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## ABSTRACT

The purpose of this qualitative interview study was to explore the perspectives of 22 parents of children with intellectual disabilities on the literacy learning opportunities the children were provided in school. It asked: 1) What are the perspectives of such parents on the literacy instruction offered to their children?, and 2) What are the perspectives of such parents on the opportunities available to them to participate in decision-making about this literacy instruction?

This study was grounded in disability studies and critical interpretivist frameworks, which provided a lens for understanding participants' views in the context of our society's historically unjust treatment of individuals with intellectual disabilities. Data sources included transcripts from in-depth semi-structured interviews, which I analyzed using Weft-QDA software and the constant comparison method to identify themes within and across the interviews

A number of themes emerged from the analysis. Parents' perspectives on the literacy instruction received by their children varied on a continuum that ranged from pleased to exceedingly dissatisfied. In the parents' views, teacher investment in the children's learning and the settings in which the children were instructed were important. In addition, when interacting with their children's schools regarding this instruction, the participants reported engaging in various styles of communication, holding different viewpoints and experiencing a number of emotions, styles I described as Present Listening, Emergent Advocacy, and Steadfast Advocacy. These findings have implications for school professionals, teacher education programs, and researchers who

are interested in developing mechanisms for drawing on parents' insights as they orchestrate literacy instruction for such children.

PARENTS' PERSPECTIVES ON THE LITERACY INSTRUCTION RECEIVED BY  
THEIR CHILDREN WITH INTELLECTUAL DISABILITIES

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DISSERTATION

Submitted in partial fulfillment of the requirements for the  
degree of Doctor of Philosophy in Reading Education  
in the Graduate School of Syracuse University  
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I'd also like to thank my parents, Geraldine and Charles, for instilling in me a passion for working for the rights of individuals with disabilities. I have learned so much from them. I am thankful to them as well as Marian and Richard, my in-laws, for their constant support and help in caring for Ian and Lily. I know you love to spend time with your grandchildren, but the help was truly invaluable to me. Thanks also to the rest of my family for all the moral support.

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## CHAPTER ONE:

### INTRODUCTION

*“I don’t have to give her the best education;*

*I just have to give her an education.”*

This qualitative interview study invokes disability studies and critical interpretivist perspectives to explore parents’ perspectives on the literacy instruction of their children with intellectual disabilities. More specifically, I asked: 1) What are the perspectives of such parents on the literacy instruction offered to their children?, and 2) What are the perspectives of such parents on the opportunities available to them to participate in decision-making about this literacy instruction? Why am I so interested in parents’ perspectives on such issues? The following personal history begins to answer this question.

My sister Christine and I began school in a very small private school with about ten children to a grade. Being such a small school, each grade was run in a way reminiscent of a one-room school house: all of the children in any one grade level were instructed together in one room. There were no special educators, no therapists, and therefore, no pull-out instruction whatsoever. My sister was the only child enrolled at this school who had a significant intellectual disability.

Beginning my early education in this setting offered me an interesting first look at inclusion and educational opportunity for children with intellectual disabilities. At that time, inclusion was not the buzz word that it is today, but Chrissy was fully included in this school by the nature of the way the school was run. She attended class alongside her classmates and did much of the same work they did: reading, math, science, social

studies; everything. Any extra support Chrissy needed was provided by the classroom teacher.

As time went on, Chrissy showed difficulty in mastering skills considered important for promotion to later grades, and was consequently held back twice. The first time she was held back was in first grade, and being that I am only 11 months younger than she, Chrissy and I ended up attending first grade together, in the same classroom. Therefore, I saw, firsthand, at the age of seven, ways in which my sister was both afforded and sometimes denied educational opportunities based on preconceived notions of what it was believed she could accomplish. This year of schooling together would be the impetus for my lifelong interest in the educational opportunities provided to children with intellectual disabilities in schools.

I remember many things from that year when Chrissy and I shared a classroom, but one memory stands out clearly as one that would forever change my perspective on others' expectations and what that meant for the learning outcomes of children with intellectual disabilities.

My mother was very involved in our learning. Each evening at our house, Chrissy and I would both sit down to do our homework, and our mother would help us practice our math facts and spelling words. Although Chrissy and I were in first grade together, we were studying different spelling words, and mine were more difficult. However, my mom didn't stand for low expectations. I remember one night, after she worked with Chrissy on her assigned spelling list, my mom began having Chrissy practice *my* list as well. I remember being so happy and proud of my sister that night because she could spell my entire list correctly. The next day, I told my teacher what

Chrissy had done the night before. I wanted to know why she had to work on easy words, not more sophisticated words like mine. In a less than supportive way, and with an air of facetiousness, my teacher challenged me with, “Let’s bring her into your group and see how she does.” To this day, I still wish I had had the gumption as a 7-year old to accept that challenge, but I was defeated by my teacher’s tone, recognizing her implication that Chrissy could not succeed in my spelling group.

The school that Chrissy and I attended as small children only went up to grade three, and so Chrissy and I moved to the area public school district for the later grades. In this district, I would see much less inclusion of children with significant disabilities, beginning with our separation during elementary school due to the districts’ policy that all of the children with such disabilities be taught in a self-contained room in one of the elementary schools and not our home school. Chrissy and I would be reunited in middle school and high school; however, Chrissy would from then on be almost exclusively segregated from our peers and me in a self-contained special education setting. These years of schooling built on my initial experiences with educational opportunity for students with intellectual disabilities as I witnessed my sisters’ inclusion in and segregation from educational opportunities over time. However, my insights were also shaped by my parents’ involvement in Chrissy’s schooling and their attempts at advocacy for her education.

My parents both became more and more involved as educational decisions were made on Chrissy’s behalf. Throughout her schooling, my parents found that sometimes teachers, therapists, and other school professionals had ways of viewing Chrissy that were different from their own. Some professionals did not always see Chrissy as

someone who was able to learn or who even deserved their respect. On more than one occasion, Chrissy was physically abused in school, coming home with bruises on her body and other injuries. Trying to ensure my sister's safety in school became a main focus of my parents' advocacy.

Issues of education were also important to my parents. They worked hard to procure appropriate services for my sister to help her succeed in school. This was not an easy path, however, and they had many challenging experiences over the years. Recently my father told me a disheartening story about a time he and my mother were at an IEP meeting, working with school professionals on goals for Chrissy's school year. My parents had wanted the school to try a particular therapy or approach with Chrissy, although, when retelling this story, my father could not remember the specifics of the request, as it had been about 15 years in the past. My parents had done their research, learning that the approach was one of the best things the school could do to address a particular need of Chrissy's. When the school professionals denied the request, my parents wanted to know why they would not want to do what was best for her education. The director of special education who was running the meeting replied, "I don't have to give her the best education. I just have to give her an education." The look on my father's face as he told this tale was telling: After all that time, he still looked offended and perplexed by this professional's uncaring comment. I could tell the memory had continued to trouble him to that very day. Interestingly, it was not the particular therapy or approach that my father remembered. It was the school professional's attitude that stayed with him.



This study is neither a study about my sister nor a study about my parents. In fact, it does not focus on our story at all. However, in reflecting on how much our family has to say about our experiences, I began to wonder what stories other families had to tell as well. Therefore, I share our story to explain how I got here, investigating and sharing the stories of parents' perspectives on the literacy instruction afforded to their children with intellectual disabilities in school.

### **Rationale**

Individuals with intellectual disabilities have often been denied the right to receive an appropriate education (e.g., Copeland & Keefe, 2007; Daniel, 2000; Kliewer & Biklen, 2001). In the past thirty years, we have seen improvements in the laws that describe appropriate education services to be provided to students with cognitive impairments. However, we still live with views that persons with such labels of disability cannot learn (Biklen & Burke, 2006). Such beliefs permeate the dominant culture of many schools, causing a negative effect on the education that is offered to such students (Copeland & Keefe, 2007).

One particular area where instruction has been denied to young people with intellectual disabilities is literacy education (Copeland & Keefe, 2007). For instance, there is much literature that recommends that these students be taught functional sight words, (e.g., Collins, Branson, & Hall, 1995; Mechling & Gast, 2003; Mosley, Flynt, & Morton, 1997), but little encouragement for teachers to teach these students to decode phonetically (Katims, 2000; Cologon, Cupples, & Wyver, 2011), and little in the literature that refers to such young people as being capable of comprehension or written expression. Some students are not taught any literacy skills at all (Kliewer & Biklen,

2001). Students with intellectual disabilities may be thought not to be able to benefit from the literacy instruction that is offered to other students and are sometimes thought to be non-symbolic in general (i.e., unable to make use of symbols to communicate). The preceding can mean that little effort is expended to assess any particular individual's capacity for participating in literacy instruction, leaving such students lacking literacy skills, and, thus, the ability to join in their schools' literacy communities and such communities in society at large (Kliewer & Biklen, 2001).

Parents play an important role when it comes to the education of their children with intellectual disabilities. They may see their children's literacy initiations at home in interactions with books and siblings, insights not always available to school personnel who make decisions about who receives what kind of literacy instruction. Recognizing the importance of these perspectives, the Individuals with Disabilities Education Improvement Act of 2004, as did the earlier Education for All Handicapped Children Act (1975), delineates parents' right to participate in planning for their children's education, that is, in developing an Individualized Education Plan (IEP). This law also gives parents the right to contest what the Committee on Special Education (CSE) ultimately recommends for their children's IEP goals. With commonly held assumptions that individuals with intellectual disabilities cannot become literate, parents may not contest when CSE members do not recommend literacy instruction for their children or when recommended literacy instruction does not occur. Yet when parents see their children initiate literacy interactions outside of the school, they may refine their opinions about a school's literacy offerings. This study explores such perspectives.

### **Discussion of Key Terms**

## *Literacy*

What counts as literacy is contested grounds. Literacy is usually thought of as reading, writing, and, sometimes, speaking in ways that are considered academically acceptable (Gallego & Hollingsworth, 2000). Yet other ways of thinking about literacy have also surfaced as scholars have begun to investigate the social aspects which must be mastered to interact meaningfully with one's world (Anstèy & Bull, 2006; Cooper, 1997). For example, Cooper states, "We must view literacy as the ability to communicate in real-world situations, which involves the abilities of individuals to read, write, speak, listen, view, and think" (pp 6-7). This broader definition encompasses newer concepts of literacy such as *multiliteracies* (New London Group, 1996), which involve "the necessity to have multiple forms of knowledge and understandings about literacy and social contexts that enable appropriate and successful performance in all aspects of life" (Anstèy & Bull, p. 21) and *new literacies* (New London Group, 1996), which involve the competencies necessary to interact with "new technologies of information, communication and multimedia" (Asselen, 2004, p. 55).

While I envision literacy in the broader sense, I wanted to understand how my participants understood literacy without interfering with their perspectives. Therefore, during interviews, if parents asked me what I meant by literacy or what I considered to be literacy, I told them that I wanted to hear about anything and everything that they believed to be "literacy" or that they viewed as pertaining to literacy.

For many of the participants, commonly held notions of learning to read and write were at the forefront of our discussions. However, these notions of literacy and literacy instruction have not always served children with disabilities well, and this was

true for the children discussed in this study. For instance, physical impairments sometimes precluded children from interacting easily with print texts. Schools have typically dealt with this issue by offering therapy services (e.g., occupational therapy) to children who qualify and by providing children with classroom accommodations, and many of the children discussed in this study received such literacy-related therapies and accommodations. Consequently, the participants' notions of literacy and literacy instruction often included discussions of these therapies and accommodations. Participants' views of literacy sometimes were extended to include multiliteracies and new literacies, including references to computers and the Internet as well as assistive technology (AT) or alternative/augmentative communication (AAC) technology.

### *Intellectual Disabilities*

For this study, I have chosen to use the term "intellectual disabilities" to refer to a collection of disability labels attributed to the children who will be described throughout these chapters. I have chosen to use this term for clarity and succinctness, but not without reservation. I have struggled with this language because, in applying a disability label, I essentially reify the concept of intellectual disability as a singular truth instead of shedding light on the nuanced individual differences masked by this IQ-delimited social construct. However, to discuss the issues that arise in schooling for all children who are perceived as having significant forms of disability, despite their differences, it is necessary to name the phenomena. Moreover, it has proven to be impractical and confusing to readers of earlier drafts when I attempted to use verbiage such as "children who have been labeled as having intellectual disabilities," each time I referred to the participants' children. Therefore, I used the term "intellectual disabilities"

but with the caveat that it is a flawed term, limited in its ability to describe any person.

Table 1 (pp. 50-51) contains a list of the children and their parents (all pseudonyms), as well as the children's specific disability labels as diagnosed by medical and psychological professionals.

### *Inclusion*

The way in which inclusion is defined varies among scholars, practitioners, and parents. Sometimes inclusion is described in its fullest sense, for example, when Biklen (1992) describes it as “participation in every aspect of...school life [where] students would have access to a very broad range of school experiences and would presumably not be excluded from any” (p. 175-176). This notion of inclusion is sometimes referred to in the literature as “full inclusion” as other versions of inclusion, or what counts as inclusion, exist on a continuum of how, when, and where a child with disabilities will be included in the school setting. For example, some scholars use the term “partial inclusion” to refer to the situation when students spend only part of their school days in the general education setting. In such cases, students would receive some “pull-out” instruction, that is, some of their instruction would take place outside the classroom, perhaps in a separate special education room. However, some proponents of full inclusion do not consider variations other than full inclusion to be “true” inclusion because, as Biklen explains, when students with disabilities are included for only certain activities, they are already positioned “as outsiders being ‘let in’ or ‘invited’ for prescribed events” (p. 174).

Because there are varying usages for the term inclusion, the way in which inclusion is implemented in schools varies, and therefore, the way in which children and

their parents experience it also varies. In talking with my participants, when discussions of inclusion arose, I attempted to understand the parents' definitions of the concept and also how it was interpreted and implemented for their children by their schools. When I have referred to inclusion in this dissertation, I have included explanations or descriptors, whenever possible, to provide clarity about the version of inclusion being discussed.

### *Augmentative and Alternative Communication (AAC)*

Augmentative and alternative communication refers to the techniques and supports used by individuals with limitations in spoken language to enhance their ability to communicate. *Augmentative* communication refers to the techniques and supports used in addition to speech, spoken sounds, or gestures, while *alternative* communication refers to techniques or supports used in place of speech and gestures (Copeland & Keefe, 2007). Numerous options for ACC exist, including “manual sign language, as well as non-electronic and electronic communication devices and software options” (p. 132). A common ACC device discussed by parents in this study is the Dynavox, a computerized system that allows users to select words and symbols on a touchscreen to indicate what they would like to communicate and which the device, in turn, speaks out digitally.

### **Overview of Chapters**

This dissertation is organized into five remaining chapters. In Chapter 2, I review the scholarly literature that informs the two research questions I investigated in this study. I begin the chapter by reviewing literature pertaining to views of disability, including society's view and what the disabilities studies perspective proposes as an alternative lens to this view, and parents' perspectives about their children's disabilities. Next, I move the discussion into issues of schooling for children with intellectual disabilities, including

how parents view such schooling in general and how formal literacy instruction has traditionally been addressed for children with intellectual disabilities. Finally, I discuss the limited literature available regarding parents' views on the literacy instruction afforded to their children with intellectual disabilities.

In Chapter 3, I describe the research method I used in conducting this study, beginning with information about my research questions and why I chose to investigate them qualitatively. I also describe the disability studies and critical interpretivist theoretical perspectives I employed in this study. In addition, I describe the methods specific to the current study, including participant recruitment techniques, data collection, data analysis, and my perspective as a researcher.

Chapter 4, "We're Gonna Go to the Moon!": Parents' Perspectives on Literacy Instruction, describes how the participants viewed the literacy instruction that was given to their children with intellectual disabilities in school. This chapter presents descriptions of the instruction as reported by the parents, including factors that they believed to affect the type and quality of instruction provided, as well as their views about the instruction that was given.

Chapter 5, "Why Didn't I Question That?": Compliance and Advocacy, describes the different ways in which the participants interacted with their children's respective schools when it came to decision-making about the literacy instruction that would be provided. In order to discuss the similarities and differences among the participants' communication styles, I grouped the styles by their features and named them as follows: Present Listening, Emergent Advocacy, and Steadfast Advocacy.

Chapter 6, Discussion and Implications, begins with a summary of the findings reported in Chapters 4 and 5. It then proceeds into a discussion of these chapters' main points, including my interpretation of the findings as well as the connections these findings have to the available literature. Finally, I discuss the implications that these findings have for research, school professionals, and teacher education programs.



## CHAPTER TWO: LITERATURE REVIEW

This chapter reviews the literature that informs this study and identifies gaps in the literature that my study attempts to address. I begin the chapter with a discussion of models of disability, including deficit models and a social model of disability. Next, I review the literature that reports on parents' perspectives on their children's disabilities, followed by a section on parents' perspectives on schooling for their children with intellectual disabilities. Subsequently, I review the literature regarding the literacy instruction typically provided in schools for such children as well as studies that have investigated other approaches. Next, I discuss the literature available on parents' perspectives on the literacy instruction provided to their children in school as well as studies regarding parent advocacy. I conclude the chapter by discussing how my study will answer questions presently unaddressed in the literature.

The way in which disability is conceptualized and understood has a strong impact on the way in which individuals with intellectual disabilities are treated in society. Our society has a long history of poor treatment of individuals with intellectual disabilities. For much of the last century, the majority of individuals with intellectual disabilities in the United States were sent to live in institutions where they were often abused, neglected, and/or treated with a lack of human dignity by the professionals and staff who were meant to care for them (e.g., Goffman, 1961; Trent, 1994; Wolfensberger, 1975).

The terms used by such professionals to refer to individuals with intellectual disabilities illuminate the devalued status these individuals held in our society during these earlier times. In the early 1900s, the term *feeble-minded* was used as well as the terms *moron*, *imbecile*, and *idiot* to delineate different levels of perceived intellectual

capability (Walsh, 2002). According to Walsh, these terms were not meant to stereotype individuals with intellectual disabilities, yet they were, in fact, derived from words that already had negative connotations. *Moron*, for example is derived from the Greek word *mōrón*, meaning foolish or stupid (“Moron,” n.d.). Thus, such terms may not have been as innocuous as they have been thought.

Subsequent terms used to refer to individuals with intellectual disabilities included *mentally defective* and *mentally retarded* (Walsh, 2002) the latter of which is still in current use. *Mental retardation* is increasingly being replaced by *intellectual disability* (American Association on Intellectual and Developmental Disabilities, 2012), the phrase I have decided to use in this study, albeit with trepidation. The terms used to refer to individuals with intellectual disabilities change frequently because these terms find their way into colloquial speech and are often used as insults. Professionals continue to change terms as they become unacceptable; however, such terms will likely continue to become unacceptable over time because they are used to describe a population of individuals who are currently devalued in our society (Walsh, 2002).

### **Deficit Models of Disability**

The marginalized treatment of individuals with intellectual disabilities and the labels chosen to refer to such individuals can be traced to what those in the disability studies community refer to as a “deficit model” perspective. Those in the disability studies community attribute this perspective to the worldview that sometimes seems to be enacted by professionals in the medical, rehabilitation, and education-related fields. Although such individuals may not intend to do so, their words and actions send the message that it is up to the individual with a disability to attempt to assimilate with

“normal” society (Michalko, 2002). When an individual is unable to assimilate well with society, this can be considered a justification for removing that person from society, that is, to segregate the individual. Persons with intellectual disabilities continue to be segregated from society in many ways, for example, being placed in an institution, hospital, or segregated school or classroom.

Two commonly held perspectives are often associated with the deficit model: the medical model and the rehabilitation model. These are models discussed frequently in the disability studies community and are attempts at describing different ways in which disability is conceptualized as a social construct. Thus, the disability studies community describes the medical model as constructing disability as a problem that resides solely within the individual, one that should be cured if possible. According to Thomas (2002), “Biomedicine has as its focus individual deviations of body and mind from socially recognized norms. Impairment, *per se*, is of central concern— its detection, avoidance, elimination, treatment, and classification” (p. 40). Those who critique the medical model suggest that, when disability is conceptualized in such a way, a person with a disability is construed as being a perpetual patient who “suffers,” who is “a mistake,” or who is an example of “nature-gone-wrong” (Michalko, 2002, p. 30-31, 41-42).

Those in the disability studies community similarly describe the rehabilitation model, asserting that it is heavily influenced by the deficit views of the medical model (Thomas, 2002). Thomas states, “In the domain of rehabilitative sciences, the biomedical perspective on disability continues to have a weighty presence in training and practice, although the focus is on a different set of issues: the adjustment and adaptation of disabled individuals to a life ‘as near normal’ as possible” (p. 41). Through the

viewpoint of the rehabilitation model, individuals with disabilities are “helped” to change, adapt, or fit in by therapists or other care providers. Those who critique the medical model tend to critique the rehabilitation model as well. They assert that the rehabilitation model often construes individuals with disabilities as needing continuous help, supporting and reifying the view of persons with disabilities as dependent and unable to be of any good to society on their own (Barton, 1996).

### **A Different View**

The disability studies perspective, also referred to as the social model or the minority model (Olkin, 1999, p. 26), represents an alternative view toward disability that differs from deficit models. Unlike the medical and rehabilitation models, the disability studies model does not consider disability to reside in the individual. Instead, it asserts that disability is a social construction based on society’s views of normal and deviant. It locates disability in “the environment that fails to accommodate persons with disabilities and in the negative attitudes of people without disabilities” (p. 26).

Further, the disability studies perspective does not view disability as something that needs to be cured or changed. It suggests that there are differences among individuals, and that these differences are valuable to society at large. This perspective recognizes the abilities and experiences of individuals with physical and/or intellectual impairments (Kluth, 2006). Understanding disability in such a way allows us to “deconstruct the procedures by which some bodies are privileged over others” (Couser, 2002, p. 112).

The disability studies perspective, therefore, has much to add to the understanding of disability, particularly since deficit views have dominated societal thinking for so long.

The disability studies perspective conceptualizes individuals' impairments as part of the human condition and suggests that they should be accommodated. It also brings to light the fact that there are both attitudinal and physical barriers that marginalize individuals with impairments, precluding them from fully taking part in their societies.

An important point regarding the perspectives described above, however, is that they are not meant to indict any individual professionals in the medical field or any other professionals who work within the domain of individuals' needs, per se. Certainly individuals with disabilities might, at times, benefit from medical attention and/or rehabilitation, as such assistance may relieve pain, permit an individual to live a more independent and fulfilling life, or even be life-saving. Those in the disability studies community raise issue with how the bases for these treatments are overgeneralized to the point that such individuals come to be viewed by society as helpless, weak, and dependent people. Even though it is helpful to critique reified able-ist social constructions, it is unfortunate that such dichotomizing assessments might also undervalue treatments that some might welcome. (e.g., Evans, 2004).

### **Parents' Perspectives on Disability**

The more dominant societal discourse is derived from medical and rehabilitation models, and this has had a significant effect on the way in which society perceives individuals with intellectual disabilities. Indeed, parents of children with intellectual disabilities were once construed by the professionals in the fields of medicine and psychology as being in a state of "chronic sorrow," constantly grieving for the non-disabled child who "may have been" (Olshansky, 1962). However, as researchers in the fields of sociology and psychology began to ask parents for their perspectives regarding

their children and their impairments, parents were able to speak for themselves regarding their understandings and experiences. Though not meant to be an exhaustive literature review since this is not a focus of my study, the following are salient examples of literature in this area (see, for further discussion, Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010).

Parents' views are, of course, shaped by the disability perspectives that are prevalent in society. Parents' initial perspectives regarding their children are often influenced by the medical perspective (Lalvani, 2008; Wickham-Searl, 1992). This is because doctors and other medical personnel are often the first to tell parents about their children's medical diagnosis(es), frequently at birth, and increasingly while still in utero (Singer, Corning, & Antonucci, 1999).

In a qualitative interview study involving mothers of children with Down syndrome, Lalvani (2008) found that, according to the parents, doctors and other health services personnel maintained mainly negative perspectives regarding their children, encouraging termination of pregnancies when the children were still unborn, and treating the parents with pity once such children were born. However, Lalvani also found that parents often thought critically about and rejected the views that others had regarding their lives and families, including beliefs that their lives were overwhelming and/or undesirable. Despite their rejection of others' negative views, the parents interviewed in Lalvani's study had concerns about the ramifications that society's negative view of disability would have on their children. Indeed, although the parents often expressed feelings of fulfillment as a result of caring for a child with an intellectual disability, they

also expressed disappointment, sadness, and anger toward a society that maintains a deficit view of disability.

Parents taking part in other studies have also raised issue with society's negative views toward disability. For example, in an interview study of 68 families of children with disabilities, Knox, Parmenter, Atkinson, and Yazbeck (2000) found that parents had concerns for their children when the agencies and organizations they went to for support maintained negative views of disability and when these groups did not understand parents' perspectives and wishes. Parents in this study felt that their beliefs and wishes regarding the support given to their children were often disregarded. The parents also believed that agencies and other organizations providing support for their children should help empower parents by respecting their views and working with them when decisions regarding their children were being made.

Parents of children with intellectual disabilities have also been shown to be proactive in pushing against negative views of disability that exist in society. For example, in a qualitative interview study of 12 women who were parents of children with disabilities and were also known for their contributions to disability related work, Wickham-Searl (1992) found that a number of parents, often mothers, took on roles as advocates, activists, or "crusaders" to protect the rights of their children and push against a system that was often unsuited to their children's best interests. According to Wickham-Searl, "It is apparent that the experience of parenting a child with handicaps can enable a mother to develop capabilities that were previously unknown to her" (pp. 272-273).

Despite society's emphasis on the negative aspects of having a child with impairments and the challenges in raising a child with an intellectual disability (Parish, 2006), parents tend to adapt well to the challenges and carry on with life activities in ways that are similar to families that do not have children with intellectual disabilities (Dodd, Zabriski, Widmer, & Eggett, 2009). Lustig's study (2002) provides an example of such positive adaptations. Lustig surveyed 89 parents of children with disabilities (not including learning disabilities), who were schooled in special education classrooms to investigate the relationship between families' coping strategies and their adjustment to having a child with a disability. Lustig found that there were positive effects on the parents' adjustment when parents used positive reframing as a coping strategy ( e.g., interpreting one's management of a stressful event as an indication of strength), and when parents believed themselves to be competent and proactive in addressing problems.

