained in the perceptions of some of the participants that they felt it was their job to help others. For example, as the older sibling of a person with a disability, Linda S felt like the needs of her sister translated into responsibilities on her part to take care of, protect, and include her sister. A few weeks before I met with Linda for her interview, the school had a “code red” alarm, which signified an active shooter in the building. Thus, the administrator placed the school on lockdown, with the students hiding in the classrooms for safety. As it turned out, a student was making threats instead of being an active shooter. Linda reported that it made her feel better that her sister was near so, in the event that this incident had been real, she would have had the access to reach her sister. She stated, “I just felt better knowing that if something happened, I could get to her quickly. So, it made me calmer knowing that I knew where she was and that she was going to be okay.”

In another instance, Alexandra related that she told her sister that she liked having her there for the things that she needed. If she needed money for a drink, she could ask her sister. If she needed help with a boy issue, she could ask her sister. Linda prioritized the needs of her sister above all else. Roles and needs were so closely tied that putting
them together in a theme called responsibilities encapsulated both the needs of other people and the roles assumed by the participants.

Roles and the needs of others. The roles the participants assumed in relation to one other were based on the needs of others. For example, felt because she had a sister with Down syndrome, Linda S felt she had a unique understanding of what it meant to be a sibling of a person with a disability, she needed to be there for other siblings of people with disabilities. This idea made her feel less isolated, while also helping others similar to her. As teacher and sibling without disabilities, she experienced the same feeling towards the students who were SWOs. Only when she talked about it, her feelings were in the form of mentorship of such young people. Linda believed she was responsible for all her students and their accommodations. Therefore, if another SWO needed assistance navigating an experience, she was there. She said she did not “wear her [siblinghood] on her sleeve” like other siblings because she felt there was more to herself than that identifier; however, she did have a student who she felt she needed to mentor. Linda took on the role as an older, more experienced SWO because that student had a strained relationship with her SW, and Linda felt she could help.

Carl, Megan, and Regina all believed they held certain responsibilities towards their students. These responsibilities stemmed from their jobs as classroom teachers and from personal convictions that led them to value differences in all of their students. They all stated they plan lessons geared toward the students’ IEP goals. Regina stated that her students worked best in 15-minute increments. She said,
I’ll get them to come sit and talk. It’s more one on one. I personally believe that the one-on-one instruction with these students is the most beneficial for them, and it elicits their attention and the social interaction that they have. Regina utilized one-on-one instruction and 15-minute timeframes throughout her day, from lesson to lesson. She had visual schedules and binders for each student; they knew their present and upcoming goals and tasks. Each binder varied according to the individual needs of her students. For Regina, this system was the best way to conduct her classroom and best meet the needs of her students.

Carl held similar ideas to Regina, acknowledging that her classroom was distinctive in that the needs of students like hers were very different. Embracing those needs to meet students at their ability levels promoted troubleshooting in the most unique way possible. He explained,

When it comes to what we can do for those students in most cases, it’s really a matter of your own imagination or ability to think outside the box. . . . You have to be willing to meet their goals in as many creative ways as you can. It’s going to take doing something different from time to time.

Carl really enjoyed the students in Regina’s class. He felt the need to support Regina more than most new teachers because he felt invested in making sure she was successful, thus ensuring the success of her students.

Megan also had students who were very different from general education students and from each other. She reported they all had gifts and talents for many different jobs and subjects. She also noted that some of what they did was quirky and awkward, but
felt it was important not to hinder their personalities. Megan believed they needed to grow and maintain who they were when they did so. Her main goals were to work on the IEP needs and use the students’ strengths to their benefit. She planned lessons in her classroom that addressed the core subjects, while also giving her students an outlet for learning social skills. Megan taught her students living skills outside of the classroom through community-based instruction trips, where each student received a job that targeted a current skill. The same was done with they went on vocational training trips. Megan often looked to the future to help families determine where they wanted their students to be and she planned their lessons to get them there in small increments. Metaphorically, those steps were a road map that allowed for minor detours when something unexpected arose.

As teachers, Linda and Betsy both recognized their responsibility to their students to meet their needs. Linda stated, “I’m here to accommodate all the students no matter what their needs are.” Betsy felt much the same way and when discussing her definition of disability, she knew that it encompassed differences she had to ensure were met to make her students successful. Just like the special education teachers, Betsy and Linda agreed that their school staff were especially effective in including individuals with disabilities in the general daily events of the school. They also both felt that they were there to help others learn about disabilities and raise awareness of these students and their lives when they were a part of the school.

Linda felt this in a different way from most teachers because she was also an SWO. She believed it was important to include students like Alexandra. She stated,
Alexandra’s class being milder, we have three classes like that, I feel as if they are more included. We have other students with different needs that are more severe than other, and they may not be as out in the school setting. I feel like being the sister of someone I look for it more, just to know that they are there, just to make sure that these students are included. I’ll see them in the halls, which is great. They are also included when it comes to elective classes they get to take.

While she noted that these students were present in the building and could attest to the level of inclusion they experienced, because of her sister, Linda did not always look to use her classroom as an open platform to advocate for students like her sister.

Teacher responsibility towards roles and sibling needs. In addition to the connection between roles and needs and responsibilities, the value of differences heavily influenced the responsibilities as well. When a teacher valued differences in his or her classroom, often the responsibilities he or she assumed reflected those values. Some teachers held a strong passion for giving access to their subject to all learners, despite differences in presentational strategies of the information. Others felt that, while they differentiated their lessons or ensured the comfort of students with disabilities and their siblings, their main role was a background role of support, guidance, and mentorship.

Betsy felt responsible for all students having access to science because she did not want students thinking they had to be smart or gifted to be a part of the scientific world. This belief led her to create the lab aide program, which provided labs for students with mild and moderate intellectual disabilities (MI/MO). Betsy enjoyed the opportunity to work with the students in these classes and enthusiastically wanted to provide them
access to science. Beyond that, she viewed it as an opportunity to expose students without disabilities to their peers with disabilities. She used her planning time to meet with the student volunteer lab aides and collaborate with them to create a secondary curriculum appropriate for meeting the learning, social, and sensory needs of the students in the MI/MO classes. Betsy explained,

They design all of it. I mean, I give guidance and feedback where they need to because, obviously, you know, it’s not what they do. and so I look at stuff. We’ll sit down, and a lot of times, they’ll end up running to the other end of the building, like, “Here’s what we’re thinking, does this work?” They’re doing all the research. They’re looking at ideas or bringing them to me. I’m saying, “Here’s what would work. Let’s maybe think about the things you considered using with these particular students.” They go back and forth like that, but they are doing it all.

While she was there to help, monitor, and ultimately agree or negate the plans, Betsy felt as if she had a responsibility to help the students in the MI/MO classes learn more about science, while teaching the lab aides more about people with disabilities and their abilities to learn.

Rather than hinder the awareness of the lab aides, the fact that they received no information on the students’ learning differences because of privacy laws resulted in the lack of assumptions held by the volunteers. They had no information about what their peers with disabilities could or could do; they learned spontaneously about each student and discovered new aspects every time. Betsy felt this was a wonderful way for her to
help her students grow in awareness about people with disabilities because they were not able to assign limitations to the students with disabilities. At the end of each lab, Betsy and the aides debriefed and modified the next one according to their newfound knowledge. She said it was the best opportunity to learn that she could provide to any group of students.

In her discussion of student mentorship, Linda T talked about a student of an SW who was hospitalized for a number of days. This weighed heavily on the family of the student, and the SWO missed several days of school as a result. Linda told the student she would work with her to complete her numerous missing assignments, but she expressed the need for the student to make her other teachers aware of her family circumstances. This was something that was hard for the SWO to talk about; however, Linda discovered her SWO did talk to her teachers and took the time to explain what was causing her so much distraction. Linda felt she had helped the student because, being an SWO herself, she knew that medical conditions or difficulties such as those often had a profound effect on the rest of the family. Later, this student shared more with Linda about her family life, seeking advice and solace from Linda. This SWO felt like her sister’s difficulties outweighed her own personal needs at times. Linda said,

I was there in a supportive way for her. I wasn’t trying to tell her what to do with her siblings. I like to think that it was nice for her to have someone to talk to her that totally understood.

In that moment, Linda felt she had done something good for another SWO and for a student. She said that she would do it again if she ever had another sibling in her
classroom because it was her job as a teacher and SWO to help students who are also SWOs navigate the joys and difficulties of being an SWO and being in high school.

Other teachers felt a duty to help students learn how to be good people and support people who were different from them. Betsy provides her gifted students the opportunity to learn more about people with genetic disabilities, such as progeria and Down syndrome. She had created a lesson in which students were part of a nonprofit organization benefiting various genetic disorders. The students conducted research on the disorders and then discussed what their nonprofit organization would do to help. The culmination of this project was for the students to present on the disabilities and teach their classmates about them. This was a lesson Betsy repeated every year because she felt it was so important for the students to learn about genetic disorders. She wanted to give her students the opportunity to put a face to the disorder so that it was no longer a theoretical or abstract concept to them.

During the same project on genetic disorders, Betsy noted that a group conducting research discovered some misconceptions about their disability topic. She did not want students to treat the misconceptions as facts, so she taught a lesson on how to tell misconceptions from facts. In this way, she helped the students realize that what they had read was wrong. Betsy also invited a person who intimately knew about the disorder from a sibling standpoint to converse with the students. She noted how they gained the opportunity to learn from the mistakes of others and felt the students were able to interact better with the correct data and ideas and those affected. It was an epiphany for the
students to learn that broad generalities about certain genetic disorders and their traits are not always true for all people affected.

Teachers and SWOs. Lessons such as the investigation of various types of disabilities not only gave students new information, they also allowed SWOs to share about their siblings. Reflecting on the results of the research project she had assigned for a number of years, Betsy reported that multiple SWO, SW, and other family members of people with disabilities shared about the disability or the disorder of the family member. Betsy noted how important these lessons were to many SWO or other family members:

I’ve had so many students over the years, with the nature of what I teach, where I had people who had siblings with some of the genetic disorders that we talked about. I think it’s given them a safe space to be open about what it’s like to live with someone who has special needs. You know, it’s like, “Yes, there are physical ramifications, but like, what does it look like on the other side?” I always let students come talk to me, and talk to me about it first and before anything is ever said in total. I had a student years ago, and his sister had Turner syndrome and he talked about what it was like to live with someone who’s going through hormone therapy and what it looked like from a real perspective inside their house.

Betsy felt it was her job to provide a safe space for expression and believed it helped her other students better understand SWO and disabilities. She noted,

I think sometimes it’s being aware, you know, as a teacher, you hear all the things that you choose not to hear sometimes while it’s like you’re trying to get through
some tough stuff and you’re trying to have these conversations, but then you hear things sometimes that you really, I will address things we hear some and I’m like, “Whoa, wait, actually that’s a misconception. Let’s talk about that.” So, I think it is just being aware and being the person that is a safe space. It’s a comfortable space that they can come and ask questions of, like, “I don’t really understand this.” Kindness matters and compassion matters. It affects how you interact with people around you and, you know, I think sometimes they’re still kids; they look like adults, but they’re kids in big shells, and this is the time we can get them to understand and embrace the differences of the people around them.

Betsy felt her main responsibility outside of teaching content was teaching kindness and compassion. The lessons she planned on genetic disorders provided many students the opportunity to increase their awareness of people with differences and gave them the safe space to ask questions on their quest to learning more about what could be a tough subject to discuss.

In addition, Betsy believed that having those students talk facilitated the understanding and knowledge of general education students in a way that they may not have otherwise gotten. She stated, “It is my job to create change makers.” She felt responsible for her students in a way that she wanted them grow into decent and good people capable of helping others and making the world better through science.

Other teachers also used siblings to help teach students without disabilities how to work with students with disabilities. Megan enjoyed having peer facilitators work with her students, but often the new peers would try too hard to assist their friend with a
disability. This action came from a place of caring, but also from a place of misconception. Megan worked with all the new peers on this aspect until they each understood that the friend with a disability needed to struggle and address his or her own learning differences to grow. Megan related that one peer, who was the younger SWO, took it upon himself to teach the other peers because he knew what it took for his older sister to master a new skill. Megan felt she had created a space for this SWO to feel comfortable in his knowledge, so she encouraged him to continue to share his personal knowledge and used him as an example for others. She noted how her role changed from an active participant in teaching the new peers to being the facilitator while he did the teaching.

When asked about working with sibling groups, Megan spoke about the current sibling pair of Linda and Alexandra and her feelings when working with other families. In the past, Megan worked with a family where the oldest of the three siblings was a sister with Down syndrome. The middle sibling, who was in school at the same time as his sister, had a strong desire to be a peer facilitator in his sister’s class. Megan felt it was important to ask her student if she wanted her brother to work in her classroom. She knew it would give her student a sense of input and control. The sister asked her brother not to be a peer facilitator while she was still in school because she thought it would be weird to have a class with her brother. She liked having her own space to shine. Megan honored her student’s request and waited to enroll the younger brother in peer facilitation until after his sister’s graduation.
Megan also worked with families that did not want the SW to have contact with the SWO during the school day. Megan made it clear that she felt it was wrong for the SWO to completely ignore the SW, but she also noted that it was her role to teach the SW some social skills and tools for appropriate interact with the SWO. She believed her students should not just be told they could not interact with their family members, for they deserved a voice in the situation. She worked very hard to hear her students and allow them some say in their educational process.

When working with the sibling group of Linda and Alexandra, Megan again took the stance that Alexandra deserved to talk about how she wanted to be included or not included with her sister, Linda, who was going to be a new teacher the same year Alexandra was starting high school. Fortunately, Linda and Alexandra had a positive relationship and Linda was willing to do anything that would make her sister happy and help her grow. Megan said the plan they created together was positive overall. She stated,

That first day of school, she [Alexandra] could walk down and say hello to Linda. We prepared Linda for the interaction. She [Alexandra] couldn’t go down there unless she asked me or if it’s planned or if it was after school, and they reinforced that and talked about it the remainder of the week before school started and so did Linda and explained to her [Alexandra], “It’s because she’s going to have her own classroom. She said she’s very busy.”

For the most part, Alexandra followed these guidelines, with the exception of one time where she switched paper delivery routes in the school with another student in her class
and delivered Linda’s papers. Megan knew that the infraction had occurred, but she thought it was sweet that Alexandra just wanted to say a quick help to her sister. She pretended not to know so that Alexandra would not feel like she did something wrong. Megan felt it was a part of who Alexandra was to have a close relationship with her oldest sister, and she should help cultivate that while the siblings had the opportunity to share experiences.

Regina had a different perspective on how siblings should interact in school because of how she and her brother interacted in school. It is important to note that Regina and her brother did not have a disability that would result in their separation in classes at school. Regina reported that she felt Hallie and Noel needed time apart because they spent so much time together at home. Regina commented,

It’s not thinking of every time I create a lesson, “Oh, let’s try and implement this into it” because the sibling that’s in my classroom also needs her space from her sibling. So being able to create that same typical environment that she would get in a general education classroom as most teachers’ wouldn’t necessarily implement it into their lessons because a lot of students have siblings.

It was not that Regina thought they should have no interactions at school, but she genuinely felt that Hallie needed an environment that could mimic a regular education classroom as closely as possible because she deserved the most normality in her life that could be afforded to her at school.

Carl echoed thoughts similar to Megan’s about the responsibilities he had towards sibling groups. He was not a teacher directly in contact with any of the groups, but he
was Andrew’s coach. He believed Andrew’s team accepted his brother, Logan. As a special education teacher, Carl felt a dual responsibility in that situation. He had to coach the males on his team and help them learn how to be decent people, but he also had to ensure that Andrew felt comfortable to show affection to his brother and that his brother was protected. Carl often encouraged his team by talking about people with disabilities in a positive way and shied away from terms like the “r-word.”

Carl also felt like it was an SWO’s duty to protect and care for their SW, so he worked to cultivate an accepting environment. Due to his desire to think creatively to meet the needs of his student with special needs, Carl did not hesitate to seek the assistance of an SWO to address an issue that might arise with SW. He noted that he resorted to this rarely so the SWO was not missing instruction, but felt it was his duty to instill a sense of duty towards the SW.

Siblings’ responsibilities. The SW played a special role in how the SWO conceptualized their responsibilities. Even though Andrew and Cathy were both younger than Logan, they felt protective of him and responsible for him, especially for his happiness at school. Logan liked the routine of riding to school with his brother, Andrew, and then when his brother went to college, he was able to have the same experience with his sister, Cathy. They would walk down the hall in the mornings, or they would meet to walk to their mother’s car in the afternoon. Logan looked forward to that opportunity every day, and his siblings liked feeling helpful and spending a small amount of time with their brother. Andrew and Cathy never went out of their way to see their brother during the day. Andrew reported not wanting to interrupt Logan’s day.
However, there were times when they were in the same environment at the same time, and Andrew was more than happy to have Logan be a part of that moment.

Alexandra talked at length about how she enjoyed having her sister, Linda, at school because, if she needed something from her, she was there. She reiterated the idea that if she needed to talk or if she needed help, her sister was available. It was important to Linda that Alexandra have the chance to have her own high school experience, while also knowing that her sister was there just in case she needed her. Linda knew it was important for her sister to get to go to homecoming. Therefore, when the administrator asked teachers to assist with the event, Linda volunteered. This made her parents feel better about Alexandra going and Alexandra knew that her sister could help her if she wanted. Alexandra liked having Linda near as well, reporting, “I like having her close in case I need her for something. Sometimes there are things I need, and my sister can help me.” Alexandra believed her sister felt important when Alexandra asked for help.

Logan was unable to articulate what he thought his responsibilities were towards his siblings, but he did say that he liked going to their various sporting events. He enjoyed attending events on Friday nights and cheering for his brother. He also liked going to Cathy’s swim meets and cheering for her as she raced. Both Cathy and Andrew reported they enjoyed having their brother at the events because, no matter the outcome of those events, they always felt supported since he was there with a hug and a high five. All three siblings felt responsible for each other, but they mostly expressed how they wanted each other to be happy in all that they did. Logan even shook his head “yes” when I asked him if it was important for his siblings to be happy.
Three of the four SWOs discussed being together as well. Cathy liked having family at the school and did not feel alone even though she did not get to see her brother all the time. Andrew reported feeling the same. Linda liked that she was there for Alexandra because she felt that if something were to happen, she could immediately take care of her sister. They all expressed that, based on the needs of their SW, they could adjust or modify how they interacted throughout the day or if they interacted at all.

Noel felt one of his main sibling duties was to ensure his sister was happy. He knew he could do that by spending time with her in and out of school. Whenever he saw her in the hallway, he made a point of talking with her, giving her a hug, and asking how she was. While Hallie expressed how much she liked seeing Noel and that it made her happy, Noel’s perception of the interactions were that she did not always think about Noel being at school with her because they were separated and had different school environments. However, he related that when she did see him, she became very happy and would say funny things to engage with him in that moment. He felt like he knew Hallie was truly happy when she was trying to make jokes or be silly in her own way. This made him feel like he was doing his job as a brother.

Noel also felt like he should be the communication intermediary for his sister when they were around his friends. Often his friend, Miguel, interacted and talked with Hallie because she was familiar with him. Frequently, Hallie would say something silly to engage Miguel, and he would not understand. Noel would intercede and try to help his friend understand what she was saying or wanting his friend to do. With new people, he took a different approach:
I don’t really like to interfere when people talk to my sister because I like to see how they handle her and how she handles them because it gives me a better sense of how to talk to people and how to really explain to them how Hallie is different. He liked being there in case his sister or the person talking to her needed help, but he really felt that because Hallie was so unique in how she bonded with people, he wanted her to have that opportunity to try. He also wanted to give the other person the benefit of the doubt that they really wanted to get to know Hallie for who she was. When he felt it was appropriate to do so, he explained to the person more about his sister. He believed it afforded him the opportunity to see who people really were—to see if they were kind and loving people.

Noel also had a sense that it was his job to help his peers understand how amazing differences in people with disabilities were. Heavily involved in musical theater, Noel participated in show that allowed individuals in specialized instruction classes to attend. Noel stated it felt so special to share music with not only his sister, who was there, but her class as well. He elaborated,

The kids really enjoyed performing for the special ed. kids because they were a different kind of audience; we really didn’t know what to expect. Opposed to a general audience, a special ed. audience is not afraid to literally jump out of their seat and just give it their all and show they are really having fun.

In addition to being thrilled about sharing the experience with his friends, Noel believed he and his friends learned a great deal from the experience. He had been trying to explain how the shows and music affected his sister, but his friends saw firsthand its
positive effect. He not only did his job as a brother performing for his sister, but he also performed a service to his peers with disabilities by giving them access to music in sensory sensitive and positive way. Noel felt like he helped to show his friends in the show what it meant to embrace differences in the audience and actually perform for the specific audience. He commented, “It wasn’t just another show.”

Noel did not express how his sister changed his role at school. Their family dynamic was a little different from the other groups. He reported that his parents tried to keep them separate in school so that he could focus on his own interests. He liked that separation, but at the same time, he did not want his parents to feel they could not rely on him for support with his sister in school. He especially liked the idea of seeing her and expressed that when they became adults, he would take care of his sister if necessary. Sometimes this sentiment transferred to the present and school when he found himself wondering how she was doing if he knew that her morning or previous night had not gone smoothly. He believed he would always worry about his sister because he felt that was his role as a brother. Noel was close with his family, including his sister, and did not ever want her to feel that she was a burden.

He admitted, “Her inability to communicate with me can be hard.” He wanted his sister to learn to communicate so that she could truly express her emotions. He felt like if he could fix that for her or make it better, then their relationship would be stronger, and they would experience less separation in school.

Noel often talked about disabilities in relation to Hallie as being a lack of ability to communicate with the world. He described it as being in their world rather than a part
of the world with everyone else. Noel said that, because of his experience with his sister, this was how he thought of other people with disabilities, even though he knew that was not the case for many people with disabilities. He felt it was his responsibility to help her be in the same world with him. He desired for her to be independent and working after she left high school. Noel was unsure if that was possible for his sister, but he believed he had to help her in some way to achieve that. He noted that his responsibility in that area may come later in life, but for now, he just wanted her to be happy in school. If seeing him at school made her happy, then he would love to say hello. He also stated that he liked to say hello to his sister because it made him happy as well.

When discussing responsibilities, the SWOs of triad group had a different group dynamic. Andrew and Cathy reported that when they had classes near their SW’s class, they would stop in and say hello just to see how his day was going. When Andrew broke his ankle during his senior year, he was unable to leave campus early after completing all of his classes. He sat in the library and waited until the end of the day when his mother would pick Logan and him up after school. Some days, Logan’s class entered the library at that time as well. Logan would get a magazine or a book he liked and sit with Andrew. Andrew reported that Logan’s friends and classmates would say hello, but they did not come over and sit with him as Logan did. Even though they were not doing the same thing, Andrew reported enjoying the time together and believed Logan felt the same.

Cathy had a pottery class that her SW had taken the previous year. She enjoyed the fact that she and Logan had the opportunity to talk about art. She often shared what she made with him, and she believed that little bit of sharing brought them together.
Cathy felt she was able share more experiences with their brother through art. She noted, “He loves anything with art.” During her ninth-grade year, she took a ceramics class. Logan also took the same class, but at a different time. Cathy especially enjoyed sharing the class experience with Logan because she was not sure that was ever going to be a possibility for them. She discussed the fact that they created the same projects, but Logan had modifications to his, so while they were learning the same skills, the teacher was meeting Logan’s needs in a way that was perfect for him. Cathy also talked about Logan’s interest in the photographs she took in her photography class:

He actually has a couple of them in his room. It was pretty cool because I didn’t think he would be interested in the pictures. He is interested in the small things I guess. He likes taking selfies. He likes to see the filter on them.

Cathy noted that she did not share a lot about school with Logan, other than to ask how his day went, because of his communication skills, but she liked that the pictures gave them common ground. That kind of sharing brought mutual happiness to Cathy and Logan. It was important for her to feel cared for by her brother, while she cared about making him happy.

Cathy also made time to teach others about her brother. She felt it was her duty to show people that her brother’s identity was so much more than the Down syndrome that was often the most noticeable feature about him. She used her platform as a sibling to speak about the “r-word” on assignments when opportunity presented itself: “I wrote an essay because we had to present a little essay. We had to write about things that impacted our lives and stuff. I talked about the ‘r-word’ and people using that word.”
She did not like the use of the “r-word,” and she believed people were just unaware of its meaning and connotations for her. Both Andrew and Cathy reported their desire to get rid of the “r-word.” They informed people that it was not a good word to use, and they attempted to teach others alternate ways of expressing frustration that often called for the use of that word. They did this because they felt they were protecting their brother from people who meant to use that word in the most derogatory way.

Cathy also encouraged her friends to get to know Logan. When they were at home, Logan joined her and her friends at the kitchen table. Because he was shy, he rarely spoke, yet Cathy felt he was at least a part of what they were doing in a way that suited him. She also had friends who became peer facilitators and entered classes similar to Logan’s to assist the teachers and learn how to be friends with people who were different from them. One friend shared with Cathy how much she enjoyed that opportunity, and Cathy felt “she built a relationship with him. He responded pretty positively”. This made her feel she had done something good for her brother by encouraging her friends to get to know him better.

Andrew did not report having the opportunity encourage his friends in this way, but he did report that his football teammates were receptive to Logan and treated him as a teammate whenever they saw him after football games. Andrew felt his teammates could interact with his brother if they wanted, but he was not the type of person to insist his mates get to know his brother. Andrew knew Logan enjoyed attending his football games, so he made an effort to see him after the game.
The sister/sister pair had a similar dynamic to the triad group. Linda discussed how important it was to her for her sister engage in some of the same experiences that she had at school. She related how scary the first year of Alexandra’s life was for the whole family,

I remember ambulances coming to the house all the time to get her because she stopped breathing, or something had gone wrong, and they could figure out why she was doing something she was. So, we would go to the hospital and would spend a few weeks there.

Because of events like these, Linda believed it was even more important for her sister to be able to experience high school in a similar manner to the general education students, for there was one point in Alexandra’s life where the family was not sure Alexandra would get to have the experience and support she has now. Linda said the best part about teaching at the same school where her sister was a student was “being a part of her top 10 moments” and knowing that her sister’s needs were met. Although she did not like to intrude on her sister while she was at school, she had the peace of mind that she could if she felt something was important enough to do so.