Hastings, Allen, McDermott and Still (2002) conducted a survey study of 41 mothers of children with intellectual disabilities to investigate the factors surrounding the mothers' positive perceptions of their children. Findings of this study were in agreement with Lustig's (2002) study, indicating that when mothers used positive reframing as a coping strategy, their own adjustment to having a child with a disability was positively affected. Hastings and his colleagues also found that when mothers made use of informal support groups comprised of other parents who have children with disabilities, the mothers' feelings were positively affected.

### **Parents' Perspectives on School**

Parents' concerns for the equitable treatment of their children extend to the school system as well. Parents frequently hold concerns regarding the safety of their children in



school, whether their children will be accepted by their peers, and whether their children will be provided the education that is best suited to their needs (Kasari, Freeman, Bauminger & Alkin, 1999; Runswick-Cole, 2008). Yet parents' perspectives concerning their children's schooling differ.

For instance, in a qualitative interview study of nine parents of children with moderate to severe disabilities, Erwin and Soodak (1995) found that a number of parents believed that their children should be schooled in an inclusive environment. These parents often noted that inclusion was a matter of social justice, that all children should be included in the classroom, and that no child should be segregated based on a label of disability. These parents felt that their children needed to be educated alongside children without disabilities to enhance the social skills of all children. They also believed that the opportunities afforded to children in regular education classes should be afforded to their children as well.

Other research suggests that not all parents believe that their children's needs are best met in inclusive settings. In fact, parents' views regarding school placement options may be somewhat etiologically-specific (Kasari, Freeman, Bauminger, & Alkin, 1999). That is, parents of children with different types of intellectual disability may have differing views regarding the best school placement options for their children. In a survey study of 113 parents of children with autism and 149 parents of children with Down syndrome, Kasari, Freeman, Bauminger, and Alkin (1999) found that parents of children with autism preferred inclusion for only part of the day with opportunities for instruction separate from the regular class. However, parents of children with Down syndrome often preferred a full inclusion setting for the education of their children.

Kasari et al. also found that parents of older students often favored mainstreaming for only part of the day, while parents of younger children tended to favor inclusion. In addition, parents of children who were currently being instructed in an inclusive setting tended to favor inclusion, while parents of children who were currently being instructed in a setting that mainstreamed children for part of the day tended to favor that approach.

Although Kasari et al. found that parent preferences for their children's educational placements may be based on the etiology of their child's disability, their child's age, and/or their child's current placement, Runswick-Cole (2008) found a different pattern. In her interview study of 24 parents' attitudes toward inclusion for their children with "special education needs" (p. 173), Runswick-Cole found that parents who took a medical model-oriented view of their children's impairments tended to prefer special school placements for their children whereas parents who took a social model-oriented view of their children's impairments tended to prefer inclusive educational settings. However, Runswick-Cole also warned, "There are dangers in offering an analysis based on a typology of parents that locates their responses within social or medical model perspectives. This can suggest that parents' responses are unitary and fixed, and that parents sit comfortably within one type" (p. 179). She explained that parents' views of disability are often in flux and that their views are more often shaped by pragmatism, not ideology.

### **Literacy Instruction for Students with Intellectual Disabilities**

Students with intellectual disabilities have generally been taught literacy through a functional skills curriculum (Katims, 2000). That is, students have been taught literacy to the extent that it would be helpful to their participation in the community and at job

sites. Through functional skills curricula, students are frequently taught to recognize and write a limited number of the sight words thought to be most important for them (Mosley, Flynt, & Morton, 1997). A number of studies have been conducted on teaching literacy skills to students with intellectual disabilities through such an approach (e.g., Burns, 2007; Collins, Branson, & Hall, 1995; Didden, de Graaff, Nelemans, Vooren, & Lancioni, 2006; Mechling & Gast, 2003; Mosley, Flynt, & Morton, 1997; Van der Bijl, Alant, & Lloyd, 2006).

Students with intellectual disabilities may not be afforded other types of literacy instruction because it is often believed that they are incapable of learning other, more generative aspects of literacy (Kluth & Chandler-Olcott, 2008). Unfortunately, a functional skills approach to literacy instruction does not equip students with the literacy skills needed to identify words beyond the specific sight words they have been taught. This inhibits their abilities to read and write for other purposes and thereby limits their opportunities to take part more fully in their communities (Copeland & Keefe, 2007).

According to Joseph and Seery (2004), “The potential for individuals with mental retardation to grasp and generalize literacy skills has been underestimated by many educators and researchers” (p. 93). Although research is still limited in the area of higher-level literacy instruction (i.e., literacy instruction that extends beyond a functional skills approach) for students with intellectual disabilities, several studies have shown that such students have learned to decode words, comprehend narrative and expository texts, and write for expression. The following sections will review such studies and are important in laying the groundwork for some of what the parents describe in chapters 4 and 5 regarding literacy opportunities for their children.

**Decoding.** The available literature regarding decoding instruction for individuals with intellectual disabilities is limited. However, several studies have investigated this type of instruction and its effects on the word identification abilities of such students. These studies explored several different ways in which to address decoding instruction for children with intellectual disabilities.

In 1986, Polloway, Epstein, Polloway, Patton, and Ball investigated the effectiveness of a decoding intervention program originally designed for older students with reading difficulties and mild disabilities when used with adolescents with intellectual disabilities and learning disabilities. The program they used was Engelmann, Becker, Hanner, and Johnson's (1980) Corrective Reading Program: Decoding Series. This program made use of direct teaching of letter-sound correspondences, blending of sounds, and word reading. A main purpose of the study was to ascertain whether taking part in this literacy intervention for the duration of one year would have a greater effect on the literacy gains the students made that school year as opposed to their previous school year. Participants were sixth to twelfth grade students, 78 of whom had learning disabilities and 41 who were diagnosed as "Educable Mentally Retarded" (EMR). These students were all receiving special education services and in the year prior to taking part in the intervention were receiving literacy instruction through either a basal program or "high-interest, low-vocabulary" books. Results of the study indicated that although the students with learning disabilities made greater achievements than the students with EMR, all of the students made improvements in literacy learning as compared with their previous schooling year. Therefore, Polloway et al. demonstrated that intensive

decoding-based literacy interventions could be effective for students with intellectual disabilities.

Conners, Rosenquist, Sligh, Atwell, and Kiser (2006) also found that students with intellectual disabilities could benefit from decoding instruction. In this intervention study, 40 children labeled with mental retardation were paired based on age, IQ, phonemic awareness, nonword reading accuracy, and language comprehension. One child from each pair was then randomly assigned to either the intervention group or control group. Students in the intervention group of this study were taught to blend words orally, recognize sound-symbol correspondences, and decode two- and three-letter words. Results of this study indicated that students in the intervention group could read instruction words, transfer words, and nonwords better than students in the control group.

Other studies have also demonstrated the benefits of decoding instruction for students with intellectual disabilities. Using a multiple probe design, Cohen, Heller, Alberto, and Fredrick (2008) studied five children with mild to moderate mental retardation and found that students labeled with mental retardation were able to develop decoding skills when instructed with a strategy known as Constant Time Delay (CTD). Through the use of the prescribed three steps they were taught, students were able to read more novel words, and when they misread words, the attempts that they made were higher in accuracy than the attempts they made prior to the instruction. Cohen and her colleagues concluded, "These results indicate that students with mental retardation need increased application of reading strategies, such as the three-step decoding strategy with CTD and maintenance of those strategies as part of their reading curriculum" (p. 77).

Decoding instruction was also helpful for such students in Joseph and McCachran's (2003) study which explored the effects of a word study phonics technique known as word sorting. The researchers investigated how the use of this technique affected the word identification, phonological awareness, and spelling skills of eight students with labels of mild to moderate mental retardation and eight struggling readers without disability labels. Results indicated that there was not a significant difference between the posttest performances of the two groups of students when pretest performances were held constant. All the students learned to sort words effectively, but only some (including those with and without intellectual disabilities) were able to transfer this knowledge to recognizing and spelling novel words. The authors suggested, therefore, that students who cannot use this analogy approach may need explicit instruction in both phonemic awareness and one-to-one letter-sound correspondences to successfully read and spell words.

These studies suggest that despite the preponderance of rhetoric and research in the literature promoting a functional skills approach to reading for children with intellectual disabilities, such students may benefit from instruction in decoding. Other studies also exist which extend beyond the functional skills approach for literacy education for students with intellectual disabilities. The following section discusses the literature available in reference to comprehension instruction.

**Comprehension.** Up until quite recently, studies concerning reading comprehension instruction for students with intellectual disabilities were hard to locate. However, in the past few years, some such studies have been published. These studies

fell into two subcategories: those regarding students' comprehension of text that was read to them and those regarding text that students read independently.

*Comprehension of teacher-read text.* Children with and without disabilities can often comprehend text that is written at a level higher than what they can read independently. Further, children with intellectual disabilities, whether through learning difficulties or lack of exposure to effective literacy instruction based on preconceived notions concerning what such children may or may not achieve, are currently often lacking in their ability to read connected text. This being the case, some researchers have investigated the listening comprehension of such students through teacher-read texts as opposed to comprehension of student-read materials.

Mims, Browder, Baker, Lee, and Spooner (2009) conducted such a study with two elementary-aged students with intellectual disabilities and visual impairments. The students were taught in different schools, but each was given the same intervention. Each student was read aloud to using the same books. The books were enhanced with removable picture clues to help the students understand particular nouns mentioned in the books. The students were then asked literal comprehension questions regarding the books, and the students were offered objects at which they could point to indicate a response. The interventionist used a system of least prompts (SLP) to help the students identify the correct answer. That is, if a child had difficulty coming up with a correct answer, the interventionist would give the child a prompt, but one that provided the least amount of help. If the child still had trouble, the teacher's subsequent prompts would become more explicit until the child could give a correct response. As a result of this instruction, both students in this study were able to answer significantly more questions

correctly at posttest when compared to their pretest scores. The results indicated that using read-alouds enhanced with objects to refer to nouns in the book used and prompting students with a system of least prompts can help improve the listening comprehension of students with intellectual disabilities.

A later study by Mims, Hudson and Browder (2012) extended the use of a system of least prompts to use with modified biographies. In this study, the authors taught four children labeled as having both autism and intellectual disabilities how to respond correctly to comprehension questions using two graphic organizers, one for sequencing story events and the other for indicating the text hints to look for when attempting to answer “wh” questions. During the intervention, the authors read aloud modified biographies to the students, and at predetermined times, asked the children comprehension questions. As necessary, when the children attempted to answer the comprehension questions, the authors would use a system of least prompts to help the students respond correctly. The least of these prompts would be to indicate to the student what kind of answer he or she should be looking for, per the “wh” graphic organizer. For example, if the student was to answer a “who” question, he or she would be reminded to listen for a person in the text. The author would then read that section of the biography again. After the least intrusive prompt was given, if a child still could not identify the correct answer, the authors would give a more intrusive prompt and continue this until the child could identify the correct answer. This study showed positive effects for this intervention on all of the students’ ability to answer comprehension questions at the conclusion of the study. Further, all of the children were able to maintain a higher level of comprehension question answering ability two weeks after the intervention concluded



and three of the four students were also able to generalize what they had learned to new biographies.

An interesting finding of Mims, Hudson, and Browder's study was that one child who participated was believed by her school to be a non-reader. As the child participated in the study, it became clear to the researchers that she could, indeed, read the biographies she was given on her own. The researchers stated that the "case illustrates that students' ability to 'show what they know' can be limited by the opportunities provided" (p. 77).

Other studies have also shown that children with intellectual disabilities can benefit from listening comprehension interventions. For example, in a multiple-probe design study, Shurr and Taber-Doughty (2012) demonstrated that conducting read-alouds of age-appropriate material with children with intellectual disabilities with the addition of content-related pictures and discussions prior to and just after a reading had a significantly positive effect on the participants' abilities to comprehend the material and respond correctly to literal questions about the reading. Further, in a series of single-subject studies, Douglas, Ayres, Langone, Bell, and Meade (2009) found that when students with intellectual disabilities were provided with e-texts and the supports that often accompany these texts (e.g., text-to-speech technology, video summaries, and visual representations to enhance the texts), students' abilities to comprehend texts and remember the information over time were positively affected. These authors also found that students with intellectual disabilities benefitted from direct instruction in the use of the e-texts and their supports.

*Comprehension of independently-read text.* The reading comprehension of students with intellectual disabilities regarding independently read texts has also begun to receive attention in the literature recently. Each of the following studies provides promising evidence that students with intellectual disabilities can benefit from instruction tailored to improve reading comprehension.

In 2007, van den Bos, Nakken, Nicolay and van Houten published one such study dealing with teaching reading comprehension to 38 adults with intellectual disabilities. In this study, van den Bos and his colleagues found that the participants' ability to comprehend both narrative and expository texts increased significantly after instruction in comprehension strategies. The adults in the study were taught how to summarize, predict, question and clarify to help them understand texts more fully. The intervention had positive effects on the participants' use of comprehension strategies and also had a positive effect on their comprehension of texts in general.

Other studies have also been conducted that indicate that teaching reading comprehension to students with intellectual disabilities may be beneficial. In a study that also focused on adults with disability-labels, Hua, Hendrickson, Therrien, Woods-Groves, Ries, and Shaw (2012) found that implementing a reading intervention known as Read-Adapt and Answer-Comprehend was an effective way in which to improve both the comprehension and fluency abilities of students with autism in a post-secondary program. In this program, students worked one-on-one with tutors to complete re-readings of texts and learn how to find answers to comprehension questions by referring to the written material. Further, Hua, Therrien, Hendrickson, Woods-Groves, Ries, and Shaw (2012) repeated this study with three adults labeled as having either mild mental retardation or

severe learning disabilities who were also enrolled in a post-secondary program. The intervention proved beneficial to these learners as well.

While the previous studies regarding comprehension improvement for students with intellectual disabilities focused on adult students, the following studies investigated this area of literacy for students still in high school or middle school. Alfassi, Weiss, and Lifshitz, (2009) conducted a study to investigate the effects of comprehension strategy instruction for students with intellectual disabilities. Their participants were 35 students ages 15-21. The students were randomly assigned to either an intervention or control group. Students in the intervention group received instruction in comprehension monitoring strategies based on those developed by Palincsar and Brown (1984) which included instruction in question generation, making text predictions, clarifying challenging words, and summarizing. The intervention was given over 24 sessions. Students in the control group received instruction in basic reading skills. Results of the study indicated that the instruction in comprehension strategies and comprehension monitoring was beneficial to students with intellectual disabilities, as the students outperformed the students receiving the traditional skills-based only approach. In addition, the authors assert that the results of their research “challenge the common perception that literacy is an organic impossibility for people defined as intellectually disabled” (p. 303).

Comprehension instruction was also proven to be beneficial for students with intellectual disabilities in a study by Flores and Ganz (2009). These authors investigated the effects of a direct instruction program for improving comprehension known as Corrective Reading-Thinking Basics on the reading comprehension of middle school to

high school aged children. The intervention was carried out with four participants, two of whom were labeled as having autism spectrum disorders and two of whom were labeled as having developmental disorders. In the intervention, the students were taught about analogies through pictures as well as inductive and deductive reasoning from textual clues. As a result of this intervention, all four students improved in measures of reading comprehension and, when assessed, had moved up one level per the placement test in the Corrective Reading-Thinking Basics program. While all of the students showed improvement in comprehension, three of the students still had trouble with higher-level comprehension questions such as those asking them to evaluate a character's feelings or explain how they arrived at a particular answer.

The preceding studies on the effectiveness of teaching students with intellectual disabilities listening and reading comprehension are promising. They also add to the evidence that presumptions regarding such students' potentials for understanding and interacting with text may often be underestimations. The following section reports on the literature available that similarly debunks long held assumptions about possibilities for such students.

**Writing.** Like other areas of literacy instruction outside of a functional skills approach, literature addressing writing instruction for students with intellectual disabilities is also sparse. However, some studies have dealt with the effects of alternative forms of writing instruction for these students. One example is a study that was conducted with 13- to 17-year-old students with mild intellectual disabilities in Turkey. In this study, Guzel-Ozmen (2006) found that instruction in text structure and writing strategies improved students' writing of expository texts. Specifically, Guzel-

Ozmen used Modified Cognitive Strategy Instruction in Writing (CSIW; Englert, Raphael, Anderson, Anthony, & Stevens, 1991) and Self-Regulated Strategy Development (SRSD; Harris & Graham, 1996) to teach students about the particular structure of problem-solution texts, how to use graphic organizers to organize their thoughts, and strategies for revising. These strategies helped the students to create lengthier, more cohesive, higher quality expository texts.

De La Paz and Graham (1997) also found that strategy instruction can help students with intellectual disabilities improve their writing. This small scale study studied three students, only one of whom would be labeled as having an intellectual disability. (The other students participating in this study had learning disabilities.) Each of the students in this study was taught two mnemonics to help them plan and write opinion essays. One mnemonic was STOP, indicating four steps: “Suspend judgment, Take a side, Organize ideas, and Plan more as you write” (p. 173). The other mnemonic was DARE, encouraging students to “Develop your topic sentence, Add supporting ideas, Reject possible arguments for the other side, and End with a conclusion” (p. 173). The specific steps of these mnemonics were taught to students through the use of modeling and collaborative practice. Students were also given ample opportunity for independent practice. As a result of the instruction given to these students, each was able to increase the length and overall quality of his or her writing pieces, including the student with an intellectual disability.

Direct instruction in writing strategies was also proven beneficial for students with intellectual disabilities in a multiple-baseline across-subjects study conducted by Rousseau, Krantz, Poulson, Kitson, and McClannahan (1994). In this study, three

students with autism and intellectual disabilities (ages 11-13), were taught to combine two sentences by inserting an underlined adjective and then dropping the second sentence. They received this instruction daily for 20 minutes followed by 20 minutes of time in which they were given to write in response to a prompt. The authors found that the instruction in sentence combination increased the students' use of adjectives in their own writing. In addition, the students also began, independently, to use adjectives that they had previously not used during the intervention. Further, the students maintained these skills over time.

Finally, in a study conducted by Pennington, Stenhoff, Gibson, and Ballou (2012), teacher prompting and the use of an augmentative assistive device were shown to be beneficial in teaching a boy with autism to tell and write stories. In this study, the authors trained the classroom teacher of a seven year-old boy with autism to work with him on a Pixwriter™ to construct a story. The Pixwriter™ had a horizontally divided screen with a word processor on top and a word bank below. Before the intervention began, the child had never before written a narrative without a complete model to copy. The teacher worked with the boy for daily 10-minute sessions for approximately 70 sessions. During the sessions, the teacher would prompt the child to use the word bank to write a story about a particular character. If the child did not select an appropriate word from the word bank, the teacher would prompt the child by pointing to a word. As time went on, the child was able to construct stories using the word bank independently. He also gained the ability to tell stories orally without a word bank, and could also transfer this ability to handwritten stories as well. Additionally, the boy showed maintenance of these skills when tested several weeks later.

While there is a shortage of literature available on the teaching of decoding, comprehension, and writing to children with intellectual disabilities, there are even fewer studies that investigate comprehensive literacy instruction for such children. That is, there is little in the literature that addresses literacy instruction that combines the various aspects of literacy into a cohesive whole. However, the following are three such studies that have been published.

**Comprehensive literacy instruction.** Citing the lack of literature available on teaching literacy to children with intellectual disabilities, Allor, Mathes, Roberts, Jones, and Champlin (2010) discussed the importance of looking to the literature concerning children *without* intellectual disabilities who struggle with learning to read in the attempt to discover what might also work for children with intellectual disabilities. From the outcomes of such literature, these authors drew on the importance of connecting important aspects of literacy into a cohesive whole, not just simply providing isolated sub-skill instruction, or focusing only on one aspect (e.g., phonics or sight words) in implementing an intervention for children with intellectual disabilities.

To test how such an intervention would work with children with intellectual disabilities, they randomly assigned participants (all of whom were labeled as having moderate intellectual disabilities) into either an intervention or contrast group. The intervention group received instruction in a phonics-based comprehensive reading intervention program that had previously been shown to be effective for children who struggled with reading but who did not have labels of intellectual disability. The intervention focused on instruction in concepts of print, phonological and phonemic awareness, letter/sound correspondences, phonetic decoding, sight word recognition,

comprehension strategies, vocabulary development, and fluency with connected texts. This instruction was provided to the children in small groups for 40-50 minutes daily for one to one and a half years. The children who were assigned to the contrast group were instructed with their typical special education literacy instruction. At the close of the study, the children receiving the comprehensive literacy instruction outperformed the students in the contrast group on all measures, with statistically significant differences evident on measures of phonemic awareness, phonics, word recognition, vocabulary, and comprehension.

A study by Hendrick, Katims, and Carr (1999) also indicated that students with intellectual disabilities could improve in their literacy skills through the use of a comprehensive, multifaceted literacy program—in this case, a program that was originally developed for general education students. Nine students were included in this study, seven of whom were classified as having mental retardation. These students were instructed through the use of the Four Blocks program, modified for the students' needs, for the duration of one year. The program involved four segments: guided reading, self-selected reading, working with words, and writing. The reading aspects focused on word identification through phonics instruction and sight word recognition, comprehension through teacher-modeled read alouds and comprehension strategy instruction, and fluency through, among other activities, choral and partner reading. The writing aspects of this instruction included encouraging students to get their ideas down on paper through the use of invented spelling when appropriate and teaching students to use the writing process. As a result of the instruction, all of the students showed improvement in their



ability to read and understand text and exhibited progress toward more conventional writing.

A third study also found positive effects in using a comprehensive literacy program for students with intellectual disabilities. Coyne, Pisha, Dalton, Zeph and Cook Smith (2012) investigated the effectiveness of Learning by Design, a program incorporating e-books and other technology-based literacy learning activities which were designed to help students gain skills in phonemic awareness, phonics, comprehension, vocabulary development, and fluency. The program was based on the Universal Design of Learning approach, which encourages teachers to find ways to include and reach all children, particularly those children who traditionally have had limited access to classroom instruction. For example, such classrooms may make available multiple ways for a child who does not speak to express his/her ideas or to attempt tasks.

For this study, the authors reported on the effects of the program for the 16 children with significant disabilities who took part who could speak. From October to May, the students were instructed in either an intervention classroom or a control classroom. In the intervention classrooms, students were instructed through the Learning by Design program; in the control classrooms, students received the instruction typically taught by those classrooms' respective teachers. Based on pre- and post-testing, the authors found that students who took part in the comprehensive Learning by Design program performed better than their control classroom counterparts on measures of reading and listening comprehension, word attack ability, and concepts of print at the conclusion of the study.

Although research in the area of literacy instruction for students with intellectual disabilities has, to the detriment of the literacy learning of such students, focused mainly on a functional skills approach (e.g., Burns, 2007; Collins, Branson, & Hall, 1995; Didden, de Graaff, Nelemans, Vooren, & Lancioni, 2006; Mechling & Gast, 2003; Mosley, Flynt, & Morton, 1997; Van der Bijl, Alant, & Lloyd, 2006), the preceding sections provide promising information regarding the ability of such students to benefit from other, higher-level forms of literacy instruction. What is perhaps more encouraging is the evidence provided that children with intellectual disabilities can likely benefit from comprehensive literacy programs that incorporate all aspects of literacy learning and provide instruction in both sub-skills as well as authentic and interconnected literacy learning experiences.

A promising research base is beginning to take form which is moving away from functional-skills-only approaches, though it is also important to comment on what has been, up until quite recently, a relative silence in the area of higher-level aspects of literacy instruction for this group of students. It is disheartening that such approaches could seem labor intensive, and thus too expensive when compared to literacy instruction needed by most children. From a disability studies perspective, lack of attention in this area may also reflect deeply ingrained beliefs that individuals with intellectual disabilities either cannot benefit from literacy instruction or are not worth the expense, leaving many such individuals at the literate margins of their schools and communities. In contrast, Biklen and Burke (2006) recommend that teachers maintain an expectation that all students, including students with intellectual disabilities, can and will learn. That is to say, teachers must “presume competence” in all students (Biklen & Burke, 2006, p. 167).

These authors say, “The notion of presuming competence implies that educators must assume students can and will change and, that through engagement with the world, will demonstrate complexities of thought and action that could not necessarily be anticipated” (p. 168).

### **Parents’ Perspectives on the Literacy Instruction Provided to their Children in School**

As discussed earlier, parents play an important role when it comes to the education of their children with intellectual disabilities. They are the adults in their children’s lives who likely know the most about the children’s needs and strengths. They are, therefore, by law, meant to be included as integral parts of their children’s educational planning committees. Parents’ views, therefore, are important, and for these reasons, it is beneficial to look to parents regarding their perspectives about what has happened in the name of literacy instruction for their children,

Using a web-based survey, Al Otaiba, Lewis, Whalon, Dyrland, and McKenzie (2009) found that parents of children with intellectual disabilities have expectations that their children will develop literacy skills. Most of the parents surveyed felt it important that their children learn to recognize the alphabet. More than 30% of the parents expected their children to learn to read chapter books, read for pleasure, read community signs for safety purposes, and develop job-related literacy skills. Al Otaiba and her colleagues also found that parents cultivated reading skills in their children by providing a literacy-rich home environment.

Parents have also been shown to be able to see literate potential and abilities in their children when others do not. Using qualitative interviews and a theoretical

perspective that draws on the social model of disability, Kliewer and Biklen (2001) discovered that such parents recognize ability when others do not because parents generally have what these authors call a “local understanding” of their children. Kliewer and Biklen describe local understanding as:

a radically deep, intimate knowledge of another human being. Local understanding of people with severe intellectual disabilities is born out of caring, interactive, and interdependent relationships in which both participants infer valued capacities and competence on the other. The intimacy of the relationship is important because it allows those in positions of relative authority or power to see in idiosyncratic behavior demonstrations of understanding that are otherwise dismissed or disregarded by more distant observers. (p. 4)

Such local understanding allows a parent to see, for example, recognition or comprehension in the blink or widening of the eyes in his or her non-speaking child. A professional without a deep understanding of the child might miss such important signals or dismiss such signals as insignificant.

Kliewer and Biklen (2001) interviewed parents and in one case a care provider/advocate regarding the opportunities for literacy growth their children with intellectual disabilities had been afforded. Several of these parents recognized that their children had literate potential and abilities, but that educators did not realize this or did not consider it important. For example, Sheila Jordan found that her son Samuel, who is diagnosed as having cerebral palsy and developmental disabilities, loved being read to. Sheila took many opportunities to read Bible stories to him, interpreting his nods and gestures as indications that he understood and enjoyed the stories. Unfortunately, the

educators who worked with Samuel at their home did not show interest in Samuel's literate potential when Jordan told them about his interest and inquired into his future literacy instruction.

Kliewer and Biklen's interviews also showed that when parents were aware of their children's literacy abilities, they did not always question the schools when the schools dismissed it and/or did not plan to instruct the children in literacy. For example, these authors interviewed Carol, the respite care provider/advocate for Steven, a child with autism and an intellectual disability and Steven's mother, Nikki, both of whom were aware of Steven's enjoyment of reading. Carol and Nikki were also both aware that Steven was able to comprehend information in books as evidenced through his drawings. Having read Steven's IEP and realizing that there were no literacy goals for Steven, Carol asked Nikki why these skills were being ignored. Nikki told Carol that reading was not something that Steven did at school, but instead, something that he did at home. Carol was astounded by this, and when invited to a planning meeting at the school, she brought the issue up with the teachers and other school professionals. The school professionals did not perceive Steven as being able to read at all, and did not have plans to help him develop literacy skills.

Although there are few studies pertaining specifically to parent decision-making and advocacy in regard to literacy education for children with intellectual disabilities in school, there is literature that describes parent advocacy for the educational opportunities of their children with disabilities in general. Erwin and Soodak (1995) for example, conducted a study of mothers of children with disabilities who were also proponents of inclusive education. These parents made use of a number of strategies to procure

inclusive education for their children such as contacting administrators, attending hearings and mediations, pulling their children from schools that refused to grant inclusion to their children, and contacting the media.

Other studies, too, described ways that parents advocate for their children's educational opportunities in schools. Trainor (2010), for example, outlined four different parent approaches to advocacy for their children who had a span of different disability labels and categorized them as follows: 1) "Intuitive advocates," who used their intimate knowledge of their children to advocate, for instance, providing information on how best to handle a particular behavior issue. 2) "Disability experts," who used the knowledge they had gained about their children's specific disabilities to enhance their advocacy, for example, providing information about the transition needs of a child with autism to attain generally undisclosed information about an upcoming placement. 3) Strategists, who used their in-depth understanding of IDEA and other special education legislation, for instance, referring to legal precedent to advocate for their children, and 4) "Change agents," who used their in-depth knowledge of special education law, educational systems and interpersonal connections, and access to economic assets to effect change in the system. The Strategists and Change agents tended to be more successful in their advocacy attempts, however, than did the Intuitive advocates and Disability experts. Based on these results, Trainor concluded that parents who advocate successfully have access to and can purposefully draw upon and incorporate the benefits of different resources including specialized knowledge about education (e.g., knowledge of IDEA, ) and connections/relationships with helpful and/or influential individuals (e.g., other parents, service coordinators, teachers, administrators).

Parent advocacy also appears to be affected by power relations in schools. In a focus group study of parents of children with various disability levels, Hess, Molina and Kozleski (2006) found that parents sometimes felt that school personnel made educational decisions regarding their children without their input. According to Hess and her colleagues, when parents experienced such situations they felt the effects of being “othered” (p. 152). In response to being “othered,” parents faced the decision to comply with or to advocate against educational decisions they found to be unacceptable.

These studies on parent advocacy indicate that many parents are not pleased with the educational opportunities available in schools for their children who have disabilities; however, none of these studies dealt specifically with parent views on the literacy education provided to their children with disabilities. This is a significant gap in the literature.

### **Conclusion**

The body of literature concerning literacy instruction for students with intellectual disabilities historically has focused on and recommended functional skills approaches. However, more recent literature suggests that students with such disabilities can benefit from higher-level literacy instruction that includes attention to developing decoding, comprehension, and writing. This denial of access to such literacy education is likely based on the deficit driven views regarding individuals with intellectual disabilities that are so prominent in schools and in society at large.

A small amount of literature shows that some parents may have alternative ways of understanding their children’s competence than do school professionals and that sometimes these parents advocate on their children’s behalf. However, few studies have

looked at parent involvement and advocacy for educational opportunities specifically for children with intellectual disabilities. One study showed that some parents believe that their children with intellectual disabilities show literate capabilities and potential; however, no studies have investigated parents' perspectives regarding the nature of the literacy instruction that is given to their children in school. Given these gaps in the literature, two important but little understood questions addressed by this study are: 1) What are parents' perspectives on the literacy instruction afforded to their children with intellectual disabilities? and 2) What are the perspectives of such parents on the opportunities available to them to participate in decision-making about this literacy instruction?



## CHAPTER THREE:

### METHOD

The purpose of this qualitative interview study was to explore the perspectives of parents of children with intellectual disabilities concerning the literacy learning opportunities their children were afforded in schools as well as their perspectives on the opportunities available to them to participate in decision-making about this literacy instruction. According to Bogdan and Biklen (2003), an important goal of qualitative research is to gain an in-depth and detailed understanding about the perspectives people hold and how they have come to develop such perspectives. One way in which to gain such an understanding is to conduct unstructured or semi-structured interviews with individuals. Because my purpose in conducting this research was to understand parents' perspectives concerning their children's literacy learning, a qualitative interview study was a well suited methodological choice.

This qualitative interview study is grounded in disability studies and critical interpretivist frameworks to explore parents' perspectives on the literacy instruction of their children with intellectual disabilities. Ferguson, Ferguson, and Taylor (1992) describe interpretivism as recognizing that "truth" is socially constructed, and that those using such a framework aim to "describe, interpret, and understand" (p. 6) what they research with empathy for the participants. Critical interpretivism includes the added component of seeking out and describing the stories of individuals who push against discriminatory practices. Thus, this perspective suggests the importance of empathizing with participants' points of view with a focus toward understanding how they experience discriminating practices. Disability studies makes use of a social model of disability, asserting that, although individuals may have impairments, it is society that creates the

disability by marginalizing individuals with impairments and denying them equal rights to participation in society (Couser, 2002).

According to Harvey (1990), “Critical social research is close and detailed study which shows how historical oppressive social structures are legitimated and reproduced in specific practices” (p. 210). To understand how literacy instruction is afforded to students with intellectual disabilities and how access to such instruction is related to larger societal structures, I chose to interview parents of individuals with intellectual disabilities so I could understand their views and analyze their stories in the context of our society’s historically unjust treatment of individuals with such labels.

This study took part in two phases. In the first phase, I interviewed a small number of participants to test the viability of my recruitment strategies and interview questions. I included these data along with the data collected during Phase Two as the Phase One participants’ stories added important insights. The methods I used did not differ significantly between Phase One and Phase Two, so I decided to combine data collected in these two phases.

### **Participant Recruitment**

I wanted to interview parents of children with significant types of disability, those disabilities that are relatively low in incidence and that appear to have a significant effect on how the children learn. While I was grappling with a term to use to describe the population of children discussed in this study, I also had to be cognizant of using a term during the recruitment process that would allow prospective participants to garner whether or not they fit the study criteria. At the outset of the study, and for recruitment

purposes, I advertised the study as being open to parents of children with intellectual or developmental disabilities.

To recruit participants, I made use of informational flyers and an informal network of parents of children with intellectual disabilities. However, this was not my original plan. During the early part of Phase One, I encountered significant problems when I attempted to recruit participants for this study through the help of the interim director at the local Developmental Disabilities Services Office (DDSO). The original plan was to email an informational letter to the parents of children served through this office. Had this plan been effective, I would have been able to extend the invitation for participation to numerous families with children with disabilities in the geographic area where this study took place, perhaps yielding a wider demographic among the participants than I was ultimately able to recruit. However, this plan was abandoned due to our inability to agree on ways to address issues of confidentiality. Others at the DDSO suggested that I contact local agencies who provide support groups and seminars for parents of children with disabilities to request permission to present my study at some of those meetings. Unfortunately, when I contacted the heads of two agencies in the area, I met with much resistance to this idea. Therefore, I decided to abandon this approach too.

Next, I attempted to find participants through an informal network of parents of children with disabilities. This process proved to be more successful, and I was able to recruit five participants to interview for Phase One. However, finding participants through the informal parent network alone proved to be a very slow process, taking several months to recruit only a few participants. Further, the participants to which I was able to gain access through this method had very similar demographic backgrounds,

leading me to believe that there might be more to learn if I could widen my recruitment network.

For Phase Two, in addition to making use of the informal parent network, I also displayed informational flyers in area libraries, grocery stores, and doctors' offices. I was also able to procure permission to display a few of the flyers in a local agency that supports individuals with disabilities in the community.

It may have seemed an obvious choice to display the informational flyers in the area public schools to access a wide demographic of parents of children with intellectual disabilities; however, I deliberately chose not to do this. I made this choice for two reasons. First, I wanted to be sure to protect, as fully as possible, the identities of any prospective study participants and their children. The nature of intellectual disabilities is low-incidence. That is, there would be few students in any one particular school building with any one particular condition or syndrome, for example, Prader-Willi syndrome. This concerned me because the children discussed in the study and their parents would, therefore, be more identifiable if it was discovered, through the pulling of a flyer's tab posted in one of their school buildings, that a member of that school's community was considering taking part in this study. Second, I wanted to allow the participants to be certain that any information they provided to me would, under no circumstances, make it back to the school personnel who provided educational services to their children. I wanted these parents to be absolutely sure that I was in no way affiliated with their children's schools and that no person from their schools was affiliated with this study.

Between the use of the flyers and the informal parent network, I was able to recruit a number of participants to begin the Phase Two interviewing process. From

there, I made use of snowball sampling to gain access to and recruit more participants. That is, as I finished an interview with one participant, I asked her if she knew of any other parents of children with intellectual disabilities who might be interested in participating in the study. If she did, and was willing to share the information with me, I would then contact the new person to garner whether or not he or she was willing to take part in the study. I also continued to gain participants through the flyers and the original parent network as well. Unfortunately, although these recruitment strategies allowed me to recruit enough participants to conduct the second phase of the study, they did not benefit me greatly in my attempts to recruit of a wide demographic of participants.

### **Participants**

Volunteers who participated for this study included 22 parents of children with intellectual disabilities in kindergarten through high school. The participants' children came from nine different public school districts and two private schools. Five of the participants took part in the Phase One interviews. The remaining 17 participants took part in the Phase Two interviews. Between the two phases combined, I recruited a total of 20 participants for the study, all mothers. Although I did not deliberately recruit only mothers for the study, it was always the mothers who responded to my call for participants. Two of the initial 20 participants, however, requested that their partners take part in the interview process with them, and so I ended up with 22 parents in all, 20 mothers and two fathers. The 22 participants are displayed in Table 1 on pages 50-51. To protect anonymity, I assigned all of the participants and their children with pseudonyms. I also changed the names of the participants' towns, their children's schools and teachers' names, and any other potentially identifying information.

The participants for this study came from a mid-sized city (and its surrounding areas) in the northeastern United States. Participants came from the city proper as well as the outlying suburban and rural towns. Most of the participants came from middle class to upper middle class backgrounds, and two came from working class backgrounds. All of the participants were of European descent except one, who was African American.

Table 1

*Participants and their Children*

Parent(s)	Child	Child's Age	Child's Grade in School	Child's Disability Label
Lara	Logan	10	3 <sup>rd</sup>	Down syndrome
Vanessa	Amy	10	5 <sup>th</sup>	Pervasive Development Delay- Not Otherwise Specified (PDD- NOS) Mild Cerebral Palsy
Iris	Tanya	8	2 <sup>nd</sup>	Down syndrome
Barbara	Elise	12	6 <sup>th</sup>	Down syndrome ADHD
Ruth	Leann	6	1 <sup>st</sup>	Autism
Theresa	Millie	8	3 <sup>rd</sup>	Mild Mental Retardation Global Delay Speech Apraxia
Annette	Jennifer	12	6 <sup>th</sup>	Multiple Disabilities
Nuala	Julie	7	1 <sup>st</sup>	Mental Retardation Autism Cerebral Palsy ADHD
Linda	Rhiannon	12	6 <sup>th</sup>	Microcephaly
Wendy	Benjamin	11	6 <sup>th</sup>	Autism
Emilie	Samantha	8	3 <sup>rd</sup>	Asperger's Syndrome Developmental Dyspraxia ADHD
Diana	John	8	2 <sup>nd</sup>	Autism

Colleen and Thomas	Parker	10	4 <sup>th</sup>	Autism
Nina	Danny	8	3 <sup>rd</sup>	Mild Autism
Nancy and Robert	Timothy	6	Kindergarten	Mitochondrial Dysfunction PDD-NOS Seizure Disorder Movement Disorder
June	Sophia	7	2 <sup>nd</sup>	Down Syndrome
Lisa	Richard	10	4 <sup>th</sup>	Prader-Willi Syndrome
Alice	Mary	13	1 <sup>st</sup>	Microcephaly
Karen	David	15	High School No Specific Grade	Down Syndrome Oppositional Defiant Disorder ADHD
Susan	Katie	15	8 <sup>th</sup>	Down Syndrome

### Data Collection

I asked the participants to take part in semi-structured interviews (Bogdan & Biklen, 2003; Bogdan & Taylor, 1975). I chose to use semi-structured interviews to allow the participants to discuss, in detail, the events and stories they found to be most important regarding the literacy instruction afforded to their children in school. For Phase One, four out of the five participants took part in only one interview session. The other took part in both an initial and follow-up interview, the results of which made it clear that I would get a richer understanding if all of the participants took part in follow-up interviews. Therefore, for Phase Two, participants most often took part in two interview sessions ranging from approximately 50 minutes to 1 hour and a half. Two mothers requested that their partners be present for the second set of interviews; in these

cases, the participants' partners participated in only one interview session each. In all, I spent approximately 38 hours interviewing participants, yielding approximately 1060 pages of transcribed interviews. For both phases, to help the participants feel safe and comfortable with the interview process, I invited the participants to choose the place that we would meet for the interviews. I offered them a few options, stating that I could meet them in a public library, café, or college campus near their homes, that I could come to their homes, or that they could come to mine. Fourteen of the participants chose to meet in a public place while the other eight invited me to their homes.

I conducted the interviews for both Phase One and Phase Two as open-ended discussions with three main prompts: 1) Tell me about your child's education, 2) What, specifically, happens in school to help your child develop reading and writing abilities?, and 3) Explain how you participate in any decision making regarding this instruction. I chose to ask these questions in an effort to guide the discussion toward literacy in general, starting with what most individuals view as pertaining to literacy: reading and writing. However, in an attempt to invite participants to define literacy more broadly, if such was the case for them, I also asked in subsequent probes for the participants to tell me about anything else that they saw as pertaining to literacy. Other follow-up questions were based on participant responses and involved further inquiry into these same topics. I audio recorded each of these interviews for later transcription.

To encourage participants to feel comfortable with the interview process, I began the interviews by telling a little bit about how qualitative interviews work. I explained to the participants that I wanted them to tell me about anything they felt was important as we talked, and that any stories or anecdotes they could provide were helpful to me. This



appeared to help a number of the participants, as a number of them chatted with me as if we were having a conversation. In these cases, I was able to use simple probes to continue the conversation or delve more deeply into a matter that a participant mentioned. Some parents, however, appeared more reserved or perhaps uncomfortable with the interview process. These participants were more likely to try to answer questions quickly and directly. They were less likely to elaborate with examples or details. In these cases I would often have to make use of numerous prompts, and sometimes would find it necessary to give the participants some choices saying such things as, “Was it more like [some example] or more like [some other example]?” These interviews were often shorter than the ones where the participants were more talkative. As a consequence, unfortunately, the more talkative participants are represented to a somewhat larger degree in the findings sections of this study. However, I also paid careful attention to when my participants were quieter, because such “non-talk” can be just as important as what it said aloud (Poland & Pederson, 1998).

As I conducted the interviews, I was careful to make sure that I understood the participants perspectives well and was not erroneously making assumptions or jumping to conclusions as they discussed their perspectives and stories with me. To help with this, as the participants spoke, I took detailed notes about what they were saying, making mention of facial expressions, tone, and manner of speaking which might have helped me interpret how the participants were feeling. As I listened and took notes, I also made efforts throughout our discussions to check my own understanding of what the participants were saying and what I was interpreting from their mannerisms. To do this, I would often state back to the participants my understanding of what they had expressed,

and would then ask them if I had understood correctly. This gave them the opportunity to reiterate a point or explain something more fully when necessary.

Another way that I checked my understanding of the participants' perspectives was through reviewing with them what they had discussed at the first interview before the beginning of the second interview when one occurred. During this process, I would often ask some clarifying questions I had developed after reviewing the audio recordings of the first interviews and my notes. This reviewing technique gave the participants the opportunity to correct any misunderstandings I may have had before a second interview began, and it also reminded them what had been discussed at the previous meeting.

Directly after each interview, I would always reflect on what had transpired during the interview, thinking about what my expectations had been, what had surprised me, and what this meant in terms of my own subjectivities as a researcher. I also took the time after each interview to re-listen to the audio recording of the interview, and take copious notes to make up for what I could not get down during the interview. Here, I also took notes about what to bring up with the participants in subsequent interviews when these occurred and also added notes about interesting, striking, or unusual things that happened during the interviews that seemed important or otherwise relevant.

### **Data Analysis**

I coded data through the use of a qualitative analysis software application called Weft QDA (Fenton, 2006). This software allows users to enter qualitative data, add notes to the data, create codes with which to categorize the data, and create hierarchies of the added codes. Once the data are coded, the software also enables users to call up instances of code overlap using Boolean-type searches.

With the Weft QDA software, I analyzed and coded my data based on the themes that arose making use of the constant comparative method (Glaser & Strauss, 1967). Specifically, I entered all of transcripts into the Weft QDA application, and then read through the interview transcripts numerous times. As I did so, I coded instances of similar stories and events that arose in the interviews. I did this by highlighting the text I wished to code, adding a code in the program, and then selecting that code for the highlighted area. Once a particular code was added, I could use that code for other sections of text as needed.

After I went through this process several times, I reread each of the interviews, checking the stories and events I had categorized for accuracy. As I did this, I added further codes into the Weft QDA program to better represent the differences and similarities that emerged between the events. I continued with this process until all the data were coded and no more codes were necessary to classify and categorize the data.

When all the data were coded, I was able to use the Weft QDA software to pull up examples of text that I had coded. I could do this for just one code at a time, or I could look for a combination of codes, using a Boolean-type search. That is, if I wanted to find all of the instances in my data that discussed a parent's positive feeling toward his or her child's writing experiences in middle school, I could search for this data by entering three codes: 1) *parent feeling-positive*, 2) *middle school*, 3) *writing instruction*. From there, the program would display all areas in the data where these three codes occurred together. I used this process often to draw further conclusions from my data.

I also found it helpful to call up the data I had categorized by a single code and read through these, one code at a time (e.g., all sections coded as *reading instruction-*

*decoding* or *parent-advocacy*.) When I did this, I could read through all of the sections of text that I had categorized in a certain way, and it allowed me to develop further understandings of that category. For example, if I read all the instances of *reading-instruction-decoding* at once, I could get a sense of the types of things that parents reported happening for their children in the way of decoding instruction in the schools. This process proved so helpful to me, that I eventually printed out all of the instances of each of the individual codes and placed them in several large binders to review away from the computer screen. Here I made further notes, often as I reflected on what those similarly-coded stories and events might mean in the context of the theoretical frameworks I had chosen to analyze the coded data.

In general, studies using critical frameworks analyze not only the empirical data that is collected, but also the way that the data relate to the social structures in place in society. Therefore, critical analysis requires “a shuttling back and forth between the particular phenomena under investigation and the wider structure and history to which it relates” (Harvey, 1990, p. 32). For these reasons, when identifying significant themes in the data, I also reflected on how each theme related to societal issues involving individuals with intellectual disabilities. I then added this information to the note sections available for use in the Weft QDA program.

Through the lens of critical interpretivism, I reflected on and deconstructed how certain themes in the data represented the dominant view in society that there are ultimate “truths” regarding individuals with intellectual disabilities and how the acceptance or rejection of such views might lead school professionals, per the parents’ perspectives, to approach literacy instruction for such individuals in particular ways. Through the

disability studies perspective, I considered how certain themes in the data related to the dominant view in society that disability is an inherent problem in an individual and how the acceptance or rejection of such a view might be related to how, in the participants' views, school professionals invite, partially invite, or do not invite students with intellectual disabilities to be important parts of their schools' literate communities.

### **Researcher's Perspective**

According to Peshkin (1988), it is important for researchers to realize how their own subjectivities affect the way in which they understand the research that they do and to "disclose to their readers where self and subject became joined" (p. 17). For this reason, I wish to share with my readers my own subjectivities regarding this research and how I developed the perspectives I hold.

My perspective is shaped by my background and education. I am a certified teacher in elementary education, special education, and literacy education, and I have worked as an elementary school teacher, a special educator, and a literacy teacher educator. My perspective has certainly been influenced by the work I have done with children, as well as the injustices I have witnessed and worked against in school settings. My perspectives have been influenced most by the experiences I had growing up with a sibling with intellectual disabilities, as I discussed at the beginning of this document. Witnessing my sister being marginalized over time, as well as my parents' attempts at advocating for her, had a major effect on my life and my viewpoints. I gained a passion for pushing against systems that discriminate against my sister and other individuals with disability labels. I currently seek to make change in school communities through advocacy work, my own research, and teacher education.

My personal experience with the problems associated with discrimination against individuals with intellectual disabilities puts me in a good position to empathize with my participants' stories of discrimination. For this reason, I chose to use a critical interpretivist framework to analyze my data because this framework emphasizes an importance in empathizing with participants' perspectives. I also chose to work within a disability studies perspective because this perspective recognizes that society creates disability in its discriminatory treatment of individuals with impairments. This perspective aligns well with my own perspective, clearly shaped by the discriminatory practices I witnessed being used to deny my sister full rights to participation in society.

In seeking to empathize, however, I have also remained cognizant of my responsibility not to influence my participants' perspectives beyond any influence caused by the questions I asked and to recognize when their attitudes and experiences differed from my own. I have attempted to reduce my influence on the analysis by representing what my participants said, using their own words when possible. My analysis was an attempt to find commonalities and variations among the participants' responses and emphasize points they found to be important.

### **Conclusion**

The purpose of this qualitative interview study was to inquire into the perspectives of parents of children with intellectual disabilities regarding the literacy instruction provided to their children. The study is grounded in disability studies and critical interpretivist frameworks. Disability studies makes use of a social model of disability, asserting that the way that disability is often construed has a way of creating disability by marginalizing individuals with impairments. An interpretivist framework

recognizes “truth” as a social construction. Critical interpretivism invites researchers to empathetically understand stories of individuals who push against discriminatory practices. Gaining parent perspectives and understanding them through such lenses is helpful in gaining a broader understanding about what happens for children educationally in school systems that have been structured around hegemonic views.

Twenty-two participants took part in semi-structured interviews guided by the following questions: 1) Tell me about your child’s education, 2) What, specifically, happens in school to help your child develop reading and writing abilities?, and 3) Explain how you participate in any decision making regarding this instruction. I used Weft QDA to code the data and used disability studies and critical interpretivist perspectives to analyze how certain themes in the data related to dominant views in society regarding individuals with intellectual disabilities. I also discussed my own subjectivities as a researcher and what I did to attempt to reduce my influence on this study.

## CHAPTER FOUR:

“WE’RE GONNA GO TO THE MOON!”:

### PARENTS’ PERSPECTIVES ON LITERACY INSTRUCTION

This chapter explores the perspectives of the 22 parents who participated in my study regarding the literacy instruction offered in school to their children with intellectual disabilities. When I spoke to the parents about the literacy instruction their children received in school, their perspectives varied on a continuum that ranged from pleased to exceedingly dissatisfied. Specifically, parents talked about issues surrounding 1) teacher interest and investment in their children’s learning, 2) their children’s access to literacy learning, and 3) the appropriateness of their children’s educational settings. In this chapter, I have described the participants’ perspectives regarding each of these issues.

#### **Teacher Interest and Investment**

For many of the participants, discussions of literacy instruction focused around their perspectives on the children’s teachers, including teachers’ apparent attitudes toward teaching their children and the amount of investment teachers appeared to possess in regard to the children’s success. Whether parents were pleased or discouraged with the literacy instruction afforded to their children, parents were clear about the impact of the teachers’ attitudes.

**A vested interest.** According to the participants, good literacy instruction came from teachers who took a vested interest in their children. Teachers who took such an interest made concerted efforts to help the children achieve success. Parents saw these teachers take initiative in regard to their children’s learning, using creativity and flexibility with their teaching while maintaining high expectations. For example, Iris



commended her daughter's special education teacher who worked with her in an inclusive environment, "I credit Ms. Hanover with laying the framework and the foundation for Tanya's reading level presently... She believed in my daughter. She believed in Tanya" (Interview, February 10, 2011).

Tanya has Down syndrome, and for Iris, having Ms. Hanover believe that Tanya could succeed was important. Iris believed that Ms. Hanover's positive outlook led the teacher to maintain high expectations for Tanya. According to Iris, Ms. Hanover taught Tanya the same reading curriculum as her peers without disabilities, and that due to this teaching approach, Tanya's ability to decode and recognize words was "at or above the level" when compared to her second grade peers. Tanya's teacher was also supportive of Tanya, finding ways to engage Tanya in the literacy lessons. Iris explained, "She challenged Tanya, and she did it in love. She was very, very creative in her ways of getting Tanya to focus and comply and to agree" (Interview, February 10, 2011).