Inconveniences of an SWO. Linda and Andrew both expressed that being an SWO sometimes was a bit of an inconvenience. They had to do things that they did not always want to do or they had to care for their sibling when they wanted to do other things. However, they both reported that, in hindsight, the rewards they felt of having their siblings often outweighed these inconveniences.
Linda reported having her sister at the same school was not always comforting. Sometimes, situations dictated that she assume the role of an authority figure or change her plans to accommodate those of her sister. Most of the time she did not mind, but sometimes she felt the boundaries between the roles of mother and sister became indistinct. One instance occurred when Alexandra became despondent in class because she was experiencing problems with her friends. Alexandra’s teacher stopped by Linda’s classroom to ask if there was anything going on at home that might affect Alexandra in school. Linda discovered that Alexandra was experiencing some trouble with a friend over a male student. Linda elaborated,

Her teacher called me into talk about it and just ask me what was happening at home and how was she acting at home. Of course, I was happy to answer her questions, but at the time I was kind of like, I wish I didn’t have to answer these kinds of questions because it sounds awful, and I don’t want to think of my sister as a bad person. . . . I had to talk to Alexandra about why you can’t do those kinds of things, and that just put me in a different role with her than I prefer to be. I love talking to her about school, and for like a week after, she was a little bit more distant. . . . It just changed our relationship for a bit.

While Linda liked the responsibility of being needed, there were times it was hard for her to accept that her sister needed her in a role other than sister. She said there was a big difference for Alexandra between Linda having a little authority at home and Linda having authority at school. She would rather just be the needed sister at school with no authority and be present for the happy moments in her sister’s high school experience.
Sometimes, Andrew inconvenienced himself to make Logan happy. For example, he took Logan to places he liked in order to get Logan out of the house. According to Andrew, Logan loved going to the library and could spend a long time there if allowed:

I would take him to the library because I know that he really enjoys going there, but I may not always want to be there that long, but I know that he is having a fun time, and it puts him in a good mood.

While Andrew experienced a small amount of inconvenience by his brother in these instances, he still felt he needed to be there for him because he knew it made Logan happy, and it was part of what he could do as a brother to make him happy.

Influence of the responsibilities. Both teachers and siblings all felt responsible for the education of individuals about people with disabilities. Through the values previously discussed, they formulated their responsibilities. All participants believed inclusion of all people was part of what they were supposed to do, and this belief influenced their main goal of education of other individuals. *Figure 7* illustrates how the participants’ responsibilities might have influenced the other participants. The SWOs wanted people to know about their siblings and wanted their siblings in school with them. This guided the teachers to support them in the expression of this desire to create dialogue and a stronger desire to include their SW. The SW also expressed a desire to be a part of the school, which influenced the teachers to create lessons and opportunities for inclusion. All of these responsibilities allowed for more students and other teachers to become more aware of people with disabilities and create some value for their differences.
Theme 3: Growth through the Value of Differences and Responsibilities

The teachers and the siblings all desired other people in the school to have an understanding of people with disabilities. Education and inclusion were both important to this happening. The teachers and the siblings felt like it was their job to educate others and advocate for people with disabilities. However, how they accomplished this depended on the growth they experienced. The teachers did not experience much personal growth in this phenomenon, but they experienced the growth of the siblings and their students. The SWO experienced growth personally and through watching the growth of their SW.
Siblings and growth. When the SWOs talked about growth, it came in two forms: personal and SW growth. These participants discussed personal forms of growth with greater frequency because the SWOs possessed more knowledge of the SWs’ impact on than confidence of their impact on their SWs. Some of the SWOs talked about their SWs growth in the form of being happy. They wanted their sibling to be happy in all that they did, and they often changed the way their schedules and interactions with them so that they ensure their happiness. For example, Noel noted that when he was worried about how happy his sister, Hallie, was, he would sing to her, which improved her mood immediately. He realized she was able to communicate better with him to get the things that she liked. She would say things to him like “ride the neigh” to get him to talk about horses, or she would ask for the “donkey” when she wanted him to turn on the movie *Shrek*. Hallie also sang parts of her favorite songs to get him to turn on that song. Noel discovered the more he did these things for her, the more her communication increased, and he determined it was because she would get to listen, watch, or do the things that made her happy. Noel also noted he grew from the experiences because he was better able to read and help people they needed it.

The siblings also conceptualized their perceptions of growth through how they valued their SW and the responsibilities they assumed in regard to their SW. Andrew and Cathy focused on stopping use of the “r-word” by other individuals as a way of protecting their brother, Logan, and ensuring others’ cruelty did not hinder his happiness. Andrew’s concern for his brother was so great that he rarely commented specifically
about his personal growth resulting from his experiences of being a sibling of a person with a disability. However, he mentioned,

    He has made me a very patient person. I have the patience to deal with him sometimes. I would say that I am the most patient maybe out of the whole family besides my mom. I am the most patient with him because I just understand that he cannot always do things as fast as others can, like myself.

While Andrew did not feel like Logan influenced his choices and growth, he did feel that he had helped him to be patient.

    Cathy felt differently about her growth and Logan’s growth. She sought ways to connect with him, and she expressed excitement when she discovered art provided a medium. She felt that sharing an interest in art promoted growth in their relationship.

    Cathy discussed how she has learned to view differences as a great aspect of people with disabilities:

    I personally love Logan and having a sibling with a disability because I think it opens my eyes to, like, different things in the world. Just because I can experience different things like Special Olympics and stuff. I mean, I think it’s pretty cool. And people that don’t have siblings with disabilities or anything like that, they don’t get to experience it. So, I think it’s something different and unique to do.

    Cathy often found herself encouraging her friends to get to know people with disabilities saying,
I would say maybe not to judge people so quick. I think some people think people with disabilities aren’t as capable as people without disabilities, which I disagree with, because in Special Olympics there are so many great athletes out there—just because they have a disability doesn’t stop them.

Cathy believed her personal growth came from living with her brother and helping others to learn about people with disabilities. She said the more she talked about ending the use of the “r-word,” or the more she shared about Down syndrome, the more confident she became as an advocate for people with disabilities. When her teachers allowed her the opportunities to share, she did, and it made her feel like she accomplished something good for her brother and for other people with disabilities.

When analyzing Linda’s transcripts, I noticed subtle ways in which she grew. She stated she did not define disabilities the same as everyone else; she thought about the more “extreme cases” like her sister and everyone else with disabilities simply had different learning needs. However, when talking with her about her classroom and being a teacher, Linda mentioned she understood the struggle and ostracism people with disabilities faced, and she never wanted her students to feel that.

Linda related a story of a student with Tourette syndrome, who was struggling with his tics which were more apparent when he experienced stress or anxiety. She passed him a note telling him to get some water and come back when he felt comfortable or less anxious. She said that she felt like it was her duty to make students like him comfortable in her class. While she said her experience as an SWO did not really affect her instruction, it did increase her compassion towards her students. Linda noted that
when she came across students in her class who were also SWOs, she viewed it as an opportunity to help them, which gave her a sense of accomplishment that she may not have otherwise had if not for being an SWO herself. This was a transformation for Linda from the beginning of the interview to towards the end because she made accommodations to address the individual learner and their differences. Whereas at the beginning of the interview she stated that she really only viewed disability as cases like her sister, Alexandra.

Hallie would be allowed to spend extra years in high school due to IDEA laws. Noel felt that extra time would facilitate Hallie’s knowledge and growth. His hope for her was to be independent, live mostly on her own, and hold a job that she loved. He noted that would be a long road for her, but he was confident it could happen. Noel believed Hallie could accommodate her current communication differences by typing:

- She communicates better when she types than when she speaks because it’s like she knows what she wants to talk about but can’t really get there; it can’t really get to her mouth to where she can say what she wants to say.

Noel believed if she continued to try to communicate and if people were patient with her processing speed, she will reach the dreams he held for her.

Noel felt increased contact at school would improve his and Hallie’s relationship because it would provide common experiences. He felt pride and hope that Hallie was able to attend his musicals. Because she would hum or sing the songs for weeks afterwards, Noel realized she enjoyed watching the shows and seeing him perform. Hallie loved music, and it was important for her to be able to support her brother and go
see him in the shows. Noel noted that even though she loved musicals and that music generally put her in a good mood,

If she is in a bad mood, and she is at risk of having a meltdown, then she doesn’t [go], but when she does go, she loves it. Because it’s so musical, and that’s sort of her escape from reality like everyone’s escape, music.

Noel also discussed how he sometimes sang to his sister to help improve her mood. He perceived Hallie’s love of music as a conduit for them to connect. When she was on the verge of a meltdown, he sang to her, and she often grew calm. Noel felt it was the least he could do to help his sister feel better. He also shared that when Hallie is starting to feel anxious, she asked for music because she understood it helped her find peace. According the Noel, this was a new strategy that she started using, and he viewed it as a sign of growth and maturity for her.

While Noel talked at length about this growth for her, he also noted his personal growth stemming from his interactions with Hallie. Hallie use of body language as a mode of communicating her feelings improved his ability to perceive the feelings of other people. Therefore, he experienced an increased sensitivity to others. Furthermore, he found his patience increased because he understood that anxiety and challenging situations have the potential to trigger strong emotions. Noel believed his ability to manage such situations derived from helping his sister. Hallie and Noel both gained insight and skills needed to help each other and to help educate others about differences.

Special education teachers and growth. Overall, the teachers felt that their main goal was to value the differences of their students. They wanted their students to grow
from experiencing differences, although the type of classroom they taught influenced their view of growth. Regina, Carl, and Megan defined growth differently.

*Carl and growth.* Carl felt like his growth was more personal. He perceived himself as a reflective person always striving to be a better teacher. If he could be better, his students would be. He reported that he changed his language to facilitate inclusion of people with disabilities, but he also talked about the different ways of talking in the different classrooms and team environments he entered. Carl sought to reach people where they were and deliver the message about people with disabilities differently. Therefore, the language may change and the delivery method may change, but the general message was the same, and he strived to be a positive role model for his students and team.

*Regina and growth.* Regina felt she did her job well when her students were able to interact socially with their peers. She noted that communication was a major deficit for students with autism. Thus, if her students exhibited general niceties in an appropriate way, she, with the help of her peer facilitators, had done what she felt was the most important aspect of working with students with autism.

*Megan and growth.* Megan believed that the opportunity for growth in her classroom was through peer facilitators interacting with her students. She viewed peer growth in their statements referencing students with disabilities. For example, she reported many of the peers grew from “that is such a cute kid with Down syndrome” to “wow, they really are so much more than their disability”. She concluded she had done
her job if the peer facilitators in her room gained an understanding of her students. Megan stated,

I think they are shocked when they find out that our children here are more like them than they thought and are better at things than they thought. It does change their impression, because they get to know them as human beings and not just that cute girl with Down syndrome. I’ve only had a few that I would say truly stepped into potentially lifelong friends, but a lot have stepped into true friendship, and a lot stay in touch via social media and would consider themselves friends. There is no doubt in my mind that they would hang out in public or just talk to each other.

Megan knew it was important to help her students reach their goals in class, and she accepted that responsibility, but she felt the true measure of growth was the student expression of their growth through getting to know each other and becoming friends. She felt it even more when the peers expressed their surprise and new awareness that the abilities of people with disabilities surpassed previous expectations. Megan noted that after such experiences, the peers were generally more willing to defend and advocate for their friends with disabilities.

Megan also related how her students with disabilities grew as well. They often gained social skills from interacting with peers and increased their independence in various school settings in the school. Her planning and direct instruction by the peers were often more beneficial than if she taught the same skills. In this case, both the students with disabilities and the peers experienced growth.
Because Megan allowed her students to ask candid questions without fear of reproach, her classroom was a space that was safe for both students with and without disabilities. For example, one student with a disability in her class wanted to talk to a girl, but he was unsure of how to conduct that conversation. Although extremely nervous, the male felt safe enough to ask his teacher the best way to ask her to be his friend.

Another example Megan provided was that of a peer who was worried about transferring to another classroom with students who rarely interacted and sometimes exhibited difficult behaviors. The peer wanted to know how she was supposed to interact with the students. She was afraid of asking the students’ teacher because she did not want to upset or offend the teacher. Because Megan had created a safe space for the peers, this peer asked her if she could change rooms because she was unsure of her ability to interact with those students well. The teacher gave that student the opportunity to work with her own students to gain confidence in working with students with disabilities, and eventually the student grew comfortable enough to go back to the original classroom. Megan felt she had done her job by allowing the student the opportunity to grow and learn more about all types of differences in people with disabilities.

General education teachers and growth. The two general education teacher participants, Linda and Betsy, experienced personal growth. They also witnessed students grow because of their attitudes and actions toward inclusion of students with disabilities. Furthermore, SWOs and SWs grew because of teachers’ influence.
Betsy and growth. Betsy created a project that allowed students to research various disabilities and how those differences affected the people who had them. She encouraged students to determine ways to assist people with the various disabilities. Once the students completed their research, they presented their findings to the class. Betsy found later that several of her students became involved in their topic beyond her class. She talked of the growth those students achieved to reach the point where they wanted to help. The opportunity to discover the abilities and struggles of individuals with disabilities was a revelation that changed the views of several of her students. Betsy hoped such lessons would result in students becoming world changers.

When she talked about the growth of her students, Betsy appeared very concerned that she set a good example for students to become “kind and compassionate” people. Betsy experienced growth through her students’ growth because her students constantly challenged her to be a better person. She explained,

Smart is important, but it’s only one piece of things. When you have really smart people who are also kind and compassionate, that’s what we need. That’s what’s wrong with our world; we need more people who, you know, can build the bridge and make the medicine and treat people, but who care about them. You know every four years or so, I go back and forth, maybe I should go back into research. Honestly, it’s a lot less work, the hours are better, and the pay is a lot, but I can’t. I can’t stand the idea of doing so because I deeply love what I do, and I feel like I’m making a difference. At the end of the day, that’s what I care about. That’s what I want my legacy to be. I don’t want people to remember I had, you know, a
good job, or I made a lot of money. I want people to remember that I was a person who helped them.