Wendy also credited a teacher with making difference for her son, Benjamin. Benjamin has autism and at this time was receiving much of his instruction in an inclusive environment. According to Wendy, Benjamin's second grade classroom teacher was adept at finding ways to help her son succeed in the general education environment. As a result of this teacher's efforts, Wendy reported seeing incredible improvements in Benjamin's literacy skills and confidence. Wendy explained:

Benjamin was visibly changing, his language skills were just, you know, growing in leaps and bounds— His confidence, his interactions with other people were improving, and so I went in and I met her... She found some keys to his growth that other teachers had not. And who knows where in her education it all came in,

but she found a way to pull it together, to make him feel like a valid member of that community, contributing member. It did amazing things for his confidence... She had neat ways of teaching the other kids that it's not about doing everything the same for every child. It's about everyone getting what they need in the same room. (Interview, January 25, 2011)

Diane also commended a teacher who took a vested interest in her son. Like Benjamin, John has autism and at the time of this study, was instructed in an inclusive environment. Based on John's kindergarten year, Diane was accustomed to communicating mostly with John's special educator and less so with the general educator. Diane was pleasantly surprised, however, with what transpired when John went to first grade:

Early on in first grade, I was always writing his special ed teacher, "Can you give me some suggestions on this...?; Let me suggest this for you...; This is what he gets interested in now..." And his first grade [general education] teacher, early on in the school year, not in a mean way, but just, you know, [said], "Ms. Quinn, if you could include me... I know [you are] sending [the special educator] ideas, but I'm John's teacher. So, if you could..." I was like, "Thank you!"... She really took ownership of John. Like [her perspective was], "He is first and foremost my general ed student who happens to have to get some services." Which is phenomenal. So she was, I mean, unbelievable in that way. (Interview, January 31, 2011)

Diane was impressed with how John's general educator saw him as one of her own students and treated him as such, wanting to be an integral part of his learning. In

addition, Diane also agreed with Iris in the view that teacher initiative and creativity were helpful in facilitating her son's growth in literacy skills. Regarding John's second grade teachers, Diane explained, "What I like is they're creative in regards to— they'll try to teach him different concepts based on his interest. So, it's not like "We're gonna modify it this way for all five kids with an IEP in second grade." They're gonna figure out what John's interests are" (Interview, February 22, 2011). In a subsequent interview, Diane explained how her son's teachers were creative in helping to improve his reading comprehension:

Let's say if, and at the time *Wow, Wow, Wubbzy* happens to be a character that he likes, so they might talk about that a little bit to sort of get his brain moving, like, 'Oh okay.' By making the connection that Wubbzy has three friends, and their names are this... [The teachers would say,] "So now, the book we're reading is about Sam's birthday, and he has three friends- Who are his friends?" and then they'll say, "Well, Jimmy, Sue, and Judy are just like Huggy, Buggy, and-" whoever from the other story. Then he'll start to make those connections more. (Interview, January 31, 2011)

With Diane, discussions of teacher investment also focused on the use of alternative and/or augmentative modes of communication. Although John's typical mode of communication at the time of this interview was through speaking, he was, at one time, non-verbal and used an augmentative/alternative communication (AAC) device to communicate. Eventually, John began speaking and gradually phased out his use of the communication device. However, Diane explained how her son's teachers were in tune with the fact that John still had trouble at times expressing himself through speaking,

and were devoted to facilitating him in communicating his knowledge through technology: “The teachers are like, ‘Okay, right now you can’t say it, but type for me what the main character’s name was or what you think the plot of the story was’” (Interview, January 31, 2011). In this case, John’s teachers’ insight and initiative were extremely important to John’s literacy education, as the teachers did not regard John’s silence to be an indication that he did not know the answer to a question or have something to respond. They believed that John had something to say, and took extra steps to ensure that John could communicate his knowledge and engage in the literacy learning activity taking place.

June was another participant who discussed teacher initiative in relation to alternative/augmentative modes of communication. June’s daughter, Sophia, had quite a bit of trouble articulating her thoughts to others through speech. Even her parents sometimes had trouble understanding what Sophia was trying to say. When Sophia was in second grade, June and Sophia’s teacher began looking into getting Sophia a Dynavox (an AAC device which allows users to select words and symbols on a touchscreen to indicate what they would like to communicate and which the device, in turn, speaks out digitally), to help her get her thoughts across to others, but getting her approved for the device was going to take some time. To help with this, Sophia’s teacher encouraged Sophia to use letter stamps to write what she wanted to say. June explained, “Often, we’ll just say, ‘Okay, go ahead and spell it,’ and just let her, you know, stamp it out” (Interview, November 4, 2008).

According to June, use of the letter stamps was also helpful for Sophia’s writing instruction. Besides articulation issues, Sophia also had trouble with fine motor skills

and had difficulty manipulating a pencil. However, according to June, Sophia's teacher wanted Sophia to be able to take part in journal writing just as the other students in her inclusive classroom did, so Sophia's teacher encouraged Sophia to compose with the letter stamps as well. Sophia's teacher then helped Sophia in using sound-symbol correspondences to communicate her thoughts and ideas through inventive spelling with the letter stamps, just as the other children did with pencils.

The fact that Sophia could not write with a typical writing implement did not keep Sophia's teacher from encouraging her use of a journal, either. She was not required to practice forming letters with a pencil before she was allowed to write with meaning. Even though using conventional writing implements might be something Sophia will work on over time, this was not a barrier to her invitation to take part in the meaningful, authentic literacy activities going on in her classroom. June was pleased with Sophia's regular education teacher's efforts when Sophia was instructed in this room. She said, "The regular ed teacher, who used to be a special ed teacher, has really taken the initiative this year to really try [to] include Sophia... She's just taken it upon herself to do it, to modify, you know, which is the way it should be, you know, it's great" (Interview, November 4, 2008).

For Iris, Wendy, Diane, and June, having teachers who took interest and initiative in their children's learning made all the difference. Teacher initiative, in fact, seemed to be the driving force in the delivery of successful literacy instruction for their children. Unfortunately, not all of the participants felt that their children's teachers were invested in their children's learning.

**A lack of passion.** Several parents in this study were distressed because they felt that their children's teachers did not have an interest in their children's literacy education. In the following interview excerpt, Robert and Nancy discussed with me a special education teacher who co-taught kindergarten with the regular education teacher:

Robert: She seemed to be spending more time with the normal kids than the special ed kids within the classroom environment. Our service coordinator kind of got that same impression. When she went in [to observe the classroom,] she thought that his one-on-one aide was actually the teacher.

Nancy: She was the aide.

Michelle: Oh, she actually thought that for a minute?

Nancy: Yes.

Michelle: Wow.

Robert: 'Cause the teacher was really hands-off and not involved. (Interview, June 6, 2011)

Previously, Nancy and Robert had been delighted with the education that Timothy had received at a private inclusive preschool called the Dóchas School. At Dóchas, the teachers, according to Robert, were "phenomenal" (Interview, June 6, 2011). He went on to say, "We couldn't say enough about those guys. They were always picking up, and just always being very proactive on stuff with him. We never felt that he was just going there and sitting and being babysat." However, when Timothy moved into the area public school system to begin kindergarten, things quickly went downhill. Nancy and Robert became increasingly disappointed with the effort and initiative put forth by

Timothy's kindergarten teachers, particularly when compared to the teachers they were accustomed to at the Dóchas School:

Robert: They were much more progressive and proactive on stuff than the school district.

Michelle: So, you don't see that kind of stuff in the schools?

Nancy: No.

Robert: No. There's not that passion, that drive.

Nancy and Robert felt that the lack of effort and initiative put forth by Timothy's teachers was negatively affecting his education. They often wondered how much Timothy was being taught, and whether the proposed model of teaching recommended for Timothy's instruction in his Individualized Education Program (IEP) was actually being implemented:

Nancy: It was easy to think that perhaps he wasn't really being co-taught [sic]. I kinda had a - I've had a year to reflect. I think I was really angry at first. For Timothy, it was probably, probably towards the end of the school year was to the point where he really didn't want to be at school.

Michelle: Right.

Nancy: I could tell by his body language what was happening. And because he had not really ever bonded with the special ed teacher- and quite frankly probably not the regular kindergarten teacher 'cause he wasn't in the classroom enough- that it became clear that what he learned so much of at Dóchas was really just kind of...

Robert: He regressed in public school.

Michelle: I see.

Nancy: Yes, yeah. And even some of the testing that was done- and I can't remember the name of it, but it has to be reflective of expressive language and... what's the other one? There's expressive and...?

Michelle: Receptive?

Nancy: And receptive. It showed that his results were actually lower than the year before when he was in preschool. (Interview, June 6, 2011)

Alice was another parent who felt that her child's learning was hindered by a teacher's lack of investment in her learning. Alice described how when her daughter, Sarah, was in elementary school, she was taught all of her subjects in a segregated setting. This classroom had many children of various ages and labels of disability, and Alice felt that her daughter's needs were not really considered when lessons were put into place in this setting. For example, Alice described what happened when she went in to observe Sarah's class one day. Alice explained how the special education teacher had several children, including Sarah, grouped together to read sight words on flashcards. The teacher was having the children read the cards quickly, in unison, but Sarah could not keep up. Alice said to the teacher, "Sarah can't go that fast." According to Alice, the teacher responded "but I have to teach all the other kids. The other kids can go that fast." (Interview, October 24, 2008).

In another example, Alice noticed that Sarah was frequently coming home with papers on which she had spelled her name wrong. Alice was upset by this since Sarah had shown the ability to spell her name correctly in the past, and Alice wanted her



teachers to keep this as an expectation for Sarah. When Alice discussed this with the teacher, however, she felt dismissed by the teacher who had reportedly said, “That’s just the way Sarah is. You know how she gets” (Interview, October 24, 2008).

Another parent, Vanessa, also discussed problems regarding teacher investment in teaching her daughter, Amy, how to read. Amy was diagnosed as having Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Cerebral Palsy. According to Vanessa, Amy had been receiving literacy instruction, along with the rest of her special class peers, through a program that was not proving to be beneficial to Amy:

I was looking at what [Amy’s reading level] was at the end of last year and what it is now, and yeah, she progressed through the [special class reading program] and got so many levels, not that many, but she got a certain amount of levels, but her DRA went up, like, one [small increment]. So, I’m like, okay, so this is not transferring over into her reading. She’s still at the same, pretty much, level with her reading. (Interview, November 2, 2010)

Because the program that Amy’s teachers were using with Amy’s class was not proving to be effective for her, Vanessa asked Amy’s teachers to consider a new approach. Vanessa explained:

I’ve asked them to look at all of Amy’s data and come up with a different reading program... And their problem with that is that they’ve got other students, and all these students are doing this, and it would be hard to implement something different for Amy. But then I have to go back to, this is an individualized education program (Interview, November 17, 2011)

Vanessa was discouraged by the teachers' lack of initiative in finding a program that might better suit Amy's needs. She stated, "I felt like they were just going to do their thing anyway... And I'm doing everything I can, and they still are just like, 'No, we're doing it our way'" (Interview, November 2, 2010).

Thomas was another participant who felt that his partner's son's teachers and therapists did not show much investment in his learning. Thomas saw this lack of investment reflected in the IEP goals of his partner's son, Parker. Thomas accompanied his partner, Colleen, to her son's IEP meeting and felt that the agreed upon goals were not ambitious enough. He said:

I think one of the biggest challenges of the IEP is like, a child like Parker really, really need to be pushed and challenged. I think the more you can set a goal—you know, like John Kennedy, "We're gonna go to the moon!" That's the kinds of things that he needs in his life. Like, "We're going to do— This year we are going to do something crazy with this goal!" Like, you know, I also understand the IEP is something that these teachers are going to be evaluated on and something they need to live up to and... funding and everything else involved around what happens on this IEP, [but] I kinda felt like the IEP didn't really push the people enough to do, like, great things with him. (Interview, March 4, 2011)

For some parents, lack of teacher investment centered on issues of alternative and augmentative modes of communication. In these cases, parents felt stress and confusion regarding the schools' disinclination to work cooperatively with them to make use of strategies that would help their children communicate and learn more effectively. For

example, Annette discussed her disappointment with the view her daughter's school held regarding the use of sign language for children who can speak:

We take sign language together as a family... because I think [my daughter's] hearing is getting worse. We talked to the school about sign language, and they've never done that... they don't want to do it. Then one time [my daughter] went to school in fifth grade and did sign language, and her teacher told her not to do it. (Interview, January 14, 2011)

Annette also described how the school's position confused her daughter, as her daughter said, "But when I get home, I have to do it."

Theresa was another participant who reported having to contend with a school's disinclination to make use of alternative and augmentative modes of communication. Although doctors and outside therapists had recommended that Theresa's daughter, Millie, who has speech apraxia, begin using a Dynavox, Millie's school was less than cooperative. Theresa explained:

The first time we were talking about communication devices, I said, "Can we have a meeting? We'd really like to get her using a communication device. This was back a year ago, when [Millie's outside speech therapist] had said, "We should be using something." And we go in there, and they talk around in circles 'til we leave, and what they decided to do is just do a flip book of pictures. And they're going to put pictures in, and she's got to flip through this whole book to find these pictures. I'm like, this doesn't work, but I do what they say, and I make my own book at home... (Interview, February 1, 2011)

As Theresa feared, unfortunately, the flip book was not a success. Not only was it cumbersome and impractical for Millie to try to find what she wanted to communicate by flipping through so many pages, but Millie also has a stereotypy (or stim- a repetitive movement or vocalization which is characteristic in individuals with certain disabilities such as autism) that affected her use of the flip book. Theresa said, “Within two days—I had spent three hours doing this—she’d ripped the entire thing, because that’s what she does, she rips everything up” (Interview, February 1, 2011). When I asked Theresa if she had any insight into why the school was resistant to having Millie use a communication device, she explained, “They are not open to any type of change from their strict, normal program with their teachers and what they do. They’re not open to anything new.” Theresa also felt that the school used excuses to avoid trying the device. She recounted a conversation she had had with the school:

And they just [said], ‘We just don’t think she’s capable of doing it.’ [And I said,] “How are you the only people who don’t think she’s capable of doing it?” Every other therapist that she’s had says she’s capable of doing it; Doctors?—Capable of doing it. Except for her [school] speech therapist— Not capable of doing it.  
(Interview, January 1, 2011)

To the participants, teacher attitude and investment in their children’s learning, including a willingness to make use of multiple ways of communicating, were tremendously important and affected how their children were engaged by their teachers in school.

### **Access to Literacy**

According to the parents, teacher attitude and initiative tied in to a larger issue regarding schooling for children with intellectual disabilities. In the parents' views, when teachers appeared to have positive attitudes towards children with intellectual disabilities and believed in their ability to attain literacy, they surrounded the children with literacy learning opportunities. Schooling for the children in these situations, therefore, and again, in the parents' views, was about learning new content, mastering a variety of skills, and being an integral part of what went on in the name of literacy instruction in the classroom and/or larger school environment. To some other parents, however, it sometimes appeared that their children's teachers did not have such positive outlooks on what children with intellectual disabilities could accomplish. In these cases, according to the parents, schooling for the children appeared to be more about issues of control, focusing on behavior and routines rather than academic growth and improvement.

**Access granted.** Some parents reported that their children's teachers engaged their children in many opportunities for literacy growth at school, such as journal writing, small group reading instruction, and visits to the library. These parents were generally pleased when the literacy instruction provided appeared to have these many facets. For example, throughout my interviews with Diane, she mentioned her son being involved in numerous literacy learning activities including poetry writing, journal writing, silent reading, group reading, and comprehension instruction. She said, "...what they're doing is very effective right now" (Interview, January 31, 2011).

Ruth, another participant, also reported that her daughter, Leann, was involved in a number of different literacy learning opportunities. She discussed letter and sight word recognition instruction, story time, take-home book sacks, instruction from a reading

specialist, and trips to the library. Ruth was pleased with the literacy education Leann was receiving. She said, “Their attention to special needs is great... This district is great” (Interview, November 8, 2010).

Iris was another participant who was pleased with the literacy instruction that her child received in school. Like Ruth and Diane, Iris’ descriptions of what happened in the name of literacy instruction for her daughter included a wide variety of literacy learning activities which she felt were engaging and effective for her child. For example, Iris explained, “I actually appreciate [the teachers’] approach to teach her the same way, using the same method as the typical children, and learning the short vowels, and the different little dances and all the fun stuff that teachers get to do with children” (Interview, February 10, 2011).

Iris, Ruth, and Diane each reported that their children made strides in literacy learning as a result of the varied and engaging approach with which they credited their children’s teachers with providing them. In their view, having their children immersed in literacy, much the way their peers were, allowed their children to attain reading and writing abilities. This is not to say that the children were always learning these skills without difficulty; however, according to the participants, engagement in a variety of engaging literacy learning activities proved valuable to their children, and the participants were pleased with the instruction and the outcomes in these cases.

**Access denied.** Some parents reported that their children’s instruction was less about academics, learning new skills, and progressing in knowledge and competence than it was about being controlled or kept out of the way. Linda commented, “As long as the

kids are contained, safe, and complying with their paperwork, that's really what it's all about (Interview, February 3, 2011).

Lara's opinion echoed Linda's. She said:

I think a lot of times, something that they— and I could be wrong—this is just my— a thought, is that [the teachers] are so worried about the special education or special needs kids following routine, and not disrupting. So the focus is on other stuff. You know what I mean? I don't want to say that they weren't focusing on academics, but... they were going through the motions is what it seemed like to me. (Interview, November 15, 2010)

Such focus on control in contrast to meaningful engagement in literacy learning was also described by Kliewer and Biklen (2001), who found that when students with cognitive disabilities presented with behaviors that did not conform to societal norms, teachers sometimes perceived this as evidence that such children were fundamentally unable to connect with the classroom community. According to Kliewer and Biklen, when this happened, the “inferred gap between the person and the community was then reified by actually restricting opportunities for social engagement and participation with symbols” (p. 11). Kluth and Chandler-Olcott (2008) also discussed this issue, explaining that children with movement differences often experience difficulty in engaging in classroom literacy activities when teachers have “rigid expectations for children's behavior” (p. 8).

While a number of parents in this study reported such restrictions of educational opportunity, some parents described more significant educational restrictions than others. For example, while Linda's and Lara's children were involved in at least an attempt at

academic work, some parents reported that often their children were removed from an attempt at academics all together. Theresa explained what she had witnessed and had heard from other parents regarding her child's frequent walks in the hall:

Michelle: You also said she's in the hall a lot?

Theresa: Oh, yes. All the kids with special needs are in the hall a lot.

Michelle: Tell me about that.

Theresa: They're just wandering the halls. You know, when they're not in therapies, if they're going to be disturbing the class or something, they just wander the hall. (Interview, February 1, 2011)

Nancy, whose child has autism as well as a mitochondrial disorder which results in seizures, described a similar experience:

He couldn't sit for five minutes while they read a book, and I was there on a few occasions, and I'm like, "He can't sit because he's sitting far in the back where he wouldn't be a disruption to the other kids that were closer." And the person isn't even reading to him! The pictures are way over here... So, why's he sitting there? So he would get frustrated and lie on the floor, and you know, [they would take him] up, out of the room. Unfortunately, over half his school year had gone, and I found out that he spent more time in a red wagon in the hallway than he did in school. (Interview, April 4, 2011)

Additionally, when Nancy tried to discuss Timothy's academic progress with her son's classroom teachers, Nancy reported that the teachers' responses were focused around behavior, not classroom activities or academic understanding. Nancy explained,



“I wasn’t getting a lot of like, ‘Well, today with the kids, we did this...’ It was more like, ‘Well, he was oppositional and resistant...’ (Interview, June 6, 2011).

According to Linda, Lara, Theresa, and Nancy, teachers seemed to spend an inordinate amount of time being concerned about and trying to control their children’s bodily differences as opposed to including the children as meaningful parts of the literacy activities taking place. In the parents’ views, therefore, the meaning and look of schooling for these children moved away from notions of learning, and relegated these children to the (sometimes literal) margins of their schools where their differences would be less noticeable.

### **Literacy and the Educational Setting**

For the parents in this study, discussions of literacy instruction nearly always prompted discussions regarding educational setting. For some parents, *where* a child was instructed was nearly as important as the instruction itself. In fact, according to the parents, where a child was instructed largely influenced the type and quality of the literacy instruction afforded to the children.

Despite the parents’ ideological positions regarding educational setting, however, the children were educated in a variety of settings, including, 1) primarily inclusive settings, 2) primarily segregated environments, and 3) a combination of settings with “push-in” and “pull-out” components. In addition, some parents’ children experienced education in more than one of these settings at different times throughout their schooling.

Parents’ descriptions of inclusive environments for literacy learning often included a wide variety of literacy learning opportunities for the children. In fact, the varied literacy activities that Diane, Ruth, June, and Iris mentioned in the previous

section were aspects of inclusive environments. As another example, Barbara's description of her daughter's inclusive classroom included the following opportunities and activities for literacy learning: story times with comprehension questions, flashcards to learn words, spelling word lists based on certain word endings, many games, and computer work. Barbara also explained how her child was held to a high standard in the general education classroom:

She went at her own speed, but she had a literacy piece. She had to be in that literacy piece with the rest of the kids...They were all non-IEP kids. They had a regular literacy lesson, and they had to go read their books and stuff like that, so when it was time for them to sit down and do their work, that's when her [modified] work would get introduced. But she was expected to sit and listen to the directions, and follow through, and try to keep up with that. (Interview, November 6, 2010)

Lisa also described the access her child had to literacy instruction in the inclusive environment. Lisa is the mother of Richard, a 10-year-old boy with Prader-Willi Syndrome. Richard is labeled as having cognitive delays and has challenges with behavior; for example, at the time of our interview, Lisa described how Richard would sometimes have temper tantrums when he became frustrated.

Lisa explained that Richard had been included in his school's classroom literacy instruction and activities with the other children since he began Kindergarten. Richard was taught phonics, vocabulary, and comprehension strategies alongside his peers. He took part in a guided reading group in the regular classroom. Lisa explained that Richard's literacy skills had improved over his years in school and that the

comprehension strategies that he was being taught in guided reading groups had been particularly helpful. Lisa said, “[Comprehension strategy instruction] actually helps him a lot, because it’s forcing him to slow down and to think about what he’s reading” (Interview, September 9, 2008). According to Lisa, this instruction had helped Richard learn to draw connections between texts. Lisa explained, “He would get [books] and draw a connection between [them] if there was something similar or a similar plot or something going on. He would draw those connections” (Interview, September 9, 2008).

Regarding his teachers’ high expectations for him, Lisa explained, “They try to say, ‘here’s the work,’ and they see what he can do, and if it needs to be modified, they go from there” (Interview, September 9, 2008). In Lisa’s view, Richard’s teachers began with a ‘can-do’ approach. She explained how his teachers understood that Richard might have difficulty with certain assignments, as they were aware that any child might have difficulty. However, they gave Richard the chance to do the work. They observed him and differentiated instruction or modified his work as needed.

Similarly, when Linda’s child, Rhiannon, was in elementary school, she received literacy instruction in an inclusive environment. Linda was satisfied with the literacy education that Rhiannon received in these early years, and recalled some activities her child was engaged in during kindergarten and first grade:

They would put together booklets. She would do worksheets in school. Like, say, [for] each letter of the alphabet, they would find something that begins with “A.” She would color the sheets and staple them together. When they were done, they would send them home. We would read through them. We still have them all! (Interview, February 3, 2011)

However, when Rhiannon moved to the middle school, Rhiannon was assigned to a segregated classroom, known as a 12-1-1 classroom, which included 12 children with disabilities, 1 special education teacher, and an instructional aide. According to Linda, her child's segregation was a detriment to her both socially and educationally. Linda described Rhiannon's new educational setting as follows:

It's a segregated classroom. It's not even in the same general area as other classrooms or instruction areas. It is down a hallway that has a service closet, a storage area. There's a music room... Then, this classroom is down at the end of the hallway. So, there's very little natural traffic or interaction... The children spend 6th, 7th and 8th grade in this room... She breaks out for specials, which are music, art, home and careers or technology... [Also] she's in a general education social studies class. (Interview, February 3, 2011)

Interestingly, although Linda perceived Rhiannon's education program to be mostly segregated, the school considered it to be inclusive because Rhiannon had the opportunity to go to special area classes and a general education social studies class. Biklen (1992) described such special education arrangements as "islands in the mainstream" (p. 146), where students with disabilities are present in the school building, but interact with nondisabled students only occasionally and in limited ways (p. 146).

When I asked Linda what sort of literacy instruction happened in the segregated special education classroom, she explained that Rhiannon was working on reading and spelling Dolch words and also reading small booklets with basic sentences such as "Bob has two cats." However, Linda also explained that when Rhiannon was able to go into the general education settings, Rhiannon was able to take part in more involved projects

that made use of higher-level literacy skills. For example, Linda discussed with me a project that Rhiannon was assigned in her inclusive Home and Careers class:

Linda: In Home and Careers, they talked about what they want to do when they grow up. My daughter's a huge Disney fan. So, she wants to work at the Disney store. Her one-on-one [aide] and she went to the library, and uploaded pictures of the Disney store, and people working at the Disney store, what the characteristics are of a good worker, you know, friendly, patient, helping, kind. Rhiannon had typed those out and posted them on: She had a made a poster of what she wants to be when she grows up.

Michelle: That sounds neat. Then, they do computer stuff with her, and she's learning to Google?

Linda: And enforce what they're teaching and trying to express herself.

(Interview, February 3, 2011)

In reflecting on the engaging aspects of these types of assignment from the general education setting and the literacy work that Rhiannon had been doing in her self-contained classroom, Linda reasoned, "If she can type Tinker Bell on the computer, I think she's capable of a lot more than, you know... 'Pete has one cat.'" (Interview, March 10, 2011).

Like Linda, Lara explained how she came to prefer that her son, Lucas, who has Down syndrome, receive literacy education in the regular class setting as opposed to the self-contained classroom where he was usually taught:

And being in that room... I actually was in the room and went through a day—

his day— and went to the special ed room with him, and it was organized chaos. I don't know how you would teach. I mean, they did calendar and this and that, but it took them a long time to get through everything because kids weren't even sitting still--which they don't--but I mean, when you only have that one person in charge, and you know, you have the wide ranges of ability and age, I mean, you know, so, I just was like, "This can be done better" (Interview, November 1, 2010)

Upon observing the learning environment where Lucas was being instructed, Lara came to the conclusion that no matter the good intentions the special educator may have had for instruction, it was very unlikely that any child was really getting what he or she needed in that particular classroom because the classroom was not conducive to learning.

Alice was another parent whose child, Sarah, was at one time instructed in a segregated classroom that served children of many ages and with a wide variety of disability labels. Alice's views toward this classroom echoed those of June's. Alice said, "Think of one special ed teacher, twelve kids with all these IEPs, ages Kindergarten through seventh [grade]... There was no teaching [and] a lot of noise" (Interview, October 27, 2008).

Susan also felt dissatisfied with the literacy instruction afforded to her daughter, Katie, when she was taught in a segregated setting. Susan explained:

Because she was in the segregated classroom, everybody got the same curriculum... They start out with, you know, all dumbing down... There was never an attempt to get [Katie and the others students in the segregated setting] to understand [or] think. It was life skills, "Today is the day..." you know, "Write

down the date,” and “The weather is...” and they’d have to draw like a cloud or sun or something like that. (Interview, September 30, 2008)

June described a similar frustration concerning decreased access to higher-level literacy instruction and resources in a segregated setting. Although in an earlier section June discussed the benefits her daughter received in an inclusive setting, Sophia was eventually pulled from the inclusive classroom for literacy instruction.