Betsy knew that if she could inspire other students to embrace the differences in people, she had done her part in helping all students realize they were important and they mattered. She wanted all of her students to know that they mattered, which is why she worked so hard to plan lessons and maintain the lab time for the MI/MO students. Science was a passion of hers, but teaching was a calling, and marrying the two gave her the outlet to help all students become world changers.

*Teachers influence sibling growth.* Many SWOs wanted to share about their SW and discuss with their peers what it meant to them to have an SW. They also wanted to make their peers aware that sometimes their siblings’ differences were difficult and unique at the same time. For example, Linda talked about her sister with Down syndrome in a pragmatic tone. Linda said, “My sister has Down syndrome, this is what it looks like, any questions, go.” Because of students like Linda, Betsy found herself working to raise awareness for those differences. She worked hard to create safe spaces for family members and siblings to discuss their experiences with people with disabilities. Betsy felt Linda helped many of her fellow classmates by telling about her siblings. She also thought Linda grew from the opportunity to share.

Although Linda recognized part of her identity was that of an SWO, she did not want it to define her. However, she recognized she had an opportunity to let people understand her sister better. Betsy noted how Linda’s tone changed from businesslike animated as she honestly explained how much a sister with Down syndrome affected her
life and that of her family. Betsy could not say for sure if that opportunity changed the sibling relationship, but she did note that Linda’s ability to talk about it improved, which led Betsy to believe Linda had experienced personal growth.

Betsy felt it was important for her students to know more about people’s differences, learn to embrace them, and hopefully grow. She elaborated,

I think that’s part of human nature; it’s things that we don’t understand we’re often fearful of it. I don’t think people are intrinsically bad, but they have not been around others that have disabilities. They are just uncomfortable and fearful because it’s different. It’s not that they’re bad people. It’s just that they just don’t know, and so someone needs to educate them and when you have the Lindas of the world and good programs that are built to blend, let’s be very honest, the kids are standing out there on opposite ends of the spectrum at school, and the fact that there is something that offers the opportunity to engage, like, I love it. I’m going to have a moment (cries). . . . I’ve had lab aides in the past tell me this is a powerful piece of what I do because it feeds my soul, because it is such . . . it’s because I’m getting something totally different from this, like they’re such cool people. It’s so much fun to be a part of this, and no, it’s not the norm, it’s not what I normally do.

Betsy felt her instruction of students in the MI/MO classes was very important. She not only felt like their learning and growth was important, but that the growth of the lab aides was also important. Her main hope for the lab aide program was for her aides to become
aware of people’s differences and embrace them by learning how to meet them and teach meaningful science labs based on those needs.

Linda also stated that the school personnel did a great job helping her sister achieve her goals. Linda wanted her sister to be able to reflect on her high school experience and discuss the positive things she did while working towards her goals. Linda spoke at length about how important it was to her that her sister’s high school experience resembled that of a “typical person”. She felt Alexandra’s teacher was invested in her sister’s long-term growth, and she was confident her sister would leave high school as a more skilled and balanced person. Her sister’s end goal was an adaptive college program where she would get the college experience. Linda said, “Anything I can do to help my sister experience those moments, I’ll do.” She also emphatically stated,

I love getting to be part of her top ten moments, if you will. Moments that she will remember about high school. The fact that I could make sure that she got to go to her homecoming, that’s a moment for me, and I know that’s a moment for her because she still talks about it and how much fun it was for her . . . in the case of homecoming I get to make sure she has that experience. Let’s be honest, she would have been fine going to homecoming without me, but it reassured her.

Linda acknowledged that Alexandra would have learned so much on her own and for the most part she did have a great opportunity to be included at homecoming, but Linda felt like she helped her sister to grow, and for her that was one of the most important aspect of being a sibling.
Other SWOs experienced personal growth through lessons that allowed them to share about their SW. For example, when Cathy worked on a class project about Down syndrome, she shared her knowledge of its effect on her brother and his ability to communicate or to interact with others. Her personal growth came from research that revealed people with Down syndrome have differences. She said she realized that many were able to communicate better than her brother and noticed that many still had to learn how to communicate. She also learned that there are three types of Down syndrome, and that her bother had the most common type. This completely changed her ideas about Down syndrome and broadened the way she thought about it. Cathy felt she gained the most growth from the opportunity to share what she learned with her classmates. She reported genuinely feeling that the more she taught her friends about her brother and other people with disabilities, the more her peers would be accepting of them and the more they would be included.

*Figure 8* illustrates the factors that led to the growth experienced by the participants of this study. The teachers created lessons and safe spaces that allowed students to ask questions and learn more about disabilities. Teachers also demonstrated their values towards differences through creation of lessons and safe spaces. These lessons and safe spaces allowed the SWOs to share about their lived experiences with their SWs. Through sharing, they were able to grow in their comfort level with sharing, and they were able to grow in their own knowledge. This led them to be able to help their friends learn about people with disabilities and helped the SWOs include their SWs
in various aspects of school because their friends had gained the knowledge they might need to include people with disabilities.

<table>
<thead>
<tr>
<th>Teachers</th>
<th>SWO</th>
<th>All participants experience growth through education of all individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Create safe spaces</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Create lessons for sharing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Demonstrate value of differences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Talk about SW</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Help increase SW happiness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Share with peers about SW</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Figure 8. Teachers and siblings without disabilities create awareness.*

**Defining Disability**

The ways in which all participants valued differences also conveyed how they defined disability. For example, Linda, who was an SWO and teacher, discussed how she felt that disability was really found in the “more extreme cases,” such as her sister who had Down syndrome, but that people with dyslexia and attention deficit hyperactivity disorder really did not have a disability as much as they had learning needs that needed to be met. Her definition changed slightly when she encountered a young male with Tourette syndrome in her class. However, she always made sure her students were safe and comfortable in her classroom, and she felt it was her job as a teacher to make that happen. She had an even stronger conviction towards that job because she was an SWO.
The participants’ ideas and definitions of what it meant to have a disability and to help a person with a disability were unique and individual. The SWs also defined their ideas of disability. For example, Logan could tell he was different, but he was unsure of how to express the difference. However, he was very comfortable with who he was because he was surrounded by a supportive family and friends who were similar to him. Another SW, Hallie, talked about how she was “special and unique”. She also knew she thought differently, and she expressed that thinking differently was what made her “unique and special”. Hallie often became frustrated because she was not always able to communicate how she felt. Through observation, it was apparent she was very comfortable receiving help from her family and familiar people because her frustration decreased. Alexandra, another SW, did not actually define her disability. She talked about herself with confidence, knowing that her sister was always there to help her if needed. Numerous times, she stated how much she enjoyed having her sister at school with her. She felt valued by her sister when her sister was willing to help her.

The different groups of teachers also defined disabilities differently. The three special education teachers reported valuing the differences their students brought to their classrooms. They each defined disability differently, but all three looked at it from the context of the students in their classrooms. Megan felt like she could provide a broader, more societally inclusive definition, but she did not want to take extra time during the interview to debate with herself. However, she did say,

“It’s different processing speed, difficulty understanding, or interpreting things that may otherwise be considered everyday normal. I think that’s more of what
Regina’s feelings were similar to those held by Megan. She stated, “I don’t like the term disability, but it’s just when there is a deficit somewhere, they are able to do it in some other way. You just have to find the way to be able to help them.” Carl expressed his definition of disability as creating a level playing field so that all students can succeed: “. . . it would be anything that impacts one’s ability to receive education at the same level as their peers.” All three felt like their students deserved the same education as their peers in the general education setting. However, adaptations and modifications in the work and lessons were necessary to meet students’ needs.

Linda and Betsy, the general education teachers, placed a high value on differences of students in their classes, but their perception of those differences varied. The majority of Linda’s classes were on-level classes that usually included people with disabilities. She believed some of the disabilities were instead needs that required different tasks or more unique teaching methods. Linda said, “When you talk about disabilities in the classroom, I definitely had a different understanding than everyone else who thought about ADHD, and I thought more about Down syndrome and Autism, and the more extreme cases.” On the other hand, Betsy worked primarily with gifted students and ran science labs with students with significant cognitive disabilities. Her perspective on acknowledging differences was a little different:
So, I think disability looks different on different people. In my experience, it often means that somebody needs something in a different way. So, it isn’t necessarily that they aren’t capable of learning a particular piece of information or understanding a piece of information, but that you can’t necessarily give everyone the same information in the same way. We don’t all receive messages in the same way as well, you know, even within our own language speaking our own languages. And so, sometimes you know you have to adjust what you’re doing and how you’re doing it to make sure that everybody gets what they need to get.

Even though they both defined disabilities with in their classrooms differently, they both felt that they embraced the differences their students presented.

Even though the definition of disability varied from participant to participant, the overarching idea was how much the differences in disabilities impacted people around them. Many participants did not define disability as a lack of something, but more as a need for extra support. While the differences were unique to each person, their differences could be met through others learning how to adjust to meet the person with a disability where they are instead of shaming them for being different or needing extra help.

**Siblings’ Unique Experiences Based on Their Family Dynamics**

Each sibling group had nuances that were unique to how they worked together. For example, Noel and Hallie’s parents wanted them separated at school on purpose because his family never wanted him to feel burdened by his sister. They wanted him to enjoy school, excel in his academics, and not worry about how his sister’s day was going.
However, because he was her brother and felt like it was his job to worry about his sister, he reported thinking about her at school and wondering how she was doing. He also reported that he enjoyed seeing his sister at school, and he was not ashamed in front of friends and peers if they witnessed her doing something that they might perceive as strange.

Hallie and Noel were siblings who were very close with each other. They interacted as many typical siblings do. Noel noted, “We are typical siblings; we are typical brother and sister. We make fun of each other. We love each other, but we have rough times, too.” Noel was referring to Hallie’s communication needs that make it difficult for her to express her thoughts and feelings at times. This can often lead to her feeling frustrated. Noel knew how important it is to allow a person to express their needs and desires, and he believed Hallie’s body language allowed him to read her mood. He explained, “When she is in a bad mood, she will squeeze her hands together really hard and breath really heavy. When she is in a good mood, she will laugh and say funny things to get my attention.” He enjoyed when Hallie attempted to get his attention in funny ways. These interactions sometimes defined their relationship, but Noel noted he worked hard to make sure her communication issues did not define their relationship negatively.

Andrew, Cathy, and Logan were unique in that they were the only triad group to participate, but even within their triad, the siblings had different experiences with each other. Cathy and Logan both loved art. When Cathy was in ninth grade, she enrolled in photography and ceramics classes. Because Logan was interested in these classes, Cathy
was able to use their shared interest in art and their overlap in ceramics class to bond with Logan in a way that was meaningful to him. Andrew reported he never took the same classes as Logan; therefore, he did not have the opportunity to share with Logan in that way, but they would see each other at the school library on occasion, and he liked the quiet time spent there with his brother. One thing the three siblings did have in common was their love of sports and celebrating each other in their successes in sports. Logan loved to watch Andrew play football and watch Cathy swim. Both Cathy and Logan reported enjoying going to the Special Olympics state Games and watching Logan swim competitively. They both reported being amazed at the number of phenomenal athletes in the Special Olympics.

Birth order affected the way that Linda and Alexandra interacted. Linda, the oldest of her sisters, reported that she and her middle sister were able to joke and tease each other mercilessly and enjoyed doing so. However, she was not able to joke with Alexandra to the same extent because Alexandra did not always understand language in a way that allowed her to “get” a joke. Linda stated she never wanted to hurt Alexandra’s feelings because of something she said. Furthermore, by the time Alexandra was born, Linda related that she had learned how to be a better sister, and she filled a role as caregiver that made their dynamic very different from the dynamic between Alexandra and the middle sister. However, she knew that she and Alexandra would always share Alexandra’s high school experiences. Linda loved being a part of the “top 10 moments” in Alexandra’s high school career, and she liked that it brought them together in a way that was unique for the two of them.
While all of the siblings groups had unique ways of interacting, bonding, and understanding each other, all of the SWOs expressed one common concern: they wanted their SW to be happy. They felt that happiness was of the utmost importance because they knew that they had to help their siblings get to a point in life where they could be happy. In some cases, their siblings would not receive the opportunity to work for it independently, so they wanted to be there to make sure it happened. The SW also reported wanting their SWOs to be happy as well. They liked spending time with each other, which indicated that happiness was important.

Teachers’ Unique Experiences

Each of the teachers valued differences in their classes and welcomed individuals with disabilities and unique learning needs in their classrooms. They all reported expending effort and time to meet the needs of their students and help them with IEP goals or with projects that furthered their learning. Betsy was the only teacher to participate who worked primarily with gifted students, and this changed her view of how to meet the needs of other students because she had to ensure her gifted students were not bored or under stimulated. Betsy also created the lab aide program, in which her gifted students worked with students in the specialized instruction classes. She felt all students should have access to science, and she worked hard with the lab aides to create beneficial lessons for these students. The lab aide program served dual purposes. It kept the gifted students who volunteered with the program engaged in learning sciences and helped them to learn more about their peers with disabilities, while also providing specialized instruction students an opportunity to experience science that they might not have
otherwise had. Betsy reported feeling very strongly that such programs continued to influence students to change the world for the better through science.