June described to me how, before Sophia was segregated for literacy instruction, her instruction in the inclusive classroom was not lowered, but modified if Sophia needed it to be and how, in first grade, Sophia had access to the same literacy materials as her peers. According to June, Sophia was doing well, learning to read a number of words in context through her teacher’s guided reading instruction. June explained that Sophia’s teacher was using predictable leveled readers with her students, and Sophia was able to read a number of these texts independently. The following year, however, June was surprised to find out that Sophia’s special education teacher had decided that Sophia would no longer be provided reading instruction in the inclusive classroom and would not be using the same reading curriculum as her peers.

According to June, when she inquired about this new curriculum, the special education teacher could not describe what she would be teaching Sophia, although June did notice that over the next several weeks Sophia began bringing home the same books that she had read during the previous year. Although June was pleased that Sophia was working in the same series of leveled readers as she had been in first grade, she was disappointed that Sophia was repeating the exact same books: level one. June explained, “She’s been working on these since the beginning of first grade and has been mastering

them since then, and we've been getting them home, and she can read them to everyone!" (Interview, November 4, 2008). June also said that when she expressed her concerns with the special educator, the special educator had not realized that Sophia was already fluent in reading the level one books and that she did not even know where the higher level books were located in the school. According to June, regarding the higher level books, the teacher had said, "I'll have to look for those." June was upset by this conversation. She said, "They didn't even give her a chance, you know what I mean? So I'm kind of, really annoyed with that."

Some parents who were proponents of inclusive education were not entirely against "pull-out" instruction, however. These parents felt that there were some times, albeit few, when segregated specialized education was appropriate for their children. When agreeing to this segregated instruction, though, it was with usually with the understanding that their children's teachers had a specific purpose for pulling the children from the general education setting and/or that the "pull-out" sessions be limited in length. For example, Diane discussed her reasoning in accepting that John's teachers would be pulling him out of the general education setting for journal writing:

A lot of times in kindergarten, what they were doing when the whole class was journaling, it would get loud 'cause kids would be talking and the kindergarten teacher would be talking to kids. So sometimes, I didn't like this at the beginning, but they would call him out to the learning center. So he has one-on-one with a specialized teacher which—I'm very big on inclusion: keep the children in the classroom as much as possible—but when they showed me what he would produce in the classroom and then what he would produce in a quieter setting... I



can't fight you on that. I mean, he, the sensory experience in the classroom was hurting his ability to show them what he knew, because—distracting—you know. Loud noises are very hard for him to concentrate when there's loud noises and things. So as much as I wanted him in the classroom, he was learning more, and they were learning more of what he knew. Then again, it was maybe half an hour of journaling. (Interview, January 31, 2011)

Wendy also discussed her decision to allow her son, Benjamin, to be removed from the classroom for some specialized literacy instruction. Benjamin's special education teacher wanted to pull Benjamin from class during tests to work with him on test taking strategies. Wendy consented, but was hesitant, being a strong believer in inclusive education. At the end of the year, Wendy was still uncomfortable with the decision to remove Benjamin from the class for the strategy instruction. She explained:

So I'm thinking, okay, so you take him out for a period. How are you going to know if direct instruction in test-taking strategies is going to help him take those tests unless you've put him back in [to the general education classroom] and see if he can apply what he's learning? But there really wasn't a plan for that. The end of the school year came, and he never went back in to see if he had learned anything in the "pull-out" sessions. (Interview, March 14, 2011)

For Wendy, having teachers remove her child from the classroom for specialized instruction was not an end point. Wendy believed that for the specialized instruction to be effective, particularly in the spirit of inclusion, a plan of action must be in place to reintegrate her child, with his new skills, into the regular classroom.

While a number of parents described inclusive environments as being excellent placements for their children, with wide varieties of literacy activities and welcoming approaches toward children with labels of disability, some parents were not as impressed with their school's versions of inclusion. Recall for example, Nancy whose son, Timothy, was meant, per his IEP, to be co-taught in an inclusive environment. Despite the fact that Timothy was, at times, present in the general education classroom, he was not provided much access to that classroom's curriculum. In fact, he was removed from the classroom when he moved or behaved in a way that was different from children without disability labels. In other words, he rarely received the inclusive education his IEP indicated that he would receive. It is important to note, however, that Nancy was not against inclusive education for her son; she was displeased with the fact that Timothy did not receive appropriate access to this education.

Although most of the parents interviewed for this study were proponents of inclusive education, two were not. Annette was one parent who believed that a special education setting would be in her child's best interest. She explained: "This is the first year she's in a special needs classroom. Up until now, it's all been inclusion... We wanted a special ed setting for her all along" (Interview, January 14, 2011). For Annette, inclusion did not work for her child because the teachers in the inclusive setting were not in tune with her daughter's needs. She discussed this problem with me:

Annette: When she was doing the fifth grade work with the inclusion, yeah, it was too hard...and they, for the whole elementary school, they would send her homework that she was unable to do. So sometimes we'd have her do it, and we'd do it with her, and sometimes we wouldn't.

And then they would give us a hassle about, we're not doing her homework.

Michelle: So, um, now you spoke to the, did you speak to the school about that it was too hard?

Annette: Yeah, they used to modify, they would modify it...for a short time.

Michelle: Then, like what? Then the same worksheets would start coming home again without modifications?

Annette: And I think they had the perception that she could do a lot more than she was doing. (Interview, January 14, 2011)

Karen was another parent who was not a proponent of inclusion for her child, David, at the time of our interview. At one point in time, earlier in David's schooling, Karen reported seeing inclusion as a feasible option for him. However, as David grew older and Karen saw his literacy needs moving further away from the needs of his peers, she began to see segregated instruction as the better choice. She explained:

He lags farther and farther behind from his peers. So, a lot of people expect their child to be mainstreamed all the way through school. Honestly, I don't see where that's possible. Because, great, when he was in second grade, and his peers were in second grade, they weren't that far off. They were learning reading; he was learning reading. Well, he's still learning reading, and they're learning geometry and physics and calculus. He's way far from his peers, so I don't expect him to be mainstreamed with his peers. (Interview, October 27, 2008)

Karen often viewed her child's needs as quite different from those of his same-aged peers. She often regarded the other students as being able to learn in such a setting but felt that her child did better when separated from his peers.

For several parents in this study, inclusive classrooms provided their children with the greatest opportunity to engage in a variety of literacy learning opportunities.

According to these parents, teachers in inclusive classrooms tended to be familiar with the children's needs, modifications were made to help the children succeed, and inclusive literacy education was a positive experience for all involved. Conversely, Nancy's and Annette's stories showed that when inclusion happened in name only, it was not enough. Without the proper supports, teacher knowledge and understanding of the children, and positive attitudes toward bodily difference, inclusive literacy education can fail as well. Furthermore, one parent was not a proponent of inclusive education for her high school aged son, believing that his needs were too dissimilar to those of his same-aged peers for inclusion to be of benefit.

### **Conclusion**

I began this chapter with a discussion of the participants' perspectives regarding the interest and initiative that their children's teachers appeared to possess in providing literacy instruction to their children. I made this choice, because, in listening to the participants' stories, it became apparent that teachers' attitudes, as perceived by the parents, infiltrated many other aspects of what the participants wished to discuss in regard to the literacy education their children were afforded. For parents, teachers' attitudes and willingness to accept and work with their children, despite any cognitive and/or bodily differences with which their children presented, were of the utmost importance. Parents

felt that when teachers were accepting and understanding of their children and showed that they believed that the children could succeed, the teachers put forth better efforts to engage the children in literacy learning. Conversely, parents believed that when teachers did not appear to accept and understand their children or believe that the children could succeed, the initiative that the teachers put forth in engaging the children in literacy learning suffered.

In addition, parents' perceptions of teacher attitude permeated their discussions of the access to literacy instruction with which the children were provided, including the types of instruction that were given, the kinds of materials and activities with which the instruction was supported, and the engagement levels of the instruction overall. Again, in the parents' views positive attitudes seemed to beget instruction similar to that which is generally provided to children without disability labels, including access to many texts, participation in higher-level projects, and involvement in engaging activities. On the other hand, less enthusiastic attitudes appeared to lead teachers to move away from literacy instruction and academic learning in general and focus more on issues of behavioral control.

Lastly, the participants described the settings in which their children received literacy instruction. Most often, according to the parents, higher-level, engaging instruction occurred in inclusive environments, while basic, routine, and less engaging instruction took place in segregated settings. This was not always the case, however, as two participants reported that their children were not served well in inclusive environments due to a lack of understanding and/or effort on the parts of the teachers. This showed that when children are allowed in a classroom, but not given access to the

differentiated instruction they need to take part in the classroom learning activities and welcomed as viable learners of the classroom community, inclusion can certainly be unsuccessful. Furthermore, another parent believed that a special class setting was more appropriate for her child, as she felt his needs were too different from his peers to be best met in an inclusive setting.

## CHAPTER FIVE:

### “WHY DIDN’T I QUESTION THAT?”:

#### COMPLIANCE AND ADVOCACY

In listening to the stories the participants told regarding the literacy instruction received by their children with intellectual disabilities, a common theme arose among the parents regarding their communication with the school. Parents of children with Individual Educations Programs (IEPs) are, by law, meant to be integral participants in the decision-making regarding their children’s educations. They have the right to and are envisioned to be members of the Committee on Special Education (CSE) where objectives are developed for their children. This committee’s job is to share important information regarding the child with disabilities, and, based on this information, devise goals and educational recommendations for the child. Being that parents are supposed to be such an important part of the decision-making process, it did not surprise me that all of the parents in this study reported participation in CSE meetings as well as taking part in informal meetings or conversations with school personnel throughout the school years.

Parents differed, however, in how they communicated with their children’s schools, some assuming more passive roles while others made their opinions heard. Some parents in the current study also changed the ways in which they communicated with the schools as time went on and as they gained more insight to the schools’ inner workings. I classified the parents’ communication styles into three categories which I termed 1) Present Listening, 2) Emergent Advocacy, and 3) Steadfast Advocacy.

#### **Present Listening**

Present Listening was characterized by parent reliance on teachers' perspectives when it came to taking part in the decision making that went on regarding their children's educations. Parents who engaged in Present Listening reported that during meetings, they listened to the teachers' suggestions and concerns and consented to the educational programs that the teachers proposed. These parents' reports indicated that they likely appeared passive when they interacted with the school. This is not to say that these parents were not involved in their children's learning or that they were less interested in their children's learning than the other participants. It only means that their typical manner of being involved was through attending meetings, listening to reported information, and accepting proposed educational recommendations.

Emilie's interactions with her child's school typified the Present Listening category. Emilie wanted to be involved in her child's learning, but felt that the teachers were the experts when it came to educating her child. She listened to the teachers' plans and suggestions and felt that she did not have the knowledge to add to those conversations. Emilie said:

I just feel like they're always prepared and know what the plan is, and I just kind of feel like a listener. You know, I don't know, like, how to ask for things that would help Samantha better. I don't know what. I kind of, like, leave it up to them because I don't know what would be better for her (Interview, February 4, 2011)

**Feeling uneasy.** Emilie's Present Listening communication style was also shaped by her discomfort with conflict. Emilie did not want the school professionals to think that she was disagreeable, and, therefore, she usually remained quiet at CSE



meetings. She also thought about what transpired at meetings and worried about things that may have made her appear oppositional. For example, Emilie discussed with me her discomfort with what transpired when she brought an advocate with her to a CSE meeting:

Emilie: I have, like, brought friends with me, like, another parent that—  
whose child is in the special ed system, and that actually even felt worse.

Michelle: Did it?

Emilie: Yeah, I felt like, um, I felt kinda like, I don't know, I felt like um, um, I don't know how to describe it. It made me even more nervous. Like, I felt like I didn't want to say anything to rock the boat, and, you know, having her there with me felt like rocking the boat. You know what I mean?

Michelle: Now, when she was at the meeting, did she try to ask for anything or advocate?

Emilie: Yeah, yeah, she asked questions, yeah, spoke up.

Michelle: And is that what made you uncomfortable?

Emilie: Yeah. I mean, I want to ask questions, and I want details and stuff, but.... Yeah, I guess I'm just kind of an introverted personality and it's uncomfortable for me. (Interview, February 14, 2011)

CSE meetings in general were difficult for Present Listeners because these parents felt overwhelmed by the number of individuals present and the large amount of

information that the school professionals provided at these meetings. Ruth, another parent who felt most comfortable with Present Listening explained:

It is overwhelming because, you know, you sit in there with the school psychologist. You sit in there with the special ed teacher. You sit in there with the speech therapist or occupational therapist, and her teacher. I don't know. I was just like, "Huh?" There's a lot of information. (Interview, March 2, 2011)

Emilie's opinion echoed Ruth's. Emilie explained, "I kind of feel, like, overwhelmed with...the committee meetings, and I just kind of feel like it's them and me. You know what I mean? So, so they kind of just tell me what they're going to do, and it's not a lot of time to absorb it" (Interview, February 4, 2011). However, Emilie did describe a way that the school might be able to help her, as an introverted person without a background in education, to be a more active member at her child's CSE meetings:

I guess, maybe like, if I met with her teacher ahead of the meeting and kinda had an idea of what they're going to say at the meeting, you know, if you knew, what they were going to ask for, as far as services for the next year, and that kind of thing, if, you know, it'd give me a chance to, like, think about it, and think about where she was at before we went there. I think that would be helpful. (Interview, February 14, 2011)

As Emilie explained, because she felt that she did not have suggestions for the teachers as to what would be a better approach for teaching Samantha, she remained quiet at meetings; however, this did not mean that Emilie was without any opinions. Emilie voiced a concern to me regarding Samantha's reading instruction. Emilie's teachers were

using, among other methods, a phonics-based approach to help Samantha gain literacy skills. Emilie was concerned about this approach, however, because Samantha was being asked to memorize certain rules, and Emilie was worried that Samantha might have difficulty with this approach because she has developmental dyspraxia, a developmental disorder that affects a person's ability to plan and execute motor and sensory functions (National Institute of Neurological Disorders and Stroke, 2011). Emilie explained:

I just think that, I don't know what the best way is for her, but I think, with the developmental dyspraxia, like I was saying, how it, you know, at one point, she may be able to do something and then another point, she may not. I don't know what is the best way, you know, as far as reading and learning the rules, spelling, and that kind of thing. The memorization of the rules, I guess, probably isn't what helps her...because she may not be able to do that the next time. (Interview, February 14, 2011)

Emilie never voiced this concern to Samantha's teachers, however. Being shy and uncomfortable with conflict, Emilie kept this information to herself. Unfortunately, though, because Emilie was afraid to voice her concerns, Samantha's teachers were never given the opportunity to learn from her mother's insight or address her concerns. For instance, had the teachers been provided with more information on developmental dyspraxia, perhaps Samantha's teachers may have considered varying their methods of phonics instruction or adding specific modifications to their phonics approach. In addition, if Emilie had voiced her concerns, Samantha's teachers may also have been able to explain to Emilie why they felt a phonics approach to reading was best for her daughter, potentially putting Emilie's concerns to rest.

**Confidence in the professionals.** Besides feeling overwhelmed, anxious, and shy at meetings and perceiving herself as unqualified to add to discussions around her daughter's instruction, Emilie felt that relying on the school professionals' guidance was the best course of action because the teachers were knowledgeable and had Samantha's best interests at heart. Emilie said, "I think her teachers are good and thorough, and I'm, like, confident in them" (Interview, February 4, 2011). Emilie also said that she was particularly confident in Samantha's special educator and looked to her as an advocate for Samantha's needs:

Emilie: I feel, like, her special ed teacher, because she has been with her right along, has been a really good advocate for her, as far as what she needs. And I have good communication with her, and that makes me feel better about the whole process, I guess.

Michelle: That's good. And let's see here. So you say her special ed teacher's a good advocate for her. Can you tell me about that—what you mean by that?

Emilie: She makes sure, like, when we're planning for next year, that Samantha's needs are met... that she's going to get the services that she feels like she will continue to need. (Interview, February 4, 2011)

Ruth also felt that her daughters' teachers and therapists made appropriate decisions for her daughter, and therefore felt comfortable accepting their educational recommendations and suggestions. Ruth explained, "I really can't complain... You know, I like what they're doing. I think what they're doing for her is great. How they're

handling her is great. You know, I haven't had a moment where I was like, 'Oh my God...I got to call them in'" (Interview, March 2, 2011).

Karen was another parent who felt that her son, David's, teachers made appropriate choices for him. She explained:

When it comes to reading and writing, he's just not interested. So, I really think the school did what they were supposed to do. His teacher, his special ed teacher, that he had from Kindergarten through fifth grade, was determined to get him to read before he left. And she feels awful that she didn't, but I don't blame her, because I know what it's like to get him to do something when he refuses.

(Interview, October 27, 2008)

Like Emilie, Karen did have some ideas regarding how David learned and what interested him. In our discussions, she mentioned something that might have made David more interested and engaged in literacy lessons, but appeared to believe that other ways of teaching literacy were outside what was possible. She said:

He's more mechanical; figuring things out, how to make things work. He can build these awesome Lego buildings and Lincoln Log buildings... If you could teach him to read, ah, [with] building blocks, [it] probably would have had some way of... You know, something more interactive... But how do you learn reading and writing with hands on? (Interview, October 27, 2008)

She also said that she understood that there were certain things the school couldn't do differently, even if she wanted them to change:

Obviously there's things that can't happen. One thing I don't like is that kids [with special needs] tend to be put together in groups. They tend to be clustered

based on their needs. And they are with these same kids year after year after year. I wish we could just split them apart. Why can't we have two classes? There's too many kids in his classroom, let's split 'em up. But that's not always an option. Two parents, therefore, who relied on Present Listening were usually confident that the teachers were making appropriate educational decisions for their children, and did not see a need to advocate for anything different. Two other parents also felt that they could not really effect change because they either thought they did not have anything of worth to suggest or that the teachers were doing everything that they could have done and that certain changes could not be made.

**Less aware.** Confidence that the school personnel had the children's best interests at heart led each of the Present Listeners to rely almost solely on the school professionals' suggestions and to follow their proposed educational recommendations. However, not being active participants in the decision-making process appeared to leave those employing Present Listening less aware about the specifics of their children's programs, particularly when compared to the other participants. When speaking with Emilie, Ruth, and Karen about what went on in the name of specialized literacy instruction for their children, their responses frequently exhibited uncertainty. For example, in my first interview with Ruth, I asked her if Leann's IEP included literacy goals, but she was unsure. Since it was still near the beginning of the school year when Ruth and I initially spoke, I revisited the question with her a few months later:

Michelle: We talked a little bit about her IEP, and you weren't sure if there were reading or writing goals on it. Do you know if there are?

Ruth: I'm sure there are both, you know. (Interview, March 2, 2011)

Ruth's response showed that she was still not entirely sure what her daughter's annual goals were in regards to literacy, or if she had literacy goals at all. In addition, while Ruth was able to give examples of some of the literacy-based activities in which Leann took part, many of Ruth's responses showed uncertainty in regard to her educational program for literacy, with replies such as "I don't know," "I'm sure they do," and "I think." The same was true for Emilie, as well. In the following example, I talked with Emilie about the services Samantha received with the literacy specialist:

Michelle: Okay, and so in second grade when she did— when they were working on reading, she went to the reading room? (Emilie nods.)  
Okay, and do you know how long she was there for?

Emilie: I think it's the same as this year. I think she goes every day. I'm trying to remember exactly how long... (Emilie looks through some of her papers). I think it's an hour a day, yeah.

Michelle: Okay. And so then, is she getting ... Do you know if she's getting any reading or any other literacy kind of stuff in the classroom or is when... or is it pretty much like when they're doing reading, she goes to the specialist?

Emilie: I think when they do reading, she goes to the specialist. (Interview, February 4, 2011)

As with Ruth, Emilie had a general sense of what the school was doing in regard to literacy instruction for her daughter, but she was not certain of the specifics. Although Emilie and Ruth were both interested in what transpired at school and wanted to help their children, they did not appear to feel a part of their CSE teams when it came to

discussions about and decisions regarding their children's literacy learning. Karen, too, seemed to be unsure about what happened in the name of literacy instruction for her son, David. For instance, after Karen had told me that, at home, her son showed interest in non-fiction books, pretend writing, and story-telling through picture walks, I asked her if any of these interests were incorporated into his literacy instruction at school. Karen explained:

It's hard for me to say, really, what they do in school. I mean, they do work on reading. They will send home these very simple, like A-level books that...they print off the computer with two or three words trying to read what's on the page that basically is telling exactly what you see, you know. The boy plays, the boy climbs, the boy rides, but, you know, he just isn't interested in it. He just isn't interested. I really think that's why he's never learned to read, is because he doesn't want to. (Interview, October 27, 2008)

As Present Listeners, when it came to knowledge about their children's literacy instruction and taking part in any decision-making regarding this instruction, Emilie, Ruth, and Karen appeared like outsiders peering in: receiving information, but not adding to it. That is, from their descriptions, they appeared not to be as connected with the educational decision-making piece as some of the other participants were.

### **Emergent Advocacy**

According to many of the parents interviewed, interacting with the school and contributing to the conversation regarding the best course of action for their children's education evolved over time. For example, some parents told of beginning their interactions with the schools with Present Listening, trusting the school professionals as



the experts. However, through further interactions with the schools, these parents became less confident in allowing the school personnel to retain the role of expert and felt the need to become more aware of the daily goings-on of their children's classrooms and take steps toward advocacy. I have categorized the ways in which these parents communicated with their children's school and refer to this style as *Emergent Advocacy*, as these parents appeared to be taking steps toward advocacy at the time of our interviews. This type of communication style was characterized by the participants' reporting that they began to think reflectively about and question recommendations and attempted to effect change, as well as that they lacked experience and resources to fully advocate for the changes they wanted to see.

**Changing perspectives.** Lara presented one example of a parent employing Emergent Advocacy. She explained, "Until you have a special needs kid, you just have no clue how it works, and you assume that the school district—they're the experts. They know what they're doing, and they're doing what's best for your child." However, as time went on, and Lara had more opportunities to meet with school personnel and reflect on her son's academic development, she began to doubt the school's choices and plans for his education:

It actually took me a few years to... realize that you have to be, even though I was involved, and I was a presence in the school, you have to question... and not in a negative way, but you have to question everything that's going on because they don't always know the best way... And then, the last couple years I started to, you know, question it, and, um... you know, it's been... you know, things were happening...I'm just not sure what her methods were. I don't know what was

happening when he was in her room, I honestly don't. (Interview, November 1, 2010)

Lara's conversations with me showed that she was uncomfortable with the conclusion she had come to regarding Logan's education. In telling this part of her story, Lara appeared to choose her words carefully, leaving thoughts unfinished in an attempt to avoid outwardly blaming the school professionals for making unsuitable decisions. She had recently begun to question what she was observing in regard to Logan's education. She had come to the conclusion that the school was not challenging Logan and that his needs were not being met in the self-contained classroom where he received most of his education. I asked Lara to tell me how she came to this understanding, and she explained it as follows:

I guess just realizing that, um, it's hard to explain. I mean, kind of word of mouth. Other people in the school saying that it's chaotic, and the kids aren't learning in the special ed room. I mean, I hate to say that, but that's kind of, you know, you hear things here and there, and that was part of it. And then, um, just knowing, I love her dearly, our [special education] teacher at the time, she was a wonderful—she's a wonderful person, she has a great personality, but she is a very disorganized, uh, harebrained-type thinker, and she switches subjects a lot. She was overwhelmed. She was overworked, understaffed, you know, the whole story... So, you talk to people in other districts and how they're doing things, and, and you realize, "Wow, we could be doing this better." You know what I mean? Like, this is crazy! And why is one teacher doing K-5? (Interview, November 1, 2010)

For Lara, coming to the conclusion that she needed to be more aware of what was going on in the name of literacy education for Logan seemed to be a painful process for her. She discussed with me how she felt angry that the school district did not realize there was a problem and felt guilt-ridden that she did not come to the realization earlier:

Lara: I'm just getting myself, you know, all together. You know and I feel like...

Michelle: I'm sure there's a learning curve.

Lara: Well, yeah, and I'm like, you know, hindsight's 20/20, all that.

Michelle: Sure.

Lara: But I'm like, oh my God, he might have been... He maybe wasn't being challenged, and I didn't know it, and now I feel like I know it, you know what I mean? Like, and you know, you just don't—you just— people who have been in that building for years never questioned it! You know what I'm saying? But you get to a point in your life, and you talk to other people... Like, seriously, you're like, "Wow, why didn't I question that?" Because all of a sudden when you do, you're like, "Oh my God, why?" (Interview, November 1, 2010)

June was another parent who also shared her experiences and feelings toward the realization she had that she should begin to advocate for her daughter, Sophia. As described in chapter 4, June had been quite pleased with the literacy instruction her daughter had been receiving in her inclusive first grade class. However, when the next year began, Sophia's special educator had plans to pull Sophia out of class for literacy, and as this happened, June began to see the quality of her literacy instruction decline.

June was unhappy about this, but she struggled with what she should do about it. She explained:

And, uh, I'm also the type of person that, I mean, I – when I come across something that I'm not happy about I struggle with how to approach it because with your child, you know, you become very emotional, and I don't want to lose that professional and that good relationship we have...So, so, and I feel like, at this point, I'm like, why haven't I gone in there and been like, 'No' you know? That's the wimpy part of me. I'm like, "Oh, I don't want to get on the teacher's bad side." So, anyway...I haven't had to be, like, a huge advocate in the schools because they've been doing [a good job] so far. But, you know, this year, I need to step up my game with them. (Interview, November 4, 2008)

Perhaps because these were such emotionally charged times for these Emergent Advocates, both Lara and June were able to pinpoint specific instances that seemed to propel them in their movements toward advocacy. However, the other participants who engaged in Emergent Advocacy did not have such clear-cut changes in thinking or 'a-ha' moments.

**Reflective thinking and questioning.** The other parents who appeared to rely on Emergent Advocacy eased their way into the role of novice advocate through trial and error. Initially, they had gone along with what the school professionals recommended for programming and educational recommendations, but they had begun to think reflectively and raise questions because of issues that arose along the way. Sometimes these parents chose to advocate when issues arose, but other times they did not. However, despite their choices of action or inaction, their reflective thinking and questioning indicated that they

were not taking in recommendations quietly or complacently as we often saw with parents who employed Present Listening.

Nina's story, for instance, is full of her reflective thinking regarding the instructional decisions her son's teachers made for Daniel, who has mild autism. One thing that surprised Nina was that Daniel's teachers sometimes made judgments about Daniel without ample time or data. For example, she told me about a teacher who wasn't convinced that Daniel had autism:

Nina: And he even had a second grade teacher [who said], "I am surprised at that diagnosis." I was just kind of like... (Nina makes an exasperated expression.)