When interviewing Linda, I asked her to attempt to separate her sibling side from her teacher side, and this proved to be a difficult thing for her to do. She answered two sets of questions: the teacher’s questions and the SWO’s questions. For the purposes of analysis, I split her interview into two sections and analyzed them as two separate cases. However, because her feelings about being a sibling were so strong, they influenced her interactions with students and her classroom management and structure. This became apparent during analysis.

The growth theme that Linda influenced was the SWO theme of growth. She talked a great deal about her growth as a sibling. She felt raising awareness for people with disabilities successfully meant she had done her job as a sibling. Linda did not discuss the growth of her students to the extent of the other teacher participants. She did work extra hard to meet the learning needs of the students in her class because she never wanted them to feel “ostracized” by their differences. She wanted them to know that she had a safe classroom for them to learn and grow. In the one example Linda gave of mentoring a young female experiencing difficulties at home, she felt she did not have enough authority to say if the female experienced growth.

Megan, Carl, and Regina were all special education teachers concerned with meeting the IEP goals of their students. Carl, a special education leader in the school who primarily held an administrative position, was greatly invested in helping all students succeed, and he often utilized “out of the box” thinking to meet the needs of his
students. He said students with special needs deserved more than a formulaic approach to education because they were all so different. Megan and Regina echoed these sentiments. However, Megan was passionate about inclusion for her students because she felt it was her duty to prepare them socially for what could come after high school. Many of her lessons reflected that idea. She often used peer facilitators to help with these lessons because they were often individuals her students wanted to emulate. Regina also wanted her students prepared socially, but acknowledged she had to be more disciplined in teaching those skills because her students could easily get overwhelmed if they did not understand a certain situation.

The way in which the teachers showed how they valued differences, took on various responsibilities, and measured the growth of their students played an important role in their classroom management and instructional techniques. They all wanted to support students to be their best, but the best looked different for each student. The teachers modified and accommodated their lessons based on students’ needs or even created lessons to help students share their knowledge. These actions facilitated the creation of a space where students felt safe and comfortable to be themselves.

Summary

This chapter presented data from interviews with siblings with disabilities, siblings without disabilities, special education teachers, and general education teachers. Analysis of the transcribed data revealed the following themes: valuing differences, responsibilities, and growth. Definitions of what these themes meant for the participants in this phenomenon were described. The vignettes for each sibling group and the
teachers demonstrated how these themes affected their lived experiences in school.

Chapter 5 presents a discussion of the findings, as well as conclusions, implications, limitations, and recommendations for future research.
CHAPTER 5
DISCUSSIONS, CONCLUSIONS, AND IMPLICATIONS

In the last several decades, laws such as the Individuals with Disabilities Education Act have resulted in increased inclusion of individuals with disabilities in public spheres. One such environment is public schools. Dunn (1968) first noted that students with disabilities were capable of attending school and each student brings a unique set of abilities and differences to the classroom. He also pointed out that special classrooms for these students may not be the best way to include them in schools (Dunn, 1968). Deno (1970) created the cascade of design in which the majority of students with disabilities received instruction in general education classes. This model closely resembles the model utilized in 21st century schools nationwide. However, including students with disabilities in schools necessitates specific training of teachers to meet the learning differences of these students. The more students are included in various environments within the school building; the more teachers are redefining their jobs and instruction to meet the needs of these students (Billingsley, 2004). Within both general education special education environments exists a unique subset of students: siblings with disabilities and siblings without disabilities.

Within this subset is an even smaller subset of these siblings who attend school at the same time, evidenced by the small sample size from the highly populated school that served as this study’s site. In this phenomenological study, I interviewed siblings with
and without disabilities and their teachers to determine if the siblings had an effect on teacher instruction when the teacher knew about the sibling’s presence in the school building and also how these perceptions affected the siblings’ relationship.

Participants in this study were current and previous students from the same school and their teachers. The school was located in an affluent area of the southeast. One sibling group was comprised of a brother and a sister; one group was comprised of two sisters; and one sibling group was a triad comprised of one brother and two sisters. Three special education teachers and two general education teachers participated. All participants were White. Tables 1 and 2, presented earlier in Chapter 3, serve as a reminder of the description and pseudonyms of the participants.

Table 1

*Description of Sibling Participants*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age (in years)</th>
<th>Role</th>
<th>Group Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logan</td>
<td>Male</td>
<td>22</td>
<td>SW</td>
<td>One</td>
</tr>
<tr>
<td>Andrew</td>
<td>Male</td>
<td>20</td>
<td>SWO</td>
<td>One</td>
</tr>
<tr>
<td>Cathy</td>
<td>Female</td>
<td>17</td>
<td>SWO</td>
<td>One</td>
</tr>
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<td>Linda S</td>
<td>Female</td>
<td>25</td>
<td>SWO/General Education Teacher</td>
<td>Two</td>
</tr>
<tr>
<td>Alexandra</td>
<td>Female</td>
<td>17</td>
<td>SW</td>
<td>Two</td>
</tr>
<tr>
<td>Hallie</td>
<td>Female</td>
<td>19</td>
<td>SW</td>
<td>Three</td>
</tr>
<tr>
<td>Noel</td>
<td>Male</td>
<td>17</td>
<td>SWO</td>
<td>Three</td>
</tr>
</tbody>
</table>

*Note.* SW=sibling with disability; SWO= sibling without disability
### Description of Teacher Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betsy</td>
<td>General Education Teacher</td>
</tr>
<tr>
<td>Carl</td>
<td>Special Education Teacher</td>
</tr>
<tr>
<td>Linda T</td>
<td>General Education Teacher/SWO</td>
</tr>
<tr>
<td>Megan</td>
<td>Special Education Teacher</td>
</tr>
<tr>
<td>Regina</td>
<td>Special Education Teacher</td>
</tr>
</tbody>
</table>

*Note.* SWO= sibling without disability

The participants engaged in semistructured, face-to-face, individual interviews with me in various environments. All data were analyzed using constant comparison (Glaser & Strauss, 1967) and stored in Nvivo, a data analysis computer program. Analytic notes and memos were also stored in Nvivo to aid data analysis and understanding of the perspective of the participants’ lived experiences (Bazeley & Jackson, 2007). I conducted single-case and cross-case analysis to gain perspective and insight on the essence of the lived experiences and determine how those experiences influenced each other to create a larger phenomenon within the school.

I completed member checking by asking a few of the teachers about their feelings during interviews and consulting them as I completed the analysis to ensure correct representation of their perceptions. I had the same opportunity with SWO, but communication and scheduling difficulties prohibited member checking with the SWs. I did run their answers by their SWOs, who all reported that they felt their siblings’ perceptions were well captured. The conclusion of this study was that when teachers
valued SWs then the SWOs valued their siblings and this led to both teachers and siblings feeling responsible for the growth of the SW and the inclusion of the SW in school, thus leading to education for others through social interactions. This study has implications in the areas of teachers, inclusion, and instruction. The following sections present the discussions, conclusions, and implications of this study, followed by the limitations and study summary.

Discussions and Conclusions

This study examined the perceptions of inclusion held by teachers, siblings with disabilities, and siblings without disabilities. It also examined how teachers may or may not change their lessons to better include sibling groups that are inclusive of a person with a disability. Due to siblings with and without disabilities often being in the same school together, I decided to examine the perspectives held by SWOs regarding inclusion of their SWs, as well as the perspectives of the SWs regarding sharing a school environment with their SWOs. In addition, I also examined how the teachers included students with disabilities in the school through instruction and how they tailored their instruction to meet the needs of the SWOs and SWs. This section provides discussions and conclusions of the research questions that guided this study:

1. How do students and teachers’ perception of disability inclusion in a secondary setting influence the school experience of the siblings with and without disabilities?

2. When working with one member of a sibling group, how do teachers modify their instruction to support the siblings?
When I conducted a case-by-case analysis and grouped each case by role, several categories showed significance for the participants in relation to the emerging themes. The SWOs focused heavily on separation and communication. The SWs focused on togetherness and personal thoughts. The teachers focused on instructional practice and support. These categories all informed the themes that emerged. Table 3 provides the categories of most significance to each type of participant: siblings without disabilities (SWO), siblings with disabilities (SW), and teachers (special education and general education). During the analysis process, three themes emerged: valuing differences, responsibilities, and growth.

Table 4

**Significant Categories for Each Role**

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<thead>
<tr>
<th>Role</th>
<th>Category</th>
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<tbody>
<tr>
<td>Siblings without Disabilities</td>
<td>Separation</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td>Siblings with Disabilities</td>
<td>Togetherness</td>
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<td></td>
<td>Personal Thoughts</td>
</tr>
<tr>
<td>Teachers</td>
<td>Instructional Practice</td>
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<td></td>
<td>Support</td>
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Valuing Differences through Inclusion

The findings for this theme suggest that teachers and siblings expressing their opinions of value towards students with disabilities might influence others to value the differences of people with disabilities as well. The SWs expressed their appreciation of differences by embracing their own differences with the use of words like “special” and
“unique”. Their language is suggestive of understanding they are different in some ways. The SWOs expressed their appreciation of differences by being available for their SWs when they needed them because they wanted their sibling to be happy at school. They also wanted people to change their language to be more inclusive of all and to stop using derogatory terms that might hurt the feelings of their siblings. They did not want their sibling to feel bad about being different or notice their differences because of someone’s negative language. This idea is consistent with the current literature. Simpson (2011) discussed the idea that degrading terms were used as a way to “other” people with disabilities and many of these terms suggested that people with disabilities could not do something because of their lack of ability. Derrida (1976) and Danforth and Rhodes (1997) also discussed the idea that language was often used to create a binary of us and them. The SWO did not wish to have people consider their SW as outside everyone else. They wanted to dispel the idea of us and them to be more inclusive of everyone.

The teachers valued how differences could liven up their classrooms and create the potential for professional challenge. This was supported by the literature as well through Kugelmass (2006) who said that how teachers viewed disabilities often lead to positive changes for those around them. Due to the limited sample size of participants, more study is necessary to determine if valuing differences was limited to this group of participants or if this is something that is prevalent in other secondary schools.

Examination of the theme, valuing differences, revealed all of the participants valued differences; whether it was their own or those of others, they placed high value on differences. Hallie, who understood her way of thinking differed from other people, said
it made her feel special and unique. She made the statement, “I am unique.” She reported she liked being special, but it was hard to determine if she felt isolated by her different way of thinking, or if she truly felt special. Alexandra also reported feeling special because of the relationship she had with her sister. She knew it was not typical to have a sister who taught at the same school she attended because she was the only one of her friends who did. Her friends liked her sister, and she liked that her friends were her sister’s friends, too. Logan felt special because he said he was “the boss,” and his siblings would do what he said. These personal thoughts on specialness and uniqueness were prevalent for all SWs and revealed their perceptions of themselves among family and peers.

Because she did not have to rely on a communication facilitator to aide her in finding answers, Alexandra was the only SW to articulate clearly. Family members facilitated the communication of Hallie and Logan during the interview process. Their presence possibly influenced their answers, but the feelings of uniqueness and specialness still existed even if they were not able to express themselves fully in the same way as Alexandra. All of the SWs enjoyed sharing their school experience with their SWOs because they reported feeling happy whenever they saw them in the halls during the day.

Several of the SWOs stated they felt unique or special because they had an SW. They all highlighted how uncommon it was for someone to have an SW. All of the SWOs said they would not change their family in any way, and they accepted their SW.

Cathy was the only SWO who had an SWO friend. It made her feel less alone in her experience: “You don’t find a lot of people that you can relate to with siblings with
Down syndrome. It’s just not very common.” She did not feel so alone in dealing with some of the difficulties having an SW might bring because she was able to talk to her friend about it. She said, “I feel like she has my back.”

Andrew said he wondered what it might be like to have an older brother without Down syndrome. It was not something that he thought of often, and he reported growing beyond that idea. As he matured, he accepted his brother the way he was.

Noel also stated he would not change his sibling, Hallie. He really liked that she loved music like him. Being able to share something so important to them countered feelings of separation and difference he felt at other times.

Linda, who expressed adoration of her sister, felt very responsible for her well-being at school. However, Linda did not always let people know that she has a sister with Down syndrome because she did not want that to be her whole identity. Despite this conflict, she was open and willing to answer questions and discuss her experiences.

Many of the siblings reported correcting the use of the “r-word” by their friends or other students in the classes. They all felt the “r-word” was tantamount to the derogatory words used in racial slurs. Because of their belief that their peers should know why that word was so offensive, a few reported correcting people and explaining why that word did not belong in polite conversation. Linda even went as far as asking a student to leave her classroom who had used that word. It was important to the SWOs that people did view not their SWs as different or bully them for their differences. They stressed this through their use of language and helping others to change theirs. This was also a way that they helped their peers to learn the value of people with disabilities.
The teachers also valued differences of students with disabilities. These findings were on par with current research by Dudley-Marling and Burns (2014) who discussed the idea of socially constructing students environments to adapt them to meet the student where they are. Linda knew that students with disabilities were in her class, and she did her best to make sure they were comfortable. She felt she did more than the average teacher did to accommodate the individuals’ needs. Regina felt like she had to get to know her students and form a relationship with them in order to teach them, so she sought to work with them in meaningful ways. Megan ensured she made time for her students in her classroom and met their academic skills, but she also protected her students’ time outside of her classroom in electives by finding peers to assist them in those classes. She even encouraged her students to join clubs and groups they were interested in because she valued their likes and dislikes. Betsy created time in her busy day to hold labs for students with significant cognitive disabilities because it was important to her that they receive the opportunity to access science. By meeting students where their abilities were strongest, Betsy lived by her motto of science for all. Carl made the most interesting statement, saying special education students breathe life into “what would otherwise be a stale environment”. All of these teachers felt it important to see the good that embracing student differences brought to their classrooms and teaching environments.