Michelle: Of mild autism?

Nina: Autism is different for every person, and she didn't understand.

(Interview, February 7, 2011)

To Nina, such comments meant that Daniel's teachers did not always have a strong understanding of him before drawing conclusions, as she described in this excerpt regarding his special education teacher's initial assessment that Daniel would not be eligible for the extended year program that he had attended for the previous two summers:

The parent-teacher conference for last year, second grade, they have a parent-teacher conference like two weeks after school started. I couldn't fathom why. And the special ed teacher's like, "He won't qualify for extended school year." I'm like, "Okay, I guess I gotta make some plans." And by the time his annual

review came up, we had a pre-CSE meeting, and they're like, "Oh we're definitely recommending him for extended school year." (Interview, February 7, 2011)

While Nina did not dispute her son's diagnosis with his teachers or advocate for his inclusion in the extended year program, she also did not allow the teachers' perspectives to change her own view of the situation. Nina did not see Daniel's teachers as being the sole experts for what he needed educationally. In fact, she felt that his teachers had a limited understanding of Daniel at the outset and felt vindicated when they came to understand Daniel as she did, finally recommending him for extended year services. Nina reported thinking, "There you go. Learned something, didn't you?" (Interview, February 7, 2011).

Nina reported feeling mostly satisfied with Daniel's literacy education and educational programming, in general, until the previously discussed issues began to arise. It was Nina's reflective thinking and questioning regarding these and other similar issues that guided her toward attempting advocacy. For instance, Nina discussed with me her dissatisfaction with some of the comments that Daniel's teachers made on his report card, and how ultimately, based on this problem, she requested that they devise some new IEP goals:

Nina: And then they put comments in the report card. It says... "He can work to improve reading comprehension and fluency." I read that. I'm like, "What the heck does that mean? ... That's such a loaded statement. He can work. He *can* work...?"

Michelle: ...to improve reading... So basically, he needs to improve it, but they haven't given-

Nina: Any strategies.

Michelle: -any strategies, and you don't know. Yeah. I can see how that would be frustrating... So then, when you have like IEP meetings, does anything happen where they take something like that and then say, "Okay, so let's devise some goals around this," or not really?

Nina: No, I think this is the first year that I've really said, you know, "We've got to... I mean, he has these very basic goals. You know, I think we need to add some." (Interview, March 1, 2011)

Other participants employing Emergent Advocacy showed evidence of reflective thinking and questioning as well. Such thinking and questioning were apparent in discussions surrounding CSE meetings and IEP development. Two parents in the Emerging Advocate category, for example, questioned their purported roles during CSE meetings. These parents viewed CSE meetings to be less about collaborating with a team to come to an agreed upon plan for their children and more of a session for the school professionals to explain what they had already decided. These parents recognized that they were lawfully supposed to be included as part of the team, but did not feel an integral part of that team. They felt that they were present at the meetings for the sole purpose of being reported to, and that their input was not truly welcome. For example, the following is an excerpt of an interview I had with Annette where she discussed with me her views of IEP meetings:

Annette: They just talk about what they're going to do and then they do it.

Michelle: Okay... So there really isn't a back and forth or...? . . .?

Annette: It seems that they're always so restricted by what they have to do or what they say they have to do.

Michelle: Okay... Yeah...?

Annette: And they definitely have an idea of how they're gonna do it, and what the mold is going to be, and then I think schools do this with all kids, they want the kid to fit the mold, not the mold to fit the kid... A lot of times if we ask for a different... but they said they couldn't, they can't. (Interview, March 3, 2011)

Thomas reported a similar experience with CSE meetings. Thomas likened IEP meetings to business meetings where the underlings are given the impression that their opinions are being asked for and taken seriously, when, in actuality, the bosses have already made up their minds. Thomas said:

I have been to business meetings before where you are brought somewhere so that you can decide how you're going to do something, but in reality, the decision's already been made. What you're being brought there for is to be told what's going to happen and to make sure that you feel like you're sort of on board. And I kind of thought the IEP, like, by the time that we got there, the IEP is already made up... We're going there to be told what's going to happen. (Interview, March 4, 2011)

Reflective thinking and questioning appeared to be important to how Emergent Advocates developed their understanding of the special education system and how it worked or did not work for their children. This thinking and questioning enabled them to perceive problems within the system and became the impetus for attempting advocacy.



**Attempting advocacy.** According to parents in the Emerging Advocacy category, they attempted to hold their own and advocate when they felt their voices were not being heard. They spoke up, gave their opinions, and asked for change, but they were less likely to keep pushing once they had been told, “This is how it is going to be.” For example, Nina explained to me what happened when she tried to advocate for continued speech services for her son:

Nina: In first grade, they stopped giving him speech. They said he didn't need it anymore. But I felt he still had-, and to this day, I still believe he has problems with pragmatic speech. He'll get words wrong.

Michelle: So that happened in...?

Nina: That was at the end of first grade that he stopped getting speech.

Michelle: And so did they tell you that at an IEP meeting?

Nina: Yep.

Michelle: Um, and-

Nina: And I had actually Karen Farley... She actually went with me. She's the Director of the Early Intervention Support Center but she also works for the parent center out of Tro- the advocacy center in Trosbury with school age issues. She's a friend too. So she came with me. We just tried to speak up a lot about pragmatic language assessment, and they just kind of pooh-poohed it.

Michelle: Really?

Nina: And I, still to this day, think he has issues with pragmatic language.

Michelle: So she went with you. They said they're gonna stop the speech. And

you guys tried to say-?

Nina: There's really nothing I could do.

Michelle: And they just pooh-poohed you.

Nina: They just pooh-poohed me. No, he's fine. He doesn't need it any more.

(Interview, March 1, 2011)

Thomas reported a similar situation where he wanted the school to work on some more challenging goals for his partner's son. He recalled, "Well, I brought up, you know, him being able to speak a word... It just kind of got sloughed off. Nobody said, 'Oh, we wouldn't want that,' I mean, but no one's willing to commit to that" (Interview, March 4, 2011). Colleen, his partner and the child's mother added, "Yeah, everybody just sort of looked down at the table. It was sort of awkward." Thomas then joked about how Colleen had looked at him at this point in the meeting, to signal that he should not make trouble.

Both Nina and Thomas appeared to know that they had some power to effect decisions at CSE meetings, as evidenced by their attempts at advocacy. For some reason, neither of these parents pushed further when they met resistance by the school professionals. It was not clear why Nina and Thomas chose to concede in these cases, but perhaps they felt uncomfortable with the conflict or did not know their rights as parents on a CSE team which could have allowed them the capacity to shift the outcome of the meetings in their favor. Perhaps they felt as if their requests would not be honored. Although the reasons these two parents conceded were not clear, there was one parent, Nuala, who engaged in Emergent Advocacy, who clearly did not seem to know her rights

as a parent. Nuala described what happened when her daughter's school decided to discontinue one of her child's related services:

Nuala: They downgraded one of her services, which, to this day, I'm not happy about, but they said, "Well we don't see that she needs it."

Michelle: Oh.

Nuala: So it goes off of, it goes off of what the school thinks the child needs, not what the parents think the child needs.

Michelle: Okay. And you told them that you didn't- you weren't happy with that change?

Nuala: I explained, like after a day or two, I said, "That doesn't make any sense."

Michelle: Right. And what did they say?

Nuala: And they just said, "Well that's what we have planned for her."

(Interview, December 8, 2010)

Nuala wanted to take part in her child's education. She spoke up when she felt that the decisions being made by the school professionals were not appropriate; however she did not understand that she had certain rights as a parent to take part in the decision-making regarding the services that her daughter would receive. She believed that the school had the final say and that she had no recourse, and therefore, she, too, conceded to educational recommendations with which she was dissatisfied.

Nina's, Thomas', and Nuala's stories show how schools can silence parents. Although parents are meant, by federal law, to be partners with the schools in the decision making regarding their children's educational goals, schools seem to hold a

more powerful position in many parent/school relationships. From my discussions with these parents, it appeared that when parents engaged in Emergent Advocacy and felt that they were not being heard, they often did not know what else to do. They may have felt uncomfortable, not wanting to cause trouble as those employing Present Listening often felt, or they may not have had the resources (e.g., knowledge of the laws) to push against the system any further. Whatever the case, when parents felt dismissed, even in their attempts to advocate, they sometimes accepted educational decisions with which they were not satisfied.

### **Steadfast Advocacy**

The remainder of the parents in this study engaged in what I call Steadfast Advocacy. These parents differed from the other participants in how they interacted with their children's schools because they viewed themselves in the role of advocate for their children. They understood that they had rights in devising their children's educational plans and that their children had the right to receive a fair and appropriate education. These parents purposefully kept themselves informed about what was going on at school in the name of literacy instruction for their children. When it came to meetings with teachers, whether during formal CSE meetings or informal chats with teachers after school, these parents paid close attention to and thought critically about what the school professionals reported and recommended. They also were strategic in how they communicated and collaborated with the school to ascertain what they believed to be the best outcomes for their children.

**Staying informed.** Parents who engaged in Steadfast Advocacy had strong convictions regarding their children's educations. They each wanted their children to

receive what they perceived to be quality educations and expected that their children's teachers would hold their children to high standards and provide their children with equitable access to learning approaches as children without labels of disability. To make sure that their children were afforded appropriate educations, they were committed to staying informed about what went on in the name of literacy instruction for their children in school and each used various tactics to do so. For example, Nancy and Robert remained informed about their son's education by keeping a notebook with their son's teachers, making phone calls to the school, and having monthly meetings with the other members of the CSE team. In fact, to be certain that monthly meetings with the CSE team would be conducted, Nancy and Robert had the requirement for these meetings added to their son's IEP.

Nancy discussed the importance of such modes of communication for keeping abreast of what was happening for her son at school. She said, "You have to ask a lot of questions, get it in writing, and make sure it's clear" (Interview, June 6, 2011). However, Nancy and Robert also explained that such tactics were not always enough to remain certain about what was going on. Robert said, "Even in writing...they're not being totally forthright with all information in that notebook." Robert went on to describe how, without their knowledge, their son went for two weeks without speech therapy at school when this therapy was supposed to be provided to him daily per his IEP. Nancy explained how her questioning enabled her to find out that there was problem. She said, "It was by pure chance I asked a question that required me to meet the speech teacher and then found out that she had been out for a week and a half and wasn't anticipated to be

back until today or tomorrow of this week.” To be sure they knew what was going on, Nancy explained, they had “to almost be super vigilant.”

Diane was another parent who attempted to stay informed about what happened at school through a daily notebook and regularly scheduled meetings. Like Nancy and Robert, Diane had the requirement for her son’s meetings added to his IEP. Diane explained, “We have team meetings for John four times a year. I put that in the IEP that I don’t, you know, I don’t want it just around report card time. I want the whole team to get together to talk about, you know, how are we reaching the goals, what can we do better” (Interview, January 31, 2011). For Diane, staying informed also meant seeing firsthand what happened at school. To this end, Diane strategically made herself a presence in her son’s school so that she could keep a watchful eye on what happened. Diane explained:

So I mean, you know, selfishly that’s why I get so involved in different things at the school—So I can be there, and it’s not like when the principal saw me, she was like, “Okay Mrs. Quinn, it’s time to go.” Parents aren’t just supposed to just hover around at school... You know, I definitely had, you know, I mean, I had my agenda, but I also had PTA things I could be doing. Yeah, so I try to strategically place myself. And it’s still— it’s helping the school, but you know, I probably had an ulterior motive. ‘Sure, I’ll be PTA president.’ (Interview, February 22, 2011)

Parents who engaged in Steadfast Advocacy used a variety of methods to stay informed about what went on in the name of literacy instruction for their children in schools as well. Staying on top of what was going on gave these parents much to reflect on, as each of them thought critically about what was going on in the attempt to make

sure that their children were receiving what they considered to be appropriate educations. When these parents were dissatisfied with what was happening, they made their opinions heard. While some of these parents had more challenging experiences than others when interacting with their children's schools, each had stories to tell regarding times in which they felt they needed to advocate for their children's literacy instruction.

**Advocating strategically.** Steadfast Advocacy was categorized by both the strategy and resourcefulness parents employed when they advocated for their children's educational needs at school. They thought critically about how they interacted with school professionals, choosing particular speaking-styles and communicative tactics and making use of resources in the hopes that the choices they made would enable them to attain the best educational outcomes for their children. Barbara articulated this perspective when she said, "To know how to walk in and communicate is huge... It's a very hard task to do as a parent because you are so emotionally wrapped... but you still have to be knowledgeable. You have to be able to advocate appropriately" (Interview, January 23, 2011). How to advocate appropriately looked different, however, for different parents in different situations.

**Being amicable and cooperative.** Sometimes relationships between parents utilizing Steadfast Advocacy and their children's schools were amicable and open enough that the parents could simply express their concerns regarding their children's educations, then either the parents or school personnel would suggest mutually acceptable solutions, and all was fine. This happened when both sides, parents and school personnel, were open to hearing each other's points of view and thinking creatively for a solution. At the time of our interview, Iris felt that she had such a relationship with her daughter's school.

She said, “Right now it has worked for us. We have teachers who, and an administration who’s willing to participate and working with me as her primary caregiver and advocate to making it work for her and the school so that we can come up with a win-win situation” (Interview, November 11, 2010).

As an example, Iris told me about the type of homework that her daughter, Tanya, was often assigned for reading comprehension. Tanya was having trouble with some of the higher-level comprehension questions on these assignments, and Iris did not feel that these parts of the homework were tailored to Tanya’s needs, so Iris brought this issue to the attention of Tanya’s teacher. She explained:

Iris: So I do give feedback on those, that it’s... you can really cut that kind of a question out...

Michelle: How do you give the feedback?

Iris: I just tell her. Yeah. Well, I write a note, “As we reviewed the lesson, ok fine, but this fourth question, don’t you think that’s a bit too much?”

Michelle: And then what happens?

Iris: [The teacher says], “Ok, appreciate that. Just in the future if you think ‘XYZ,’ then either present it this way or you know, it’s ok not to answer it.” (Interview, February 10, 2011)

Here, Iris’s attempt at advocacy was successful and relatively easy because Iris and her daughter’s teacher were able to come to an understanding about Iris’s concern and agree on a workable solution. In fact, not only did the problem get resolved, but



Tanya's teacher also gave Iris some advice on how to help her daughter become successful at answering questions that were challenging for her.

Diane was another parent who employed Steadfast Advocacy whose child had teachers who were often willing to work with her to come to win-win solutions to problems. Diane was a strong believer in inclusion, and one of her biggest pushes was for her son, John, to be included in a general education setting as much as possible. However, as discussed in the previous chapter, John's teachers had indicated, and Diane agreed, that John produced better writing in the resource center where he was less distracted from the natural noise of his classroom. Although Diane agreed to having John pulled out of general education for writing, she did not want her child to miss out on the benefits of being instructed with his peers, so Diane proposed a solution:

And then what they ended up doing after I worked with them is, I said, "How about, is there anything wrong with taking another kid down to the learning center with him?" So what they did was, which was great in kindergarten and in first grade, they were able to do this, is they would find kids that were—kind of gravitated to John and kids John was gravitating to. Then they would send the letters home to those parents and say, "Hey, we have some children with special needs, and your child has been looked upon as one of the kids that might be able to help. Do you have a problem with your child doing this during journal time or...?" And so some parents were for it; some parents weren't. So those that were..., so then he would start to have like kind of a buddy system. So then it started just to be a small group was going to the learning center, and it wasn't all kids with special needs. It was basically John with a couple of typical friends.

Because then, he could share what they were journaling about, and sometimes, I think that could give him ideas from like, “Oh, what did you do this weekend?”

And then he would start to answer those questions. (Interview, January 31, 2011)

Diane believed that her child could receive the best of both worlds: the quiet setting for writing and education with his peers who did not have labels of disability. To advocate for this, she came up with a creative solution, one that worked for all involved. Of course, the receptiveness of her son’s teachers to trying something new was also an important piece in the success of this compromise.

More often than not, unfortunately, Steadfast Advocates reported having to push against school systems rather than work cooperatively with them. Even Iris and Diane who had generally amicable relationships with their children’s schools recounted stories where they had to advocate strongly against educational practices with which they did not agree. However, while those parents who employed Emergent Advocacy were often silenced by authoritative school personnel, those utilizing Steadfast Advocates made use of tactics and resources to persuade or even, at times, compel school personnel to acknowledge their concerns and concede to their educational requests and recommendations.

***Being direct.*** Participants making use of Steadfast Advocacy often found it important to make their positions and requests very clear. Being direct and forward helped these parents in their efforts to garner the supports and changes that they felt their children needed at school. For example, Nancy said:

You can’t be vague and you have to- you can’t put it off. You have to—you know, because then you can say, “Look it. I’ve done this, and I’ve made it clear

that I need this by this time, and so what's happening?" And put it like that. Be really clear what you want. (Interview, June 6, 2011)

Nancy's husband, Robert, described a method he once used to make Nancy's and his questions and points clear. He and Nancy had become increasingly frustrated with how their son was being educated in his school and were not satisfied with how the school was addressing these problems. Therefore, Robert decided it was time to become more direct. He explained:

So I haven't done it in a while, but the one meeting we had I went into, and I came out with this spreadsheet and I gave everybody... and I said, "Here's our action items for today," and it was three pages long. That really got everybody's back up, but I really don't care... The list I made because we were just so frustrated because we'd go into these meetings... And it's hard to prepare for them not knowing. So back when we had so many issues I just said, okay [to] this person or OT, "Here's your items. Here's my questions to you..." (Interview, June 6, 2011)

Although the school personnel were used to running the CSE meetings, and, in Robert's opinion, were not happy when he came in prepared to do so instead, Robert found a way to make his concerns and requests clear. He and his wife felt that with everything written down and directed to the appropriate person, the meeting could be productive because everyone present could stay focused on the issues at hand.

Vanessa was another participant who was direct and forward during meetings and at other times when she voiced her concerns and requests. In regard to her communication approach, Vanessa said, "I'm pretty forceful with them" (Interview,

November 17, 2011). As an example, Vanessa explained how she had been unhappy with her daughter's IEP because the document contained a number of errors, including a misalignment of the months in which her child was supposed to reach certain literacy goals. To Vanessa, it was important that the IEP be correct as it affected many aspects of her daughter's learning, so she made her concerns and expectations clear. She said:

So I went in and I sat down with the teacher and I said you can't have November as a final reporting period because her IEP goes 'til October. So how can you have November? You can't do that. So I'm kinda nit-picky about the IEP just because I want it to make sense to me.

Wendy was another parent who found it necessary to be direct and forward at times. Wendy discussed with me how she would become very frustrated if she felt that the school professionals were making assumptions about her child and his abilities, and that when this occurred, she felt the need to speak up about it. She said, "I have no tolerance for people who make assumptions" (Interview, March 14, 2011).

As an example, Wendy told me about an instance where her son, Benjamin's, English teacher reported to her at a team meeting that her son did not know what a simile was. This confused Wendy, because her son enjoyed pointing out similes and metaphors for fun at home. Upon further discussion, Wendy found out that the teacher made this assessment after asking Benjamin to come up with a simile on the spot during a class lesson. Wendy explained her feelings about this and how she felt the need to be direct in addressing the issue with the teacher:

To test someone one time under those conditions and make the determination that he doesn't get something is not fair, and so I just—I was cringing in my seat. You

know, I had to make sure she knew that he knows exactly what a simile is and speaks in similes when he feels like it 'cause he thinks they're cool... And so I said, "I just want to let you know that he's been making up similes since fourth grade, and whenever we're reading at home, and we read out loud, and we see a simile, [he says,] 'There's a simile mom, there's a metaphor mom.' So please know that he does know what it is. He can point it out. He won't be able to cough it up on demand." (Interview, March 14, 2011)

Each of the participants who utilized Steadfast Advocacy reported having had times when he or she felt the need to be direct and forward with their children's teachers and other school professionals. They often felt that doing so was the only way in certain instances to make sure that their voices were heard.

*Treading carefully.* Conversely, there were times when those using Steadfast Advocacy used a less direct approach to achieve what they wanted for their children. Two participants, for instance, discussed using caution in how they asked for things from the school. They were concerned with how much they asked for, and wanted the school professionals to see them as reasonable. They also wanted to be sure not to rub folks the wrong way, so to speak, because they felt that having a positive working relationship with their children's schools would result in the best outcomes for their children in the long run. For example, Barbara discussed her feelings in regard to making any further requests for her daughter after she had recently advocated for her daughter to be able to stay in preschool an additional year and also to get an FM system to aid in her hearing in kindergarten:

I think at that point you had to be really careful of how I was pushing...Because right now I got two very big things out of them, and I didn't want that type of relationship to start her in the years ahead, because I have 12 years to go. So I got to look at and say "Okay. What does Elise need?" I don't need anything above or beyond what she needs. I'm not asking for anything above and beyond what she needs. But if this is going to work, then, okay, we will. Let's try it. So I have to give, too. You know, that's important. You have to show them you are willing to work with them and say "Okay" and believe that what their expertise is. And, you know, even though the parent's got the expertise, and getting and listen to them and their expertise, and just say "Okay, okay, I'll trust you." (Interview, November 6, 2010)

Wendy's concerns echoed Barbara's regarding the teachers' perspectives, and although she reported needing to be more forward at times, she also wanted to make sure that her son's teachers did not feel upset or angry towards her, because, based on a previous experience, she feared that animosity on the teachers' part would negatively affect her son. For this reason, when Wendy had requests or suggestions, she would often hint at what she wanted in an attempt to keep the school professionals on her good side:

I have to tip-toe all the time: I communicate a lot... but, I have to be really, really careful. I cannot go in and start questioning the teachers' decisions because they will get resentful, and they will take it out on Benjamin. He's the one with the mom who complains. So, I shut up, and email his special ed teacher, "What do you think about buh-buh-buh?" and "Have you noticed da-da-da?" I have to tip-

toe all the time, because we had a very bad experience in our other school district.  
(Interview, January 25, 2011)

*Getting angry.* Several of the parents employing Steadfast Advocacy discussed experiences that caused them to feel as if their children were not getting the educational opportunities that they deserved. They also explained that after many attempts at collegiality, they felt the need to show their anger and become more aggressive. Robert told the following story about a time he and his wife received a note indicating that their child might be without a special educator for a period of time:

The first day, I called the principal, the head of special ed, and I tried calling the superintendent's office. And I got back ahold of the principal, and I basically, you know, my direct comments were, "We put up with this shit last year, and I'm not putting up with it again." I said, "Whenever we have an issue, the same day I call you, I [also] call [the state], and I call the superintendent of schools." So, I said, "I don't ever want to have a problem. We just had one come up that we weren't aware of that I've got to take care of, but," I just said, "I'm not putting up with this. Last year was a waste. It wasted a year of Timothy's life and he shouldn't have been there. That's neither here nor there but," I said "We're not going to put up with it this year. I'm sensitive to budget cuts and everything else, but I don't really care." (Interview, June 6, 2011)

Theresa also had a frustrating experience with her daughter's school district concerning the methods with which the speech teacher was addressing her daughter's speech goals. Millie has speech apraxia and had received helpful outside therapy involving oral motor therapy. As Theresa explained, oral motor therapy is quite different

than traditional speech therapy, but the school speech therapist only had a cursory knowledge of how to provide it. Theresa wanted the school district to provide this type of speech therapy to Millie in school, but the school was resistant to getting the speech teacher the proper training. After addressing her concerns to school personnel on a number of occasions, she discussed the issue again at the annual CSE meeting. After making her position clear, but feeling that she was not being heard, she became extremely frustrated and left the CSE meeting in anger. She described the meeting as follows:

This is where we were talking about...that they needed to have... either start paying for [our outside speech therapist] to come to school or [the school speech therapist] had to be trained, and she needed to be trained over the summer, and I mean properly trained. She had to go to training. She had to be educated on it. Pick one. We're giving you two options here. We're not burying you in a corner and saying you have to pay for her. We're saying train your teachers for what is needed... They kept talking in circles, and circles, and circles and going, "Well, we'll add more oral motor therapy here." I kept saying that "That doesn't matter." The same argument I was telling you. "It doesn't matter. You can write down you're going to teach my daughter to be a world class gymnast. If you don't have the tools to do it, it's not ever going to happen." And I kept saying that, and they go, "Well, we'll just increase her oral motor and then, [I thought,] "Oh my God, what are you not getting?" And I finally said—turned to my husband, I go, "I can't do this anymore. I'm done. Finish it." (Interview, February 1, 2011)

For Theresa and Robert, showing their anger was an important aspect to their advocacy styles, as they needed to find a way to show seemingly uncooperative school



personnel that they meant what they said. Collegiality and even firmness did not always appear to work for these parents, and so other more aggressive tactics were sometimes needed.

*Law as a resource.* Three parents who employed Steadfast Advocacy also used their understanding of federal and/or state law regarding students with disabilities in their attempts at advocacy, bringing up different aspects of these regulations to remind school personnel that often what they were asking for were not just requests, but protected rights. Although each of these parents attained their knowledge of the regulations in different ways, they understood that being knowledgeable in the law could be an asset when attempting to persuade school districts to concede to their requests and recommendations.

Diane's knowledge and usage of the law to advocate grew out of her involvement in the disability community in her area. Diane reported that she first learned how to advocate for her son through the teachers and other professionals who worked with her son at an inclusive preschool. From there, Diane then became involved in a number of different organizations having to do with autism and advocacy, including working for a university-based advocacy center through which she gave training sessions to other parents of children with special needs. Through these experiences, Diane became an expert on the laws regarding the education of children with special needs and the rights of parents of such children. This knowledge became an important resource for Diane when she advocated for her son in the educational setting because she knew what was legally expected of the school, what her own rights were as a parent, and how to use her rights to her and her son's benefit. For example, in the following excerpt, Diane explained what

happened at her son's annual IEP meeting in regard to the type of state testing the school was recommending he take, how she reacted to the recommendation, and how she planned to counter the recommendation if she met resistance. Diane recounted:

But then as we got to talking about different things with the IEP, and you know she explained that 3rd grade is definitely more heavily academic, and so then she is recommending that John doesn't take part in the statewide assessments for 3rd grade—that he does alternate assessments, and so I said, “No, absolutely not.”  
...And I'm like- And I think it's more because in my job now... at the advocacy center- I'm like, “No, you will let him take statewide testing, and you will give him supports to do that, and you will modify the test as you can per the State... I want him to score, I want him to have it because, you know... my hopes and dreams for him are that he will continue to progress, because he is progressing wonderfully, and that he will be headed towards a regular diploma.”