Responsibilities

Another theme that emerged from the data was responsibilities. The participants of this study all took on various responsibilities based on how they valued disability.
Unfortunately, the SWs did not really speak about this in their interviews. Hallie and Logan focused on their differences and feelings about seeing their siblings at home. Alexandra felt like she was special to have a sister at school with her. She was the only SW who mentioned how she helped her sibling. She could go see her sister, Linda, if she wanted after making sure her teacher agreed for her to leave the classroom. Alexandra also talked about helping her sister with schoolwork, such as grading papers. She liked being helpful to her sister and felt she was doing something good by helping her older sister with her work. In this way, Linda made her feel valued by allowing her to help.

These finding suggest that SWOs and teachers feel responsible for the well-being of students with disabilities in the school environment. The findings that SWOs were worried about the well-being of their SWs were consistent with Ward, Tanner, Mandeleco, Dyches, and Freeborn (2016) who found that while SWOs often have conflicting thoughts about their SWs, they did wonder what they were doing at school and other places where they were apart. The findings were also consistent with Jones (2004), who reported that special education teachers had to discover their own personal identities when working with other teachers, and this could affect their views of their students.

The SWOs felt they had a responsibility to help their siblings be happy at school. The triad group of Andrew, Cathy, and Logan talked about this the most. Andrew would approach Logan if he was passing by at class change. He reported how happy Logan was to see his brother: “He would always smile and give me a hug”. Cathy reported doing the same. In the mornings, both siblings would walk their brother to class or to the bus zone
to meet his class’s paraprofessional in the mornings. They both felt this was something they could do to spend time with their brother and help their mother.

Linda reported allowing Alexandra and her friends to come to her classroom after school to change for cheerleading practice. She would also take Alexandra home from school sometimes. Linda reported the desire to make Alexandra happy and to ensure she was safe throughout the school day.

Noel enjoyed seeing Hallie happy at school, but he felt responsible for her happiness when they participated in music activities together because he knew music was very important to keeping her in a great mood. None of the participants talked in a significant way about their SWs being a burden to them, although Noel expressed that their parents did not want them to feel that way.

All of the SWOs felt responsible for ensuring no one made fun of or bullied their SWs. They often corrected people for making offhanded comments or slurs about people with disabilities because they felt it was their job to advocate for their siblings. They wanted their siblings to feel welcome at school and extracurricular events they attended together, so they did not hesitate to correct someone for a rude comment or common misconception about disabilities. They did not want people to view their siblings as something or someone that needed to be fixed because of their differences. This was consistent with the research conducted by Dudley-Marling and Burns (2014) who wanted to dispel the deficit thinking about people with disabilities requiring fixing. The SWO made sure that through positive language that people knew there was nothing wrong with their siblings.
The teachers held more responsibility for all of the siblings. They felt it was their job to provide opportunities for SWOs to feel safe and comfortable enough to share their experiences. Megan allowed all of her students to ask her any questions about students with disabilities so she could provide them with true and informed answers. She felt this was a way of dampening fear of the unknowns or little knowns about disabilities. She also believed this gave the students the opportunity to form better relationships with her students. Carl reported wanting to include all students in the best ways possible. He often took the time to include them in afterschool sports activities, giving them a job and the opportunity to show others their capabilities in performing many different tasks related to sports. Linda felt she had a unique opportunity to be a mentor to other students who were also SWOs. She assumed responsibility for helping them cope with some of the difficulties they could face being SWOs while dealing with high school issues.

Betsy, perhaps, held the greatest amount of responsibility because she sought to create world changers. Her lab aide program allowed gifted science students to develop and run lessons on various science topics for students in the moderate and mild intellectual delayed classes at the school. She believed this exposed the lab aides to students who could teach them about patience and empathy toward others. Furthermore, Betsy assigned classroom projects that required students to research genetic disorders, which often cause individuals to have learning differences or to look different physically, and determine instructional methods aligned to those differences. In addition, these tasks created a safe and inviting venue for family members, especially siblings, to share their experiences of living with people with differences. Not only would those students
provide a firsthand account of their life experiences, they also gave their classmates the opportunity to interact with the genetic disorders on a personal level. Such projects promoted student connection to different genetic disorders that students likely would not experience otherwise. This made Betsy feel her students gained greater understanding, compassion, and empathy for people with disabilities. Betsy often constructed an environment for her students that met them where they were in their knowledge of disability and challenged them to learn more. This aspect of her instruction is supported by the research of Dudley-Marling and Burns (2014), who postulated that adaption of the environment to students results in increased learning and improved performance.

Teachers and siblings also felt responsible for convincing people to understand and accept the differences and abilities of individuals with disabilities. They believed this was to keep students with disabilities from feeling like the “other” or separate from the school body. The SWOs wanted their siblings to feel happy to be a part of the school and not feel different from other students. Thus, the SWOs taught their peers to refrain from mean slurs about people with disabilities. By openly showing students how to treat people with disabilities and creating opportunities for learning, most of the teachers encouraged student advocacy for students with disabilities. Betsy wanted students to be world changers because science, ultimately, meant more medicine, better research, and improved devices to make the lives of people with disabilities easier.

Growth

The theme of growth was evident in the interview responses. These finding suggest that when teachers create opportunities for SWOs to share about their SWs, the
SWOs learn more about their sibling’s disability from conducting further research, and they have the opportunity to educate their peers about disabilities. This could potentially lead to more advocacy and better inclusion by the peers, which in turn could lead to a more inclusive school environment overall.

The participants rarely discussed their personal growth when the ideas of learning more or being better arose. The SWOs worried about the happiness of their sibling and their progress in school. The teachers worried about the growth of all their students, but when they talked about the siblings’ growth, they reported they wanted them to feel safe to share about disabilities and their experiences with their SWs. Teachers expressed the importance of sharing by the SWOs because it not only aided in the SWOs learning more about their sibling or about themselves, but it helped their peers to learn more about people with disabilities.

Although the SWs did not address their personal growth, they mentioned multiple times that they enjoyed seeing their siblings at school. Alexandra and Hallie both wanted to see more of their SWOs. When the SWOs talked about growth, it appeared their concern was the growth of their siblings rather than themselves. The main tenet that kept surfacing was the happiness of the SWs. SWOs wanted their siblings to be happy at school and with friends. They talked some about their friends getting to know their siblings, saying it was “cool” when the SW became friends or formed a relationship with their friends. Sometimes this happened when their friends were peer facilitators in the classroom of the SW, or sometimes this occurred because the SWO’s friend was frequently present. The SWOs felt comfortable talking to their friends about their SW
because they knew their friendship was safe, but they also liked the opportunity their friends might provide to the SW by advocating for people with disabilities. The SWOs who reported conducting projects or sharing in class about their SWs were also more likely to desire better ways to have their sibling included in school. They felt their sibling deserved more and better opportunities to make friends. Simplican et. al. (2015) supports the idea of people with disabilities placing a high importance on increasing their friendships. The SWOs gave their SWs the opportunity to increase their friendships by making sure that their friends understood their SWs and would interact with them in a positive manner.

The teachers noted the growth of their students when they provided them opportunities to interact with students with disabilities in class. Teachers also reported growth of the SWOs when shared their knowledge and experiences through lessons and conversations with the teachers. The special education teachers, Regina, Megan, and Carl discussed the peer facilitation classes at length. Regina contended her students with autism had the opportunity to grow socially through peer interaction, and students without disabilities grew personally through interaction with her students with disabilities. Through interactions, both groups learned patience and social skills. In addition, the peers learned to be compassionate for their peers with autism, who often had difficult days that resulted in behavior problems. Regina’s students also worked towards their IEP goals with the help of the peers and received the one-on-one attention they needed to master a skill. Carl’s beliefs reflected those held by Regina. Megan’s feelings about the peers were enhanced compared to the others’ feelings. She stated that she knew
her students and the peers had grown because many of them reported keeping abreast of
one another on various forms of social media, and some of them planned to get together
after they had graduated from high school. The research from Simpican et. al. (2015)
also supports the idea that peers included in classes with students like Alexandra, Hallie,
and Logan are more likely to make friends with their peers with disabilities. This type of
inclusion gave them the opportunity to learn how to form the friendships they desired to
have.

The general education teachers agreed that they worried more about student
growth than their own. Linda talked more about the growth of her sister. She did not talk
as much about student growth because her status as an SWO and a teacher hampered her
ability to determine if her students grew.

Betsy, on the other hand, believed many of her students experienced growth in
numerous ways. First, she noted the growth of the lab aides. She felt she could
confidently say they grew into kinder, more compassionate people because several
reported feeling being a lab aide with the MI/MO class enriched their souls and gave
them a reason to look forward to the lab days. They loved their interactions with the
students in those classes. Second, she felt her students who were siblings or family
members had grown because they were willing to learn more about the genetic disorder
of their family member and share their own personal experience. Betsy believed it took a
lot of courage for a person to share something so personal.
Linearity of Themes

An analysis of the themes from this study reveals the findings are very linear (see Figure 5). Valuing differences influenced responsibilities, which influenced growth. It is important to note that the themes influenced the education of all individuals about disabilities through social interaction and connection. It seemed if any part were missing from the line of influence, then the education of individuals did not happen. This occurred during one of the analysis passes I made with my data. I was exploring the relationship among the themes that had emerged and when I reshuffled the themes and removed the responsibilities there was only a tenuous connection between valuing disability and growth. When I added back responsibilities then the connection from the beginning to the end was stronger. For example, Andrew did not specifically talk about his brother’s growth or share during school projects. He did report sharing his brother with his football team, which his coach confirmed. This can be potentially perceived as sharing about his brother in a learning environment that was important to him. This intersection of SWO and teachers is unique to this study, and it adds to the body of knowledge since teachers may be unaware of SWO in their classes and the effect these students might have on lessons and student interactions. However, encouragement of participants to think about the ways they had influenced SWOs produced examples they felt they might have helped and created safe spaces for sharing.
The findings also support the idea that the more the teacher values differences in his or her classroom, the more the students will value it as well. This creates a safe space where siblings feel they can share their experiences with peers in the class, thus leading their peers to gain a better understanding of people with disabilities. These findings are
consistent with current research that noted when teachers dealt with students with disabilities in their classrooms in positive ways, the peers of the students with disabilities were more accepting of their peers with disabilities because the teachers set a good example of a positive relationship (Kugelmass, 2006). Furthermore, the findings of this study support Fellner, Comesanas, Duperoy, and Duperoy (2017), who claimed if a school is willing to take on an attitude of inclusion, SWOs might be more willing to advocate for their siblings, and SWs might receive a larger voice in their educational process. Ideas of Foucault (1976) on the idea of docile bodies being acted upon because they are viewed as lesser, play a role in how schools view disability, however the findings in this study support the idea that many teachers and SWO offer ways to make changes in inclusion so that people with disabilities are given more autonomy in their education. Also supported by current research is the idea that students with disabilities should be included as participants in studies and receive a voice (Meltzer & Kramer, 2016). Although the SWs did not have the strongest voice in this study, they were active participants, and I gave their voices equal power and consideration during the analysis and reporting of the findings.

In regard to the findings on friendships, Galvan, Spatzier, and Juvonen (2010) conducted research that supported the idea that general education peers could be friends with their peers with disabilities if this was a social norm in the school. Simplican et. al. (2015) also supported the ideas of friendships as being one of the most important things for people with disabilities because they desired to find acceptance in their environments.
While research supports various parts of this study, the findings highlight the idea that teachers have a profound impact on both SW and SWO through their instruction and educational interaction, which, in this study, allowed the SWO to feel safe in sharing their experiences with their peers, thus educating students without disabilities about their peers with disabilities through social interactions. Initially, Linda felt she did not change her instruction to effect change in the way students viewed people with disabilities, but as she talked during her interview, it was apparent that she had, in fact, adapted a writing lesson and chosen an SWO to help because this student wrote so movingly about her sister with autism. Betsy created the lab aide program and lessons that allowed siblings, both SWO and SW, and general education peers to grow, understand, and embrace the uniqueness of the differences of students with disabilities. Megan and Regina also provided opportunities for growth because they allowed peers without disabilities to interact with their students with disabilities, resulting in the forming of many new friendships. The findings add to the body of current knowledge by demonstrating that the values of the teachers influenced the values of SWO, which led to greater responsibilities and growth, thus allowing SWs, SWOs, and their peers to learn and educate one another in a positive and inclusive environment accepting of the differences of all students.

Implications for Inclusion, Teachers, and Instruction

Despite the small sample of this study, there are implications worth considering. These include implications for inclusion, implications for teachers, and implications for instructional strategies. The following sections provide these implications.
Inclusion

In the United States, inclusion of students with disabilities is an expectation in public schools. In the case of the SWs and teachers at this school, the SWs in the specialized instruction classes received inclusion in a way that Megan referred to as “reverse inclusion,” or peer facilitation. In this model, general education students visit the classrooms of the students in the specialized instruction classes as part of a class that they take for elective credit in the state where they school is located. At some point during the day, peers spend time with students with disabilities. The findings of this study suggest that SWOs often feel that their SWs is not included enough in the school, even though they each knew at least one person who was a peer facilitator. Despite the fact that they were unable to give suggestions for accomplishing greater inclusion for their siblings, still, they felt it necessary.