If you start now in 3rd grade making that assumption that he can't do it, uh-uh, I'm not in agreement with that. And I just know that alternate assessments really are meant for children with multiple disabilities that really, unfortunately, probably are never going to be able to take a statewide test. And even the State says it should be like 1% of your special ed population should be taking the alternative assessments. So I think she was a little taken aback, too, that I was so upset about it. So I have a meeting in a couple of weeks with the CSE chair just to talk about it. 'Cause I'm like, you know what? I'm not going to agree to it... You know, if that's what they want to say, then we're going to stop the CSE meeting or we'll at least agree to the services part to it, but we're going to have to

table it until, you know, we can have further discussion. (Interview, February 22, 2011)

Diane used her knowledge of the law to explain to her son's school why he should be allowed to take the same exams as his peers without labels of disability. She also had a plan in place of what she would do, per her parent rights under IDEA, if she met resistance at the next meeting. She knew, for example, that she could refuse to consent to the recommendation with which she disagreed and table the issue until further discussion could be had.

Another parent, Vanessa, also had knowledge of special education law which enabled her to advocate for her daughter. Vanessa's knowledge stemmed from her training as a special educator herself. She knew, for example, that the goals devised for a child's IEP must be measurable and specific to a child's needs, and she explained to me how she advocated strongly for this when her daughter's IEP goals were not written appropriately:

And I went through their IEP, and I used my schooling and I said, this goal is not measurable, this goal needs to be changed....I mean, I picked that IEP clean...even this year's goals for OT, I'm like, this is not specific enough. And the OT teacher's like, 'I like it to be vague.' So then I say, "Well I don't want it be vague. I want it to be specific and measurable," and you're not going to get to wiggle out of anything because that's the way an IEP works. (Interview, November 2, 2010)

Nancy and Robert were other Steadfast Advocates who were aware that knowledge of the law could help them in their advocacy efforts. However, they were not

as familiar with the laws as Diane and Vanessa were. When Nancy and Robert had legal questions, they contacted an advocacy group based out of their state capital. Nancy described the group as follows:

It's a group in [the state capital], and they are advocates for people with disabilities and especially in the school setting. And what they do is they try to bridge you between your team at school. So it's more like a diplomatic way of asking questions that are the parents' right, but not stepping on toes. (Interview, June 6, 2011)

Nancy and Robert reported making several calls to this group to find out about their rights as parents and to ascertain whether what they were being told by school personnel was accurate.

*A more drastic measure.* Sometimes, however, despite numerous and varied attempts at advocacy, parents could not sway school professionals to see things from their perspectives and effect change. When this occurred, some parents resorted to a more drastic measure to be sure their children received what they perceived to be proper educations: They removed their children from the uncooperative school. Vanessa was one parent who felt the need to pull her daughter from her school after her attempts at advocacy met resistance. Vanessa explained that, initially, things went well in the particular school her daughter attended, but as time went on things “started to fall apart” (Interview, November 2, 2010) in regard to her child's safety and education, and that despite her requests for change, attitudes of school personnel were poor and things did not improve. Vanessa recalled,

I really didn't want to move her from her home school because it was close and because she had made some friends, but after the walking off campus twice and the lack of supervision there and the fact that she was in a reading program that I didn't agree with—she was reading the same seven books over and over again for an entire year...[Also] the principal, in front of another parent, told me that my child was 'different,' and, I had it out with the principal. And we—that's why I moved her to Gordon Road. (Interview, November 2, 2010)

Wendy was another parent who, despite numerous attempts at advocating, ultimately removed her son Benjamin from his school. In the following interview excerpt, Wendy described to me the situation that led her to make this choice:

Wendy: So I guess what we discovered very early on his kindergarten year was that he had a special education teacher who had never dealt with a child with autism before. And didn't even know how to read the IEP. Didn't know what some of the terminology meant, so instead of figuring it out, learning about what it was, it scared her. And so, um, you know, the second week into school she still had not gone into even observe him in his kindergarten classroom. And she was required to spend a half hour a day working directly with him.

Michelle: Oh wow.

Wendy: So we had, we had a lawsuit possibility. I mean, other people said, 'Holy cow! You could have really had a good lawsuit there.' We knew right from the beginning we would never go that route. It was a lose-lose situation for everyone. We told these people over and

over that, “We want to work with you. We want to stay here.” We loved the house that we lived in, and it just didn't work out.

Michelle: Did she ever kind of come in and start to get to know your son at all?

Wendy: Well it was hard to tell because when I would go to pick him up at the end of the day, I would ask the kindergarten teacher, “Did the special ed teacher come in today to work with Benjamin? And, when, if she looked down to the floor I knew that the answer was “no.” And she couldn't tell me “no” because she was untenured, I think, and didn't want to blow in this... 30-year veteran special ed teacher who had a lot of power in the building. So she was not willing to advocate for Benjamin with his parent, when she *knew* that he was not getting the services that he needed that were on his IEP. And it blew my mind that she made that professional decision.

Michelle: The regular teacher?

Wendy: Yeah, and she was a great teacher. She was young, didn't have a lot of experience, but she was afraid to say he's not getting all the services that he's supposed to be getting that will really help him, because of what it would do to her reputation in the building.

Michelle: Right.

Wendy: And so when people are willing to compromise their professional values like that, we don't belong there, and that's where we decided to sell our house and move. (Interview, January 25, 2011)

Wendy's convictions regarding this issue were clear. Keeping her son in a school with professionals whom she felt made unethical decisions was not an option, so she pulled her son from that environment.

Like Wendy, Linda also felt it was necessary to remove her daughter, Rhiannon, from school when the school would not provide Rhiannon with what Linda perceived to be an appropriate learning environment. Linda described to me what led her to make the decision to pull Rhiannon out of school in the following interview excerpt:

Linda: She started out in this inclusion class in third grade with a different team of teachers, third graders.

Michelle: Right.

Linda: And then, she moved to the second year with third graders and the same team of teachers.

Michelle: Okay.

Linda: And then, when it came to fifth grade, they wanted her to stay in this room.

Michelle: Okay.

Linda: And I felt it was inappropriate. Because you had incoming 9-year olds, and she's going to be eleven.

Michelle: Right.

Linda: and she's not a small child, where physically you could get away with it.

Michelle: Right.

Linda: We'd had some behavior issues at the end of her second year. I think it

had to do with repetition and expectations. I think we were setting her up to fail.

Michelle: Okay.

Linda: So, the team teachers told me that our options, at that point, were for her to continue in this inclusion class, for yet a third year, or go to the middle school, and do 5th grade in the middle school.

Michelle: Okay.

Linda: We were not prepared for her to go the middle school; because I hadn't really taken a look at it. I didn't know what the options were there, and I was not comfortable with setting her up to fail. So, we took her out of school, and I home schooled her. I home schooled her for the fall semester of 2009. (Interview, February 3, 2011)

For Linda, removing her child from school also had the added benefit of effecting change within her child's school. Linda went on to tell me about how she had had a meeting at Rhiannon's school during the time Rhiannon was being homeschooled and what happened as a result of her decision to remove her daughter from the school:

During that time, we had a meeting with the building principal and the director of special education to tell them why she wasn't in school...I told them the options that were given for her for 5<sup>th</sup> grade, which was to spend the third year in the inclusion class or go to the middle school, and they agreed that it was inappropriate. And they did something about it. They had a special education teacher working, kind of floating, in the 5th grade. They dedicated her to a particular room and hired a one-on-one aide. And Rhiannon went back to school



in January of 2010, in 5th grade, in a regular class...And had a wonderful year.

(Interview, February 3, 2011)

Steadfast Advocacy involved parents' use of numerous strategies and tactics to ascertain what they perceived to be the best educations for their children within their school settings. Using such tactics often proved fruitful for these parents, as they varied their approaches for the appropriateness of each situation.

**Feelings of powerlessness.** Unfortunately, using Steadfast Advocacy did not always cause things to work out for their children's education in the way the parents deemed best, and the emotional effects of pushing against a system that was not always suited to their children's best interests left some parents using this communication style feeling angry, dejected, and sometimes helpless. Iris described her view of the current educational system and the pain it has the propensity to cause as follows:

Our academic system, while it's getting there, it's still young...it was never intended to accommodate... [It's] an educational setting that was never designed to begin with [for special needs] and there are new forces within that system... Some of them are still resistant to having children that behave differently, think differently, do things that perhaps their children don't do or they're not accustomed to...Or just downright biased...Indifferent, and uncaring. So you put those children in that type of environment without the exposure to training, or very little training, with those kinds of attitudes and mindsets, we add a new stressor to the child's perception of life in school. And when they don't respond as we think they should, and I don't... I know my daughter doesn't respond to

that type of stress and pressure, understanding her reaction to all of these things goes beyond the academic setting. (Interview, November 11, 2010)

Although parents utilizing Steadfast Advocacy worked hard to push against the types of discriminating practices Iris described, they also, at times, expressed feelings of powerlessness in pushing against practices that they deemed unsatisfactory or objectionable.

Theresa was one parent who experienced feelings of powerlessness after many attempts at advocating for her child. In the following excerpt, Theresa explained how difficult and emotional it can be for a parent to have to advocate so often and how despite her many attempts at advocacy, she sometimes felt that change would never come:

And you got to think that with these people, do they not think that parents of kids with special needs have enough on their plates without having to jump through hoops and fight a battle every time they need something? It's really frustrating...It is like talking to a brick wall. They don't get it. They will never get it. They just don't get, they just don't care...I can't even do it anymore. I can't even deal with them anymore because it's just, you're spinning your wheels. You're talking to a brick wall. They're not listening to your input. They're not going to change anything. (Interview, February 1, 2011)

Linda was another parent who experienced feelings of helplessness in pushing against her daughter's school. As Linda explained, her daughter, Leann's, special education teacher had recently implemented a behavior program for all of the students in the special education classroom. According to Linda, the program was inappropriate because it required her daughter to be monitored at all times: Every five minutes of every

day, her one-on-one aide would tell her whether she had had a good or a bad five-minute segment, and then would have Leann record this assessment on a behavior chart. Linda felt that this behavior plan was inappropriate because it subjected her child to unfair scrutiny, much more than any child without disabilities in the school, and that it detracted from her learning time. However, she did not feel that she had much recourse against it. She explained:

Linda: I said to my husband with these behavior plans...I don't want to be in the principal's office every week here.

Michelle: You mean to discuss...?

Linda: To talk about this, and to talk about my feelings, because quite frankly my feelings don't matter.

Michelle: What do you mean?

Linda: My feelings about this cannot matter.

Michelle: to...?

Linda: Anybody. Okay, somebody's come up with this for a purpose. How I feel about it doesn't matter. They have a purpose for doing this. And if I feel it's unfair or busy work or unnecessary scrutiny. What's this going to accomplish?

Michelle: I just want to make sure I understand you when you say what you think doesn't matter. Do you think that, if you think that you said something to them that, because they have this purpose, they prefer to keep going with it despite what you think?

Linda: I think they would continue with it and just not send it home.

(Interview, March 10, 2011)

Linda was upset by the behavior plan that had been put into place for her daughter. She felt it was unreasonable, that it took away from valuable learning time, and that her daughter was being treated in an unjust manner. However, she didn't think that advocating against this practice would do any good, so she remained quiet about this particular issue. Evidently, even parents who employ Steadfast Advocacy can feel helpless and silenced, and will sometimes comply with tactics they believe are inappropriate in a system that, as Iris described, "was not designed to grow" (Interview, February 10, 2011).

### **Parental Advocacy and Knowledge of Literacy Education**

As described, some participants in this study raised concerns when they felt their children were not being given appropriate access to literacy instruction. However, some of what the parents celebrated (and therefore did not advocate against) in the name of literacy instruction, seemed to me, as a literacy specialist, to be incongruous with what I might consider to be best practices in this area (See, for example, National Research Council, 1998; National Institute of Child Health and Human Development, 2000; National Early Literacy Panel, 2008). That is, there were times when parents did not seem to have the background necessary to decipher marginalizing literacy instruction practices from those that were more appropriately structured and educationally sound.

For example, although Karen's son, David, generally received literacy instruction outside of the classroom, there was a year that David was in the general education classroom when the classroom teacher read aloud to the class. Karen explained:

[The teacher was] reading a chapter book, and he would ... sit at his desk and draw a picture while they were reading... The story was above his head. A chapter book is way more than he can understand, so by letting him sit and draw he was still hearing the story, yet he was still being occupied to keep him still, otherwise he wouldn't have been interested (Interview, October 27, 2008)

For Karen, having her son sitting away from the rest of the group of children during reading time did not give her concern, because she felt that he would not have been able to understand the story. Also, she knew that David had trouble sitting still, so she felt that his drawing instead and hearing the story in the background was a good way to keep him occupied. Unfortunately, in such a situation, at least how Karen described it, David was not really engaged in any literacy activity at all. Karen was pretty sure that David could not understand the story being read even if he could hear it. If that were the case, what would be the point of his listening to it? If he could understand it, which might even be more likely, since children can often understand stories written at levels much higher than those they can read independently, David wasn't being encouraged to participate or interact with the text being read at all. He was physically removed from the group, and little (if any) effort was being expended toward his educational benefit.

Karen, however, being one who tended to ascribe to the school's view of her son's abilities, at least when it came to literacy goals, was not one to question decisions that the school had made. Being a Present Listener, it was not surprising that she accepted this activity as making sense for his literacy needs. However, other parents who were more opinionated and outspoken (i.e., Steadfast Advocates) also accepted literacy practices that appeared to me to marginalize their children.

Such an example arose when Susan described her daughter, Katie's, introduction to reading, with which Susan was pleased. Before Katie went to the school where she was segregated and taught lower level skills, she had attended an inclusive elementary school. At the inclusive school, Katie had been being taught to read through the use of sight words, aligning with the typical functional skills approach that I described in chapter 2. When I asked about the reason for the focus on sight words, Susan explained, "They started out with the way the word looked, because somebody like Katie couldn't, out of the gate, I guess, understand sounding things out" (Interview, September 23, 2008).

Here, based on Susan's description, Katie's literacy instruction was developed from a preconceived notion concerning Katie's *presumed* struggles, that is what "somebody like Katie," might struggle with, but not necessarily Katie herself. Although Susan had noticed many other instances where her daughter's literacy instruction appeared inappropriate and reported advocating against them, she did not mention this case as one of them. She did not seem to realize the significance of what she had reported.

Theresa was another parent who acted as a Steadfast Advocate who described a literacy learning situation with which she, herself, did not take issue, but which, again, to me, did not appear to be in line with literacy education best practices. In our first interview, I had asked Theresa to tell me about the IEP goals her daughter, Millie, had which corresponded to literacy. She began to tell me about handwriting and speech, and then explained to me why there were no goals specifically related to reading on the IEP:

Theresa: They're not doing right now like "/c/ /at/, /cat/."

Michelle: They're not.

Theresa: No because they've got to get her to say the /c/ first, and the /a/, so they go /c/-/a/, or the /g/-/u/...

Michelle: but they don't say it for her, and think that, receptively, she's getting it?

Theresa: Yeah, they don't. She's got to... They have to concentrate on her ability to make those sounds first before the reading. That's the way they're making it sound me anyways. (Interview, November 23, 2011)

Theresa's daughter, as explained earlier, had speech apraxia. That is, she could not physically speak any words. In this case, Theresa explained that the school was attempting to get her to speak before teaching her to connect sound/symbol correspondences. Of course, speaking ability is not a prerequisite to learning to read, and so, such a reason for delaying reading instruction is not a valid one.

In each of these cases, Karen, Susan, and Theresa accepted literacy practices which may actually have marginalized their children in the context of literacy learning. Of course, parents who do not have a background in literacy education would not be expected to have the knowledge to recognize every such instance. However, it is important to point out that no matter the type of communication a parent may most often utilize, Present Listening, Emergent Advocacy, or Steadfast Advocacy, a parent may not always be in the position to push against marginalizing practices, because he or she may not be aware that particular practices are pedagogically unsound.

### **Conclusion**

Taking part in decision-making regarding the education of a child is usually a new experience for parents, and therefore a learning experience for each of the categories of parents described. Parents of children without labels of disability, for instance, are not usually partners in discussing most of the educational plans for their children, as this is generally left up to the school professionals. However, when a parent has a child with an intellectual disability, he or she is often thrust into a world of academic and therapeutic decision making for which the parent may not be prepared.

When interacting with school personnel, the participants in this study employed various styles of communication, held different viewpoints, and experienced a number of emotions as a result of their years in the decision-making process. In this chapter, I categorized the parents' communication styles in order to discuss the similarities and differences among them. These overlapping categories of communication included Present Listening, Emergent Advocacy, and Steadfast Advocacy.

Present Listening was used by those participants who listened to and accepted the recommendations of school personnel regarding their children's literacy educational programs. Parents who engaged in Present Listening reported having trust in their children's teachers and believing that the teachers had their children's best interests at heart. In addition, one parent reported that she used this communication style because she was shy and uncomfortable with conflict, so she did not feel comfortable expressing her opinions or speaking against what the school professionals suggested. Two out of the three parents who engaged primarily in Present Listening found CSE meetings to be overwhelming, with much information being provided but with little time to process it. In addition, parents who relied on Present Listening tended to take a passive role when



plans for literacy goals were discussed, so they were sometimes less aware of the specifics of the literacy goals for which they consented than some of the other participants.

When parents engaged in Emergent Advocacy, it was because they had begun to question the interactions they had with school personnel and subsequently attempted to advocate for what they believed their children needed. Parents who utilized Emergent Advocacy often reported that they had begun their interactions with the school by listening to the opinions of the school personnel and consenting to their suggestions for their children's educational plans; however, as time progressed, these parents had come to doubt that the school personnel were always making the best decisions for their children. These parents reported trying to advocate on their children's behalf. However, they did not appear to have the experience or resources to continue pushing if school professionals resisted their advocacy attempts.

Those participants who utilized Steadfast Advocacy positioned themselves obviously as advocates for their children. They reported the belief that school professionals did not have all of the information necessary to make all of the educational decisions for their children. They believed that, as parents, they had much to add to the decision-making process. Like those employing Emergent Advocacy, parents utilizing Steadfast Advocacy thought critically about what school professionals reported and suggested regarding their children. They also used a number of communicative tactics and resources to acquire for their children what they felt was best. These parents generally began by trying to be amicable with school personnel, but they often reported feeling the need to become stern and even aggressive at times to make their opinions

heard and have their requests granted. Despite taking this stance, sometimes parents could not persuade school professionals to see things from their perspectives. In these cases, some parents using this communication style reported removing their children from a school where they did not feel their children were being given appropriate access to education. Other such parents reported feeling helpless and powerless when their children's schools were not receptive to their attempts at advocacy and continued practices that the parents found unacceptable.

Finally, regardless of the communication style particular parents most often used, parents in all three groups sometimes seemed not to recognize certain times when their children's literacy learning was marginalized. Even the most steadfast of advocates could not always decipher between practices that would make pedagogical sense to literacy experts and those that were based on preconceived notions of what their children with intellectual disabilities might be able to achieve. This, however, seems understandable since most parents lacked the background in literacy education to do this. The idea that parents would be able to analyze the appropriateness of their children's literacy instructional experiences may not be possible in every circumstance.

## CHAPTER SIX: DISCUSSION AND IMPLICATIONS

This study explored parents' perspectives regarding the literacy instruction afforded to their children labeled as having an intellectual disability. My research questions investigated 1) Parents' perspectives on the literacy instruction afforded to their children with intellectual disabilities and 2) the perspectives of such parents toward the opportunities available to them to participate in decision-making about this literacy instruction. In the following chapter, I will summarize the findings of this study and discuss the significance of these findings in relation to the available relevant scholarly literature as well as in light of the social structures that have historically marginalized individuals with intellectual disabilities. In addition, I will assess the limitations of this study and discuss the implications of the findings for parents, school practitioners, and teacher-education programs.

### **Summary of Findings Chapters**

In Chapter Four: "We're Gonna Go to the Moon!": Parents' Perspectives on Literacy Instruction, I reported on the participants' observations and insights regarding the literacy instruction their children with intellectual disabilities were afforded in school. For parents, teachers' attitudes and willingness to accept and work with their children, despite any cognitive and/or bodily differences the children had, were of the utmost importance. Parents felt that when teachers were accepting and understanding of their children and showed that they presumed competence (Biklen & Burke, 2006) in their children's abilities to attain literacy skills, the teachers put forth better efforts to engage the children in literacy learning. Conversely, parents believed that when teachers did not appear to accept and understand their children or believe that the children could succeed,

the initiative that the teachers put forth in engaging the children in literacy learning suffered.

Accordingly, parents' perceptions of teacher attitude permeated their discussions of the access to literacy instruction with which the children were provided, including the type of instruction that was given, the kinds of materials and activities with which the instruction was supported, and the engagement levels of the instruction overall. In the parents' view, teachers' positive attitudes seemed to beget instruction similar to that which is generally provided to children without disability labels, including access to many texts, participation in generative literacy instruction, and involvement in engaging activities. On the other hand, parents felt that less positive and less optimistic attitudes appeared to lead teachers to move away from literacy instruction and academic learning in general and focus more on bodily difference and behavior.

Lastly, the participants also described the settings within which their children received literacy instruction. Most often, according to the parents, the more engaging instruction they described occurred in inclusive environments, while basic, routine, and less engaging instruction took place in segregated settings. This was not always the case, however, as some participants reported that their children were not served well in some inclusive environments. In addition, one parent believed inclusion for her child would not be beneficial now that he had entered high school.

In Chapter Five: "Why Didn't I Question That?": Compliance and Advocacy, I reported on the different styles the participants employed when interacting with school personnel and taking part in decision-making regarding their children's literacy education. When interacting with school personnel, the participants in this study reported

that they enacted various styles of communication, held different viewpoints, and experienced a number of emotions as a result of their years in the decision-making process. Parents' reports suggested that they tended to make use of one of three communication styles: Present Listening, Emergent Advocacy, and Steadfast Advocacy.

When participants took part in Present Listening, they most often heeded the perspectives of the school personnel regarding their children's needs and abilities and frequently accepted the educational programs that the professionals recommended. Judging from their reports, three participants appeared to do this. These participants reported maintaining trust in their children's teachers and feeling assured that the teachers had their children's best interests in mind. In addition, one parent reported being introverted and uncomfortable with conflict, so she did not feel comfortable voicing her opinions or speaking against what the school professionals recommended. Two parents in this category found CSE meetings to be overwhelming, with considerable amounts of information being provided, but insufficient time being allowed to process it. When engaging in Present Listening, parents reported taking a passive role when plans for literacy goals were discussed, so they were not as in tune with this part as were other participants in this study who engaged in other styles of communication.

A number of participants engaged in what I categorized as Emergent Advocacy. These participants had begun to question certain interactions they had with school personnel and made subsequent attempts to advocate for alternative approaches to be used with their children. These parents reported beginning their interactions with their children's schools by listening to the views of the school personnel and consenting to their suggestions for their children's educational plans; however, as time passed, these

parents confessed to doubts that the school personnel were always making the best decisions for their children. These parents then reported trying to advocate on their children's behalf. However, they did not appear to have the experience or resources to continue pushing when the school professionals resisted their advocacy attempts.

The remainder of the participants took part in what I termed Steadfast Advocacy. These participants deliberately situated themselves as advocates for their children. They suggested that school professionals did not possess all of the information necessary to make all of the educational decisions for their children. They explained that, as parents, they had much to add to the decision-making process. Like those parents who engaged in Emergent Advocacy, these parents sometimes questioned what school professionals reported and suggested regarding their children and their literacy learning.

Participants who engaged in Steadfast Advocacy also used a number of communicative tactics and resources to acquire for their children what they felt was appropriate. Parents employing this style of communication generally began by trying to be amicable with school personnel, but often reported feeling the need to become firm and even aggressive at times to make their opinions heard and have their requests granted. However, despite Steadfast Advocacy, sometimes parents could not convince school professionals to agree with their standpoints. Some of these parents reported removing their children from a school where they did not feel they were being given suitable access to education. Other such parents reported feeling powerless when their children's schools were not amenable to their many attempts at advocacy and continued practices that the parents found unacceptable. In such cases, these parents sometimes conceded to practices with which they were unhappy.

Further, no matter what their communication style was, parents seemed to reach points where their abilities to assess the appropriateness of particular literacy practices became hindered by the fact that they were not formally educated in the area of literacy instruction. Even when parents wanted to be advocates for their children's literacy learning, there were times when some of the parents did not seem to notice that their children's schools were not providing suitable literacy instruction to their children. Their ability to advocate was, of course, hindered when this happened.

## **Discussion**

### **Literacy Instruction, Opportunity, and Presuming Competence**

The perspectives provided by the parents in this study indicated that they perceived both extremely positive but also decidedly negative aspects to the literacy instruction their children were provided in schools. In the parents' views, some of the children were provided with enriching, engaging, and appropriately challenging literacy learning experiences, while others may well have been denied suitable literacy instruction and marginalized because of their disability labels.

According to the participants' descriptions, perceived teacher attitude toward and investment in teaching literacy to children with intellectual disabilities appeared to be significant factors in the type and amount of literacy instruction that their children with intellectual disabilities tended to be provided. This finding is in agreement with what Hess, Molina, and Kozleski (2006) found in their study regarding parent advocacy and decision-making in the special education of their children. While these authors' findings concerned special education in general and the findings of the current study concerned literacy education specifically, the sentiment was similar: Parents felt teachers' attitudes

were of the utmost importance. When this study's participants described teachers who appeared to believe that their children could benefit from literacy instruction, they coupled their descriptions with stories of how the teachers appeared to invest themselves in the children's success, providing many opportunities for learning to read, write, and interact with texts. According to the parents, when teachers seemed to have positive beliefs and maintained investment in their children's learning, the teachers took extra steps to ensure their children's success.

Conversely, some parents reported that when teachers did not presume competence (Biklen & Burke, 2006) in the ability of children with intellectual disabilities to attain literacy skills, they seemed less invested in their children's learning and subsequently provided more limited opportunities for literacy learning to such children. In the parents' views, children with disabilities were not always given the same enriching opportunities to learn and interact with reading and writing materials as children who did not have disabilities. In fact, sometimes they were even temporarily removed from classrooms and given no access to literacy instruction at all.