However, all of the SWOs except Linda failed to mention their siblings were included in an adapted science lab run by student lab aides with Betsy overseeing the programing and implementation. They may have not known that their SWs participated in science. This program gave extra time for inclusion for these students, for they were in an environment outside of their specialized instruction classes, and they received instruction from the lab aides, who were fellow students. More opportunities for similar lessons in other subjects outside of their classrooms might be what the SWOs wanted when they discussed more inclusion for their siblings. This means that teachers in the general education classes could seek the help of other students in adapting and presenting the information in their subject area to students in specialized instruction classes in a
more meaningful way that utilizes their strengths. This would give more students without disabilities the opportunity to interact with students with disabilities and create a more inclusive school environment as a whole. The finding about student with disabilities being included with their general education peers were consistent with current research, however, Betsy’s science program is an unanswered gap in the research that could implicate that students with significant cognitive disabilities could be included in different subjects when given help from peers to participate.

Teachers

The findings of the study emphasized the importance of giving SWOs opportunities to share their experiences with their SWs with other students. This often came in the form advocating for their sibling while changing classes or during interactions with other students. However, the teachers in this study played a unique role for the SWOs by creating safe spaces and lessons that allowed the SWOs to share their experiences. Although only five teachers participated in this study, data support implications for more lessons and opportunities that allow siblings to share their experiences. The findings in this study suggest teachers do their best to create spaces that allow students to feel comfortable with sharing, but this is something that may need to be commonplace in other educational settings as well. The SWOs often had experiences unique to their family and life, and some frequently felt alone because they did not have trusted individuals outside of the family with whom to discuss matters. By offering to listen through mentoring and extra guidance, teachers can provide the opportunities for
SWOs to speak freely about their experiences. They could also help them find other individuals who have encountered many of the same experiences.

Teachers also need to be willing to share their own experiences with people with disabilities and set an example for the students. As Kugelmass (2006) noted, teachers who are open to sharing and willing to demonstrate acceptance of students’ differences and disabilities can often set the tone for acceptance in their classroom and other educational environments. If this is something accomplished from the first day of class, students ultimately emulate the teacher’s attitudes. They do not receive the opportunity to learn negative behaviors directed at students with disabilities because the example and expectation are a natural embodiment of the classroom. None of the SWOs reported their teachers ever spoke poorly of students with disabilities, but if teachers are cognizant of their language and use inclusive language, then students would have positive examples of that as well. This would naturally lead to more inclusion in schools. This idea is consistent with current research in the area of teachers and disability, but needs to be something that is on the forefront of teachers minds when working with siblings with and without disabilities.

Instruction

In the area of instruction, more lessons that allow students to share their experiences are essential. The findings of this study suggested that when SWOs feel comfortable and safe, they are likely to share their experiences with their teachers and peers in the class. However, not every subject offers the opportunity for SWOs to learn more about disabilities or to learn more about their SWs. These lessons would be helpful
to further their growth and relationship with their siblings. When SWOs share what they know and what they have learned with other students, the result is typically raised awareness that other students may not possess prior. Furthermore, shared knowledge has the potential to create a more inclusive environment overall. These findings add to the body of knowledge because of the gap in research that directly addresses classroom content or lessons planning of teachers and the concerns or issues that disability raises in school.

Recommendations for Further Research

This study found that many SWOs, SWs, and teachers value difference, hold responsibilities for each other, and feel concern with the growth of one another. These findings suggested that the more a teacher values differences in his or her classroom, the more SWOs are willing to share about their SWs, thus allowing their peers to learn from their experiences. This created awareness and education through social interaction, which could potentially lead to a more inclusive environment. While these findings were fairly robust, some unanswered questions remain that could be addressed through further study.

The findings of this study suggested that SWOs were willing to share when they felt like they were in a safe and supportive environment for doing so. It was clear from the data that their sharing helped to raise awareness for people with disabilities and help the SWOs learn more about their SWs. However, more research could determine the direct effects of sharing their experiences on the learning environment. Knowing the thoughts of the students about their peers’ experiences might lead to feedback and
learning that would help teachers know what is important when creating opportunities for sharing. Furthermore, knowing how the sharing changed the mindset of students and teachers could be informative and maybe transformative towards better more supported inclusion.

While SWO sharing was an important finding in this study, it was also clear that the participants in this study valued differences and disabilities in their classrooms. This study included a very small sample of people with in the school itself. The participating school was comprised of 3000 students and approximately 250 staff members. To determine if they hold the same thoughts, other teachers in the school could be asked the same questions of those posed to this study’s participating teachers. Their responses could also verify if the school is as inclusive as reported by the small sample of participants.

In the same vein of determining how inclusive a school is, further research could be conducted on ways that a school as a whole could create programs that would open the doors to sharing schoolwide how disability impacts the students in the school who have disabilities or who have siblings with disabilities. This would allow teachers and SWO the opportunity to create “global” lessons about disabilities. This could potentially raise more awareness about people with disabilities in the school and out in the community if this is something that is brought to the front as a social justice issue within schools. Research could be conducted on the impact programs like these might have on school perceptions and the overall culture of inclusion.
Replication of this study on a larger scale to include more schools might provide support of the findings. The replication of this study in at the elementary and middle school level might provide data regarding the effect of age on the perceptions of the siblings, as well as the effect of teaching younger students on the perceptions of the teachers. In addition, conducting this study in different income areas would be beneficial to discover if privilege changes the ideations of the participants. Finally, investigating the cultural impact of students of color (i.e., Latino siblings, African American siblings, or immigrant siblings) on perceptions may also be helpful to inform the creation of more inclusive environments in other schools.

The last implication for further study is something so unique that it deserves to be highlighted. Betsy talked at length about the lab aide program she created for the students in the mild and moderate intellectual delay classes. Gifted students volunteered to help teach science to their peers with disabilities. The lab aide students used their lunch periods to plan and create curriculum under Betsy’s guidance that would meet the individual needs of the students participating. They would then teach these lessons and assist students during the lab to meet their current academic standards. Betsy felt science was meant for all people, not as an “elitist subject,” and she believed these students should receive access to science in a way that was meaningful to them.

This program provided students with disabilities many opportunities to learn about the world around them, while providing the lab aide the opportunity to learn more about their peers with disabilities. Betsy felt there was mutual growth from the aides and the students they were teaching. However, research could be conducted to better
understand how the program worked for all of the students with a focus on the achievement and social outcomes of the students with significant cognitive disabilities. Further research on Betsy’s lab aide program could be conducted to understand the perceptions of the aides and the students with disabilities on how participating in an inclusive science programs changes their previous conception of differences. More could be understood about how Betsy and her aides created curriculum that Betsy believed was nonexistent for high school students with intellectual delays. If research were conducted on this program to gain insight into its successes and failures, programs like this could be replicated to help other students in other high schools to provide access to various subjects for students with significant cognitive disabilities.

Limitations

This study had several factors that created limitation. The fact that no people of color participated in this study might influence and change the conclusion drawn because the culture, language, and view of people with disability are likely different in a predominately White school. In this same vein, this study was conducted in a very affluent area of town, and the views of people with disabilities derive from a place of more privilege than the average person from middle- to low-income areas. Furthermore, there was little diversity in the type of disability represented by the SW. Two individuals had Down syndrome and one person had autism, and, while they represent many people with disabilities in school, their representation varies significantly from the number and types of different disabilities represented in schools across the United States.
Another limitation was the lack of data to completely answer the second research question: “When working with one member of a sibling group, how do teachers modify their instruction to support the sibling?” It seemed that many of the teachers were not always aware they had siblings of individuals with disabilities in their classes unless the SWO explicitly stated the fact. It was a simple situational awareness deficit. When confronted with this knowledge, the teachers did not always make an extra effort to allow for sharing of the siblings’ lived experiences, and not all content areas in high school are well suited for those types of activities. This became partially apparent in the recruiting process of general education teachers. Many of the general education teachers identified by the SWOs declined to participate, stating, “This study doesn’t apply to me,” and “I don’t work explicitly with SWO”. This seems to be due to teachers’ lack of knowledge or the tools to address the unique needs of these students. In addition, the cause could be that siblings have similar sentiments to those held by Linda—a simple case of not always wanting to be identified as an SWO. If a teacher does not know that students in these situations are in their classes, it would be difficult for them to feel the need to address or discuss disability.

One of the biggest limitations in this study came from the recruiting process of families. When talking with Megan, the teacher who helped me identify students and families to recruit, I discovered she identified students who had positive and negative relationships with their SWOs, as reported to her in IEP meetings with the families. All students received an explanation of the study and the study consent forms. However, only the students reported to have positive relationships with their SWOs returned the
forms. This could be due to the dynamics of the families in that they do not want their SWO to feel burdened by the SW. Noel reported this situation in his family. However, this could be a greater concern for the SWO than it was for Noel. Initially Megan identified six families, and only three returned forms to participate.

The final limitation of this study was the communication aspect for two of the siblings with disabilities. They both were verbal when they were working with people they knew well and trusted, but they had limited verbal abilities when working with someone who was unfamiliar to them. Neither of these students displayed proficiency with alternative, augmentative communication devices. As a result, they required a communication facilitator to help with their communication. Their facilitators were family members. Having family member present while they answered questions could have potentially influenced their answers or changed them in a manner that was inconsistent with their actual perspectives. This led to a slight loss of voice for them in the analysis process. I tried to regain it during the reporting of findings and discussion of the study; however, their voice is not as strong as it was the day of the interview.

While I really wanted to capture the voice of people with significant cognitive disabilities, because there is not much research conducted in conjunction with them, I now understand why researchers have chosen other populations of people with disabilities to represent the disabled voice in the literature. I also understand why many family members become the voice for their children, brothers, and sisters with significant cognitive disabilities. They want to make sure they are heard and do their best to represent their best interests; however, this inability lead to limited data within this study.
In order to represent the disabled voice better, people with fewer cognitive and developmental disabilities could be included in the study. These individuals tend to be more verbal or they can precisely use an AAC device. If this study had included some of them as participants, the voice of the people with the disabilities would have rang clearer and would not have been lost as much during the analysis phase.

Summary of the Study

Through the use of disability theory, informed by the ideas of Foucault (1977) and Derrida (1973, 1976) and enhanced by the researchers discussed in Chapter 2, I sought to discover the perceptions of teachers, and siblings, with and without disabilities, regarding inclusion. I also examined how the instructional practices of teachers might change due to working with the siblings. Three sibling groups and five teachers, both special education and general education, participated in the study.

All participants participated in interviews that I conducted. It is important to note that students with disabilities received the opportunity to express how they felt about school. Through communication facilitators, two of the three participants with disabilities were able to answer questions using devices and “yes” and “no” response options. Alexandra was able to answer all of her questions verbally, so she did not require a communication facilitator.

Three themes emerged to describe the perceptions of the participants: valuing differences, responsibilities, and growth. Depending on their role in the study, all of the participants valued differences in different ways. The siblings typically defined
disabilities by those of their siblings and felt inclusion in school was important for their siblings. They also worried a great deal about the happiness of their siblings.

The teachers valued differences in different ways. The general education teachers acknowledged that it was part of their classrooms and worked to create an environment where students felt safe. The special education teachers enjoyed the individual differences of the students and viewed them as a challenge.

All of the participants talked about their responsibilities as well. The siblings wanted to make each other happy. The SWOs wanted to protect their SWs by making sure people used inclusive language and avoided the use of the “r-word”. Teachers felt they had to make their students feel the same as other students. They did not want them to be embarrassed about their differences. They also created lessons and opportunities for SWOs to share about their SWs. Safe spaces were something all the teachers worked to achieve in class to make the students comfortable enough to share their experiences.

Finally, the participants worried about the growth of the other participants. The teachers wanted their students to feel safe and to share their experiences, while the SWO wanted their SW to be better included in school. Teachers and SWOs wanted general education students to grow to accept and appreciate the differences of individuals with disabilities.

When the teachers displayed their value of the differences of all students by creating lessons and opportunities that created safe spaces for asking questions and sharing, the peers of the SWOs gained understanding, awareness, and insight for disabilities. The SWOs grew from the experience because they not only shared their
experience, but they had the opportunity to learn more about the disabilities of their SWs. Sharing allowed them to teach others what it meant to live with a person with a disability. It also showed other students that people with disabilities were valued. It taught teachers where they could add more to their lessons to continue the safe space sharing of experiences. The more teachers showed how much they valued differences, the more the SWOs were willing to participate and share their experiences, thus raising awareness, education, and acceptance from their peers without disabilities. The findings from this study imply the more this is practiced in secondary settings, the more inclusive the educational environment may become. Further study on a larger scale is necessary to determine if this is true for multiple schools in the secondary setting.

Final Thoughts

At the beginning of my project for this dissertation, I had to put aside the fact that my sister has had great influence in my life. I had to set aside how positive our relationship is to not get sucked into the trap of desiring to make the relationships of other siblings better. My experiences were my own as theirs were their own. However, I feel greatly fulfilled to know that many of the siblings I came in contact with felt the same as I do as a sister of a person with a disability. We all want the best for our siblings. We want them to be happy in all of the things that they do.

In the 30 years that I have had the opportunity to be a sibling and grow up with my sister, many aspects of school have changed for the better to make sure that people with disabilities are better included. When my sister was in school, there were not peer facilitation programs that allowed students without disabilities to get to know people with
disabilities and even become friends. I felt that I spent time demanding that people look at my sister for who she was as a person and not what she had genetically that she could not erase. Through this study, I feel grateful knowing that people with disabilities have a stronger place in school where more people are willing to interact and learn about how their lives are the same and different. We are all the same and different in many ways. That is what makes each of us unique and special.
REFERENCES


APPENDICES
APPENDIX A

IRB APPROVAL
Friday, June 22, 2018

Ms. Elizabeth Williams Durbin
Mercer University
Tift College of Education
1501 Mercer University Drive
Macon, GA 31207-0001

RE: Inclusion, Instruction, Achievement: A Phenomenological Study of Siblings With and Without Disabilities in the Secondary Setting (H1806149)

Dear Ms. Durbin:

On behalf of Mercer University’s Institutional Review Board for Human Subjects Research, your application submitted on 08-Jun-2018 for the above referenced protocol was reviewed in accordance with Federal Regulations 21 CFR 56.110(b) and 45 CFR 46.110(b) (for expedited review) and was approved under category(ies) 06, 07 per 63 FR 66264.

Your application was approved for one year of study on 22-Jun-2018. The protocol expires on 21-Jun-2019. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

Item(s) Approved:
A new student application for a phenomenology research study using interviews and focus groups to contribute to the body of knowledge on the sibling relationship in the school setting where there is limited research.

NOTE: You MUST report to the committee when the protocol is initiated. Report to the Committee immediately any changes in the protocol or consent form and ALL accidents, injuries, and serious or unexpected adverse events that occur to your subjects as a result of this study.

We at the IRB and the Office of Research Compliance are dedicated to providing the best service to our research community. As one of our investigators, we value your feedback and ask that you please take a moment to complete our Satisfaction Survey and help us to improve the quality of our service.

It has been a pleasure working with you and we wish you much success with your project! If you need any further assistance, please feel free to contact our office.

Sincerely,

Ava Chambliss-Richardson, Ph.D., CIP, CIRM
Associate Director of Human Research Protection Programs (HRPP)
Member
Institutional Review Board

“Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice.”

Mercer University IRB & Office of Research Compliance
Phone: 478-301-4101 | Email: ORC.Mercer@Mercer.edu | Fax: 478-301-2359
1501 Mercer University Drive, Macon, Georgia 31207-0001

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APPENDIX B

PERMISSION TO USE FIGURE
Dear Liz Williams Durbin,

Thank you for your request. You can consider this email as permission to use the material as detailed below in your upcoming dissertation. Please note that this permission does not cover any 3rd party material that may be found within the work. You must properly credit the original source, *Exceptional Children*. Please contact us for any further usage of the material.


Best regards,

Craig Myles

*Rights Coordinator*

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APPENDIX C

PARENTAL INFORMED CONSENT

Parent or Guardian Informed Consent Form

Your child is being asked to participate in a research study entitled, Inclusion, Instruction, Achievement: A Phenomenological Study of Siblings with and without Disabilities in the Secondary Setting. The study is being conducted by Elizabeth Williams Durbin, 404-388-4848, Elizabeth.w.durbin@live.mercer.edu. The results will be used to further my understanding of siblings with and without disabilities in the school setting. Your child’s participation is voluntary. A decision to participate in the research will not affect his/her relationship with Forsyth County Schools, his/her relationship with other teachers, or his/her academic standing.

I. The purpose of my study is to explore:

This research will contribute to the body of knowledge on the sibling relationship in the school setting where there is limited research. It will also determine if the sibling relationship affects instruction and achievement in the classroom. It will also provide students with disabilities a voice in the research that they participate in. The data from this research will be used to contribute to my understanding in a dissertation project. This will help fulfill the requirements for a PhD program.

II. Procedures:

If you allow your child to volunteer for this study, your child will be asked to participate in an interview about their sibling, school, and how that might affect their achievement in class and participation in other school activities where their sibling might be involved. Your child’s participation will take approximately 1-3 hours split into a couple of interview sessions or segments according your child’s ability to participate.

Your child will be asked to assent to participate in this research (Assent means that your child will be asked to voluntarily participate in this research). Your child will tell the teacher they want to participate by answering YES or NO after the teacher verbally reads to your child what the research is about and what he or she will be asked to do. Your child will be asked to participate in a few interviews segments that will ask them about their relationship with their sibling/s, how they feel they are performing in school, and if their teachers are sensitive to the relationship they have with their sibling.

Parent/Guardians who allow students to participate must:

Allow their student to participate in the interview without swaying their child’s responses in any way. If the parent is a communication facilitator for their child they must assist with answering the question in the most objective way as possible. If the child chooses to interview with the researcher away from the parent, the parent must understand that the confidentiality of the student will be upheld.

III. Potential Benefits to Students and/or Society

Mercer IRB Approval Date 01/22/2019
Protocol Expiration Date 06/21/2019
Some potential benefits for students and society are that people with disabilities will be given a significant voice to discuss their feelings and thoughts on this topic. Also, it will possibly provide teachers and other school personnel the opportunity to understand how siblings with and without disabilities affect their classrooms and their instruction.

IV. Potential Risk and Discomfort:

As researcher well versed in working with students with special needs, breaks will be given as students fatigue. It may be hard for students with short attention spans to attend to the interview for an hour or more so they will be given the opportunity to ask for a break. It may cause students with and without disabilities to think more about their relationship with their siblings and their school experiences and it may be hard for them to answer some of the questions.

V. Withdrawal of Participation

Your child’s participation is voluntary. Your child will not be penalized or lose any benefits that he/she are otherwise entitled to if you decide that your child will not participate in this research project.

If your child decides to participate in this project, he/she may discontinue participation at any time without penalty or loss of benefits. You have the right to inspect any instrument or materials related to the proposal. Your request will be honored within a reasonable period after the request is received.

VI. Payment for Participation

Students will not be paid for their participation. There is no financial obligation for participants.

VII. Confidentiality and Data Storage

Students will be given nick names during the transcription and analysis process of this study. No identifying marker will be made other than to state the type of disability they may have to establish relevance for participation in this study. Also no markers will be made other than to establish relation between the siblings of each group as to not confuse the various responses.

Data will be provided to both Mercer University and to Forsyth County schools prior to publication and presentation of this dissertation project.

All interviews will be recorded in order for the researcher to transcribe and analyze data.

A nick name will be given to each child by the researcher for purposes of analysis and transcription. Your child’s name will not be associated with his or her individual responses and will be identified only by an assigned coded number. At no time will your child's name be associated with the results of the research or shared with parents or others. Any identifying information provided by your child will never be used as part of the research or associated with the results of the study.

Your child’s responses will be stored in a locked location and will only be used for research purposes by Mercer University School. A number will identify the information that I collect from the audio recorded interviews.
from your child. The list connecting participant numbers and names will also be kept in separate locked cabinets.

Questions about the Research

If you have any questions about the research, please speak with Elizabeth Williams Durbin. If you have questions later, you may contact Dr. Sherah Carr, 678-547-6064.

You have been given the opportunity to ask questions and these have been answered to your satisfaction. If you agree to allow your child to participate in this research, please complete the information below.

I, ____________________________, grant my child, ____________________________, permission to participate in this research study.

Name of Parent or Legal Guardian ____________________________ Name of Child Participating in Study ____________________________

Parent/Guardian Name (Print) ____________________________ Name of Person Obtaining Consent (Print) ____________________________

Parent/Guardian Signature ____________________________ Person Obtaining Consent Signature ____________________________

Date ____________________________ Date ____________________________

Please return to Elizabeth Williams Durbin as soon as possible.

In order to conduct this research, this project has been reviewed and approved by Mercer University’s Institutional Review Board (IRB). If you believe there is any infringement upon your child’s rights as a research subject, please contact the IRB Chair at (478) 301-4101. The IRBs are the governing bodies that are set in place to ensure responsible and safe conduct of research investigations.
APPENDIX D

INFORMED ASSENT FOR PARTICIPANTS
Inclusion, Instruction, Achievement: A Phenomenological Study of Siblings with and without Disabilities in the Secondary Setting

Informed Assent for Participants Ages 14-18

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators at Mercer University are doing a research study where we are trying to learn about the sibling relationship and how that might affect your achievement and your teacher’s instruction.

Procedures

You will be asked to participate in a one-on-one interview with the researcher. You have the right to refuse to have your information included in the research. Refusing to include your information will not jeopardize you receiving any services related to your school experience.

Questionnaires

No questionnaires will be used.

Videotaping

No video taping will occur.

Any questions regarding the purpose of the videotape should be directed to.

Interviews

You will be asked some questions relating to the nature of your relationship with your sibling and relating to your classes at school. Your sibling will be asked the same set of questions. The researcher will ask you the questions, but then may have additional follow up questions as well. These interviews can take about an hour to an hour and a half depending on how in depth your answers are and how much clarification the researcher needs. You may be asked to participate in a follow up interview.

Potential Risk and Discomforts

Some of the questions being asked may be hard to answer you may make you feel slightly uncomfortable. If at any point you do not wish to answer that particular question just ask to move on.

Mercer University Office of Research Compliance
1201 Mercer University Drive, Macon, Georgia, 31207
Phone: 478-301-4101 Email: ORC.Research@Mercer.edu Fax: 478-301-2359
Potential Benefits of the Research

The benefits of participation in the research may not directly assist you but will hopefully provide ideas for further discussion on how to help siblings who have a disability or how to help siblings of a person with a disability.

Confidentiality and Data Storage

You will be given a pseudonym at the beginning of the study that will be associated with your answers. Your name will not be associated with your responses and will be identified only by an assigned coded number. At no time will your name be associated with the results of the research. However, any identifying information you provide while being videotaped will never be used as part of the research or associated with the results of the study.

Your responses will be stored in a locked location and will only be used for research purposes by Mercer University School.

Your parent(s) have said that it is okay for you to be in this research study. You do not have to be in this study if you do not want to be. You can change your mind at any time by telling your mom, your dad, or your therapist.

______ NO, I do not want to be in this study.       ______ YES, I want to be in this study.

______________________________  ______________________________
Signature of Participant          Date

______________________________  ______________________________
Signature of Person Obtaining Assent Date

Mercer IRB
Approval Date  06/27/2018
Protocol
Expiration Date  06/21/2019
APPENDIX E

TEACHER INFORMED CONSENT

Informed Consent

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators
Elizabeth Williams Darbin, PhD Candidate Tift College of Education at Mercer University.
3001 Mercer University Drive, Atlanta, GA 30341, 404-388-4848
Dr. Sherah Carr, Mercer Faculty Advisor, Tift College of Education at Mercer University. 3001 Mercer University Drive, Atlanta, GA 30341, 678-547-6064

Purpose of the Research
This research will contribute to the body of knowledge on the sibling relationship in the school setting where there is limited research. It will also determine if the sibling relationship affects instruction and achievement in the classroom. It will also provide students with disabilities a voice in the research that they participate in.

The data from this research will be used to contribute to my understanding in a dissertation project. This will help fulfill the requirements for a PhD program.

Procedure:
If you volunteer to participate in this study, you will be asked to participate in a focus group or individual interview.
Your participation will take approximately 1-3 hours total depending on the depth of question needed to satisfy the answers to the questions or for clarification of answers. More than one interview may be needed.

Potential Risks or Discomforts:
No foreseeable risks are associated with this study, however should you feel uncomfortable with any line of questioning you may skip that question or remove yourself from study participation.

Potential Benefits of the Research
Your participation will add to the body of knowledge of inclusion and how siblings with and without disabilities may be better included in school. There will be no direct benefit to you other than your understanding that your interview answers could potentially contribute to further and better understanding on this study subject.

Confidentiality and Data Storage
You will be given a fictitious name that will be associated with your interview transcripts and will be used in reporting of this data, but in no way will your name be associated with any identify markers, thus your answers will be kept confidential. Storage of your answers will be kept in a secure place and only used for the purpose of this study.
Participation and Withdrawal
Your participation in this research study is voluntary. As a participant, you may refuse to participate at any time. To withdraw from the study please contact Elizabeth Williams Durbin, 404-388-4488, Elizabeth.w.durbin@live.mercer.edu.

You may call or email and simply state that you no longer wish to participate in this research project.

Questions about the Research
If you have any questions about the research, please speak with Dr. Shera Carr, 578-547-6064, SE_CARR@mercer.edu

In Case of Injury
It is unlikely that participation in this project will result in harm to subjects. If an injury to a subject does occur, he or she may be seen at a local or regional medical facility. All expenses associated with care will be the responsibility of the participant and his/her insurance.

Incentives to Participate
For use of your time and thanks of your time, coffee and treats will be provided during the interview time.

Audio or Video Taping
All focus groups and interviews will be audio taped for the benefit of transcription and analysis. Only your given nickname will be used on these tapes and no other identify information about who you are will be given.

Reasons for Exclusion from this Study
Only those educators chosen by the students participating in this study will be asked to participate in the focus group and interview sessions.

This project has been reviewed and approved by Mercer University’s IRB. If you believe there is any infringement upon your rights as a research subject, you may contact the IRB Chair, at (478) 301-4101.

You have been given the opportunity to ask questions and these have been answered to your satisfaction. Your signature below indicates your voluntary agreement to participate in this research study.

Research Participant Name (Print)   Name of Person Obtaining Consent (Print)
Research Participant Signature     Person Obtaining Consent Signature
Date                              Date

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