In addition to what occurred in the classroom, parents also reported that teacher investment, or lack thereof, was sometimes reflected in the IEP goals that teachers developed for such children. For example, some parents felt that teachers who appeared to lack investment and/or who seemed to hold negative preconceived notions regarding the children's learning did not see much need to set goals that might push the child further. Such concerns have beset other parents of children with intellectual disabilities. For example, in a study by Davern (1999), parents of children with disabilities expressed the hope that their children would be pushed to their potential but sometimes felt that



their children's teachers possessed lowered expectations based on their children's disability labels. Davern found that when school personnel did not attempt to teach children with disabilities through modifications and adaptations to the curriculum, the parents felt that the teachers conveyed their lack of confidence in the children's abilities to learn.

The finding also agrees with what Titone (2005) found in a focus group study comprised of teachers, parents, and administrators regarding teachers' attitudes toward teaching children with disabilities. Titone summarized their views as follows:

The ways teachers think about students with diverse needs is as important as the lessons and activities they use to teach them in the classroom. Above all else, teachers need to begin with the belief that they are capable of teaching all children in order to be able to do so effectively... If teachers do not believe in the need to differentiate instruction in order to meet individual students' needs and that it is possible to achieve this goal, they will not be motivated to attempt it. Without the rationale and without having bought into the need for adaptations, it will be easier for teachers to disengage before the goal is reached. (pp. 16-17)

Overall, parents in this study seemed to believe that teachers' attitudes toward and investment in teaching literacy to their children with intellectual disabilities was critical, and could make the difference between whether or not a child would be afforded with opportunities for literacy learning.

Of course, parents' perceptions of teachers' attitudes do not grasp all there is to know regarding the teachers' beliefs. What a parent perceives to be a professional's negative attitude toward a child with disabilities might well be a reflection of that

teacher's lack of knowledge, his or her stress from juggling too many demands, the teacher's concerns over building politics and funding sources, and any number of other pressures. I do not wish to convey the opinion that the teachers described in these studies had positive or negative attitudes toward the children with disabilities. It is impossible for me to make any conclusion about the teachers' actual attitudes without talking to them and observing them myself. I only know that, in the parents' views, what the parents perceived as the teachers' attitudes seemed to have an effect on the literacy instruction provided to the children.

### **Segregation and Inclusion**

**Inclusive settings.** Most of the parents interviewed for this study were proponents of either fully or partially inclusive literacy education for their children. Parent preferences for educational placement were not etiologically-specific, contrary to what Kasari, Freeman, Bauminger, and Alkin (1999) found in their study of parent perspectives on inclusion. Kasari and her colleagues found that parents of children with autism preferred mainstreaming their children for only part of the day while parents of children with Down syndrome preferred full inclusion in the general education setting. In this study, however, most of the parents of children with autism preferred full inclusion for their children and agreed to "pull-out" instruction only in very specific instances, while the parents of children with Down syndrome had varying views of what they preferred along this continuum.

When, in the parents' views, schools appeared to favor an inclusive model of literacy, the parents' expectations often were met more fully. According to many of the parents' descriptions, inclusive environments tended to have qualities that welcomed

students into the literate community as opposed to those that relegated students to the literate margins of the school. Even in inclusive classrooms of older children, where it is likely that students had widespread levels of literacy strengths and needs, some parents reported that the teachers were able to find ways to involve their children meaningfully in the literacy learning activities taking place. In most of these cases, parents reported that their children made strides. This finding is supported by Kliever's (1998) study which indicated that children with Down syndrome could flourish in an inclusive setting when the children's teachers actively involved them as "full participants in the regular routines and general lessons of classrooms made up of children with and without disabilities" (p. 117).

The idea that children with intellectual disabilities can thrive in inclusive environments when they are full participants in the classroom seems to be crucial. A child's presence alone in a general education setting is not enough for that child to be successful in literacy learning. My study adds to this conclusion because although a number of participants described their children's inclusive settings as having a wide range of literacy education opportunities for their children, a few did not. There were a few participants (some of whom were proponents of inclusive education and one who was not) who felt that their children needs were not met in their inclusive classroom communities. Some of these parents reported that their children were left off to the side when literacy activities were going on or were removed from the classroom all together. They also reported that when the children were in the classroom, their teachers did not engage with them.

In such cases, children with intellectual disabilities were not being welcomed as full participants in the inclusive classroom community and were likely not getting appropriate access to literacy instruction, as their needs were not being assessed and subsequently met in these settings. Unfortunately, such marginalization in general education settings is not uncommon (e.g., Erwin & Soodak, 1995; Kliewer, 1998,) and can have devastating effects on the literacy development of such marginalized children. According to Kliewer (1998), “Restructuring classrooms to support all students’ participation appears fundamental to realizing individual children’s literacy capacities. Physical presence, however, is not enough” (p. 117).

**Segregated settings.** Parents in this study more often described segregated placements as maintaining lower expectations and offering decreased access to literacy instruction and materials than did inclusive settings, provided the inclusive settings did not marginalize the children. In analyzing the parents’ descriptions, it appeared as though segregated settings offered students fewer opportunities to read, write, listen, and speak with others. Although not a focus of this study, it is important to note that segregating students with such disabilities may well put them at a disadvantage for internalizing written and spoken language conventions because they do not get the regular practice and immersion needed for such development (Copeland & Keefe, 2007). Similarly, such children are denied the chance to show what they can contribute to the literacy and language learning in regular education settings.

Another point to consider, however, is that good literacy instruction is not impossible in segregated settings. On the contrary, there are a number of excellent literacy interventions for students with a variety of needs that have taken place in settings

other than the regular classroom (See Woodward & Talbert-Johnson, 2009, for a discussion). While some may advocate inclusion at all times, it is important to emphasize that an intervention taking place for a limited part of the day, in a quiet setting that allows for a small teacher-to-student ratio is quite different from a requirement that children labeled with certain disabilities be schooled in a program that is entirely segregated from their peers.

In addition, the school communities that favored segregated approaches overall, according to many of the parents in this study, may have marginalized students with intellectual disabilities more so than schools that favored inclusive approaches. Reports from participants indicated that when children were segregated for literacy instruction, these children's educations no longer seemed to be approached individually, addressing each child's personal strengths and needs. Instead, parents reported instruction with such characteristics for which only lower achievement was possible (e.g., lack of access to higher-level texts or little instruction beyond life skills). One reason for this may be school professionals' preconceived notions concerning students labeled as having an intellectual disability (Kliewer & Biklen, 2001). If a school maintains a policy of segregating students labeled as having certain disabilities, the school is not considering each of the students on an individual basis. It is also important to note, however, that the wide-ranging needs of students in such settings, especially as students get older, can make more generative literacy instruction difficult to manage.

According to Kliewer, Biklen, and Kasa-Hendrickson (2006), "Misguided preconceived notions create dangerous slippery slopes where students may be subjected to *legal* segregation and its consequential separation... from valued access to the

citizenship tools of literacy” (p. 164). That is to say, when teachers and schools hold beliefs that students with labels of intellectual disability cannot learn to read or write in a way that is valued, that they will not be able to benefit from the valued tools of literacy, or that addressing their needs will limit opportunities for other students, these teachers and schools might unintentionally deny students the very instruction and resources that they need. Then, when the marginalized students’ academic achievement is subsequently shown to be subpar, low achievement is in turn used as proof positive that the original preconceived notion of the deficit was valid.

Placement of children with intellectual disabilities in inclusive or segregated settings, therefore, appears to have a significant effect on the type and quality of literacy instruction with which the children might be provided. In the current study, inclusive literacy education most often appeared to have provided the children with the superior literacy instruction, but marginalization of such students can and, according to the parents, did still occur in inclusive settings when the children’s needs were not addressed.

### **Communication Styles**

All of the participants in this study reported communicating with their children’s schools and taking part, at least to some extent, in decision-making regarding their children’s literacy learning. However, as described in chapter 5, as well as at the beginning of this chapter, the ways in which they did so varied. Despite these variances, similarities in the communication styles between certain participants emerged, which allowed me to categorize their styles based on their most prominent ways of interacting with school professionals.

As Runswick-Cole (2008) asserts, however, categorizing communication styles can imply that participants always fit decidedly in one category and that their styles do not change. Therefore, it is important to point out that, although similarities existed between the participants' reported styles which allowed me to draw comparisons, the styles had further complexities that I would like to address.

**Styles in flux.** First, it is important to point out that although I categorized the parents as engaging in certain kinds of communication styles, (i.e., Present Listening, Emergent Advocacy, and Steadfast Advocacy), parents were not inextricably tied to these specific categories. That is, while participants in this study appeared to be most comfortable adhering to one of the styles of communication described, this was not always the case. For example, there were a few participants who reported changing their communication styles as situations prompted them to step out of their comfort zones or approach situations in different ways to attain for their children what they believed they needed and deserved in regard to their literacy instruction. In this study, this happened most often for Emergent Advocates. These parents often reported that they had originally been more open to listening to the school professionals' perspectives, seeing them as the experts (i.e., Present Listening)—until they began to question the appropriateness of the educational programming that the school professionals had been suggesting.

Therefore, it appears as though looking out for the needs of one's child can be an impetus for a parent to change styles and, perhaps, advocate (Hess, Molina, & Kozleski, 2006) even when he/she would have been more comfortable due to personality (e.g., shyness, discomfort with conflict, etc. ) or expertise level (e.g., no background in education) remaining compliant. Furthermore, such shifts show that parents'

communication styles need not be static or unwavering, but exist in flux, changing as parents learn to navigate a complex system that is not always well suited to their children's best interests.

Second, with respect to the communication style categories themselves, some communication characteristics which generally belonged to one category sometimes appeared in others. That is, there were times when certain communication strategies, tactics, or characteristics used by a particular parent might have, at first glance, appeared to belong to a different communication style from where I had it classified. For example, this sometimes happened when a person who most often took part in Steadfast Advocacy described times when they gave in and conceded with educational recommendations with which they were not entirely pleased. While such an action may seem to be associated more with the Present Listening style, and in opposition to the Steadfast Advocacy style, in many cases, it was not, as the parents described these concessions as being strategic in nature. That is, the parents who conceded in these cases often did so with the goal of showing the school professionals their willingness to give or to trust in an effort to pave the way for further advocacy. Thus, parents choosing to comply in such cases were not, necessarily, for those moments, employing a different communication style (i.e., Present Listening). On the contrary, in such cases, compliance, although generally a characteristic of Present Listening, became a part of Steadfast Advocacy as parents chose to comply, but with further advocacy in mind. These parents also complied sometimes when their attempts at advocacy failed. However, again, when they complied in these cases, they were mindful of the compliance, the effects it might have, and how they would proceed in the future.



Therefore, the categories by which I classified the parent's communication styles need not be fixed. They existed in flux, as there were complexities involved in how parents chose to navigate different discussions at different times with different school professionals. Also, some communication styles which may be ascribed to one group of parents may appear to be enacted by another, but with other motives in mind.

**Communication styles and children's literacy opportunities.** While complexities exist, and parents' styles cannot be fully understood through typology, the fact remains that similarities existed among how certain parents who took part in this study communicated with their children's schools. This finding is in line with what Trainor (2010) found in her study of parents' approaches to advocacy as well. In addition it appears likely that other parents who have children with intellectual disabilities might also communicate in similar ways to the ways that the parents did in this study. This is significant as it appears as though usage of some communication styles, at times, has an effect on the type of literacy instruction that might be provided to a child with intellectual disabilities in his or her school, particularly when parents are positioned as listeners or are otherwise silenced by their children's schools.

According to Childre and Chambers (2005), many IEP meetings are conducted in a way that position parents as listeners and not as active participants. Many participants in the present study, despite communication style, felt the effects of such positioning by the school professionals leading their IEP meetings as well. These included Emilie, who took part in Present Listening, and stated that she felt, "mostly like a listener," Nina, who utilized Emergent Advocacy and felt that her child's teachers and therapists "just pooh-poohed" her concerns, and Valerie who used Steadfast Advocacy and sometimes felt like

she was “talking to a brick wall.” The difference here is that Present Listeners most often felt comfortable in the role of listener (or at least did not feel comfortable trying to step out of this role), while Emergent and Steadfast Advocates felt dismissed when school professionals attempted to position them as listeners and not active participants.

There are a few issues of concern here. First, we have the parents who, through comfort level or personality (i.e. shyness), complied when they were positioned as listeners. These parents were, of course, those parents who felt most comfortable engaging in Present Listening. While these parents felt more comfortable in this role, there was really no one outside of the school professionals to look critically at the literacy education options offered to their children. Parents often felt that the literacy options being provided were appropriate, but they also looked to the school professionals as experts because they knew little about the ins and outs of literacy instruction.

On the one hand, it is possible that the literacy instruction being offered to the children in the cases of those taking part in Present Listening was appropriate (e.g., engaging, tailored to the child’s level, addressed from a position of presumed competence, etc.). However, based on the stories told by some of the other participants in this study as well as the information provided in other studies discussed previously, students with intellectual disabilities may not always be being afforded appropriate literacy instruction. What happens for the children in these cases? If no one is available who can look critically at the literacy instruction being offered, these children might continue in a system that marginalizes their literacy learning.

This problem may be somewhat better addressed by those parents who engaged in Emergent or Steadfast Advocacy as these parents reported thinking critically about the

type of literacy instruction being afforded and attempting to advocate when they felt that the instructional opportunities were subpar. However, despite these efforts at advocacy, many parents did not have the training necessary to fully investigate the literacy learning opportunities that were provided to their children. Therefore, they were not always aware of times in which inappropriate literacy instruction was being provided (at least per their descriptions) and what to ask for instead.

For example, many parents in this study advocated for inclusion in their search for improved literacy instruction, as they felt that better literacy opportunities were available in these settings. However, parents who push solely for inclusion in hopes of improved literacy instruction might be disappointed in what might transpire in the inclusive classroom if specifics regarding the child's literacy education are not also discussed.

As another example, there were times when parents believed the information given to them by school professionals which, in the light of my training as a literacy specialist, seemed to me to be inappropriate (e.g., when Theresa was told that her child must be able to articulate sounds before receiving instruction in sound/symbol correspondence). Parents are not always equipped with the educational knowledge that would be needed to advocate for the literacy needs of their children as parents will certainly have varying levels of knowledge regarding the fields of education and literacy development.

Certainly, I am not suggesting that parents should not advocate. On the contrary, parent advocacy seems to be one of the few grass-root ways in which schools are being helped to effect change when it is needed. However, the findings of my research do beg

the question of whether or not parents should be the only ones available to take on this responsibility. Schools may want to do more to provide support for parents who are trying to navigate the morass of educational decision-making, ranging from providing an ombudsman to help them understand instructional options, interests, and laws that affect decision making, to earlier involvement for parents as sources of quality data regarding their children's literacy initiations, to access to community resources who can help parents to understand literacy acquisition and instruction from a more neutral stance.

Another issue is that the interactions that parents who advocate have with the schools are not without problems. Although some parents reported having amicable relationships with their children's teachers and therapists, where problems could be easily solved, more often than not, parents reported having to struggle to push against the system. When these parents attempted advocacy, they described encountering strong pushes back from the schools against their attempts. They described feeling dismissed, being told they were wrong, or meeting with absolute refusal at their suggestions and requests. According to Childre and Chambers (2005), "Not considering or requesting family suggestions is... [a] way that schools fail to support families, [and when] professionals convey a preset agenda...this serves to hinder family participation" (p. 224).

According to Ferguson, Ferguson, and Taylor (1992), family members of individuals with disabilities have also "historically belonged to those groups of devalued people without much voice in what was done to and for them by more powerful groups within society" (p. 7). A number of my participants felt the effect of such a devalued status when they tried to take part in the decision-making for their children's literacy

instruction. Although, by law, these parents were meant to be partners in the decision-making process, many felt that they were not. A number of parents, for example, felt that they were positioned as listeners, being told information, but not being given the chance to add to it. Some wanted to advocate for their children but felt dismissed by school personnel. Others felt that their children's schools were not being honest with them about what was happening in the name of literacy education for their children. Still others felt that no matter how hard they tried to advocate, certain school members would never care to make change for their children. In such cases, parents felt "othered" (Hess, Molina and Kozleski, 2006) by the school professionals and felt the need to either accept the schools' educational recommendations or "fight" the school system.

None of these situations, when they occurred, left the parents feeling positively. When parents felt dismissed and subsequently accepted instructional proposals with which they did not agree, they described feeling concerned about their children's learning, uncertain about what to do and unconvinced, at times, about whether anything really could be done. While I certainly do not fault the parents who chose to concede in these cases, it is important to point out that when they did, unfortunately, the status quo was maintained. Disability remained firmly situated in the individual child, and the school systems were not compelled to check themselves.

Parents who chose to fight the system also dealt with negative emotions. They worried about their relationships with school personnel and feared possible reprisal against their children. During arguments and disagreements, they reported that they felt anger, anxiety, disillusionment, and sometimes hopelessness. Positively speaking, in

such situations, the status quo was sometimes upset; however, parents still noted that they were fighting to grasp for power.

**Power in a flawed system.** It appears to me, therefore, that there is a significant flaw in the way the system currently operates. As stated, per the law, parents are meant to be integral parts of the team that makes the decisions regarding their children's IEPs. From the perspectives of a number of the participants in this study, the way the system is set up is not effective. Parents reported feeling as if they are not being heard or that their perspectives do not matter to the school professionals. Instead of enabling parents and school professionals to work with each other, share their perspectives, and come up with suitable literacy instruction for children with intellectual disabilities, somehow the system seems to have pitted parents and school professionals against one another.

I believe that the problem, at least in part, lies beyond any one person's perspective (parent or teacher) regarding what would work best for a particular child. An obstacle that I perceive to be quite problematic in the way the system currently operates is the unequal power in parent-teacher decision-making (Ruppar & Gaffney, 2011; Harry, Allen, & McLaughlin, 1995). On the one hand, we have the school professionals who are the purveyors of the services that children with intellectual disabilities need to be successful in school. School professionals are also the individuals who are responsible for the children's care, safety, and education throughout the school day when they are not with their parents. On the other hand we have the parents of a child whom they love deeply, often a child with a number of needs that make him or her more vulnerable to injury, illness, abuse, and/or marginalization (at least in our society, the way it presently operates.) If a parent disagrees with a school professional's opinion and feels it

necessary to push against the school professionals in a school system, he or she may be, as a number of parents were in this study, concerned about the possible negative outcomes that could result from upsetting the individuals who have a significant amount of authority concerning their children (Soodak & Erwin, 2000). Although the Individuals with Disabilities Education Improvement Act of 2004 protects the rights of parents to take part in IEP meetings, if a parent must fear reprisal on any level against his or her child when asking for what he or she feels is appropriate, he or she cannot effectively advocate. Of course, I am not suggesting that school professionals are going to lash out against a child of a parent who advocates, but if just an iota of doubt exists in the mind of a parent, he or she cannot proceed as a participant with equal power.

Secondly, despite what the law envisions and indicates in regard to parent participation in the decision-making process, when many parents go to IEP meetings they, as discussed, often feel cast as the listeners. As described by the parents in this study as well as others (e.g., Ruppert & Gaffney, 2011; Harry, Allen, & McLaughlin, 1995), school professionals tend to hold much of the power during such meetings. School professionals often run the meetings, and parents listen as teachers take turns reporting scores and offering suggestions. This is not to say that parents have no power or are without agency. Indeed, several of this study's participants were able to use advocacy to sway outcomes in their favor. However, even when parents advocate and ask the teachers and therapists to try something else, their suggestions can still be refused. Granted, parents who feel that their children are being treated inappropriately per the law can bring in advocates, refer to laws, and even go to a due process hearing to attempt to sway the outcome in their direction; however, in using their rights to mediation and due

process, relationships between the parents and the school are often completely destroyed, leaving the parents in an unfortunate situation for further advocacy (Lake & Billingsley, 2000).

I do not wish to suggest here that parents and school professionals should or should not have equal power in deciding the educational recommendations for literacy instruction. That is an argument that goes beyond the scope of this study, as this study seeks to represent the parents' views. However, I do wish to point out that there are power relations at work between parents and school professionals at IEP meetings and that parents do not have the luxury of being in the more powerful position. Power matters in these situations and this should not be ignored as laws, rules, and policies are determined.

**Change on the horizon.** It is important to reiterate that not all of the parents' stories were negative ones. Some of the parents' stories indicated pronounced efforts on the parts of school professionals to enhance the literacy learning opportunities of their children with intellectual disabilities. The dominant deficit view of children with intellectual disabilities regarding their literacy learning may be beginning to lose its hold in schools. According to some of the parents' stories, some teachers have really gravitated toward their children with intellectual disabilities, taken a keen interest in their learning, and have welcomed them whole-heartedly into their classrooms. Parents talked about how these teachers found ways to break down barriers and support both children with and without disabilities in learning effectively and feeling a significant part of their classroom literate communities. Such actions are likely to increase with new legislation



that requires all students to make adequate yearly progress regardless of learning needs and that connects teachers' and schools' evaluations to such progress (Engage NY, 2012).

### **Limitations and Implications**

#### **Limitations and Implications for Further Research**

In discussing the findings of this qualitative interview study, it is also important to discuss its limitations. An important limitation of this study involves what my own influence may have been on the data I have gathered, analyzed, and reported. I am a person with strong convictions regarding individuals with labels of intellectual disability, their treatment in society, and their access to education, particularly in the area of literacy. I have deliberately attempted to make my subjectivities on these issues transparent in this dissertation. However, as I explained in the method section, I tried to conceal this information from my participants by, among other things, keeping my responses during the interviews to nods, neutral conversational replies, and simple probes whenever possible. There were times, however, when too many neutral responses appeared to make my participants feel uncomfortable, as if they thought that I did not care about what they were saying or perhaps even disagreed with what they were saying. To help with this, I also repeated their words back to them at times and also tried to reflect in my responses what they appeared to be feeling. For example, I might say “wow,” if a participant seemed particularly emphatic about a point he or she made.

As much as I attempted to mask my own beliefs and perspectives from my participants, it is possible that I still had an effect on the types of responses my participants gave and the stories they told. While I do not question the truthfulness of my participants in any way and certainly believe the stories they told me were in fact their

perspectives, I do believe that simply by who I am, how I come across, and the kinds of questions I asked, I could have had some influence on which stories were or were not told to me. I also think, however, that by the fact that some participants made their positions clear even when they were in conflict with my position showed that I did not fully impede my participants from discussing their views.

My personal subjectivities may have caused limitations in my analysis of this study as well. For example, in analyzing the study for themes, I may have seen as important aspects of conversations that other researchers with different perspectives would have disregarded. I also may have overlooked aspects that other researchers would have highlighted. Overall, it is important to point out that in such a study, it is certainly possible that a person with a different perspective may have elicited different responses from this particular set of participants and come to different conclusions than I did based on the differences between our own lenses and subjectivities.

Beyond my own possible influence on the findings of this study, there are other limitations to this study that should be discussed as well. First, this was a small scale study due to its qualitative nature. I only spoke to 22 participants whose children were of varying ages. In speaking to these individuals in depth, I was able to gather quite a bit of information on these particular parents' views and perspectives. However, discussing the views of 22 parents does not allow for a broad understanding of parents' views of the literacy instruction afforded to their children in general, or, more specifically, of how school recommendations might have varied due to differences in the children's ages and needs. I recruited many of the participants through snowball sampling, which likely drew participants with some similar perspectives, as some participants were friends.

Furthermore, my participants represented similar demographics. Most of the participants were white and from middle to upper-middle class backgrounds. Although during the recruitment phase I made several attempts to open my study to parents with a wider range of backgrounds through the help of the DDSO and local agencies, these efforts were unsuccessful, as discussed in chapter 3. Therefore, the participants' positions should not be understood as generalizable to every parent of a child with an intellectual disability. For example, it has been asserted that parents who come from higher socio-economic backgrounds tend to benefit from possessing more "cultural capital" (Bourdieu, 1986), which provides such parents with more power when it comes to their children's schooling (e.g., Lareau, 1992). Parents who come from a lower socio-economic background may not have the luxury of struggling with advocacy. Therefore, although the experiences and views shared by the parents in this study do give insight into some of the issues with which other parents may deal and how some parents might feel in regard to these issues, it would be beneficial for future studies to include parent representatives of a wider demographic.

Another limitation to this study is that most of the participants who were interviewed were mothers. Only two fathers took part, and this only happened when the mothers were present and requested that their partners join them. Although during recruitment I advertised the study as being open to parents, not just mothers, it was always the mothers who responded to my call for participants. It is possible that this occurred because parental involvement in children's schooling is gendered (Reay, 1995; Lareau, 1992), with women more often taking the active or at least more visible role. Interviewing only two fathers did not give me enough data to decide if fathers' views or

communication styles differed much from those of the mothers'. As an example, one couple (Nancy and Robert) seemed to share their views and approaches, but although the other couple (Colleen and Thomas) shared views, the father may have been more outspoken than the mother. Furthermore, both of the fathers in this study made use of their backgrounds in business during CSE meetings. However, with only two fathers taking part, there was not enough data here to draw any substantial conclusions regarding these observations. It may be, therefore, that fathers have similar, different, or additional views and communication styles concerning their children's educations which were not grasped here and would contribute more to this literature. Therefore, it would be beneficial for further studies to gain the perspectives of more fathers as well. Future research might also consider more directly the gender (e.g., Biklen, 1993), race (e.g., Delpit, 2012), and class (e.g., Heath, 1983) issues woven through the threads of these results, from recruitment, to who speaks during meetings, to what power structures influence school decisions made on behalf of children with intellectual disabilities. In addition, this study looked at parents' perspectives only.

No teachers or other school professionals were interviewed. It is likely that teachers would have different opinions and explanations regarding the events described by the parents, and why they chose to provide services, make educational recommendations, and instruct in the way that they did. Teachers and other school professionals are as constructed by the system as are the parents. It may be beneficial for further studies, therefore, to consider teachers' perspectives and to investigate how teachers approach literacy learning for students with intellectual disabilities in various settings and age ranges.

Although this preliminary study does not offer clear guidance, more research could also explore alternative, more collaborative structures for parents and school professionals when considering the goals and needs of children with intellectual disabilities. It may also be beneficial for future research to reconsider what children can do based on what parents describe as competent literacy initiations, for example, exploring more about literacy instruction in regard to functional skills approaches versus those that are more well-rounded. In addition to the implications that this study has for future research, it also has implications for school professionals and for schools of teacher education. Following is a discussion of these implications.

Some readers may wonder if this study has implications for parents as well. Conventional wisdom may suggest, for instance, that parents with more resources, knowledge of their rights, and perhaps more outgoing personalities might be able to advocate more effectively and procure better literacy instruction for their children. Although I don't dispute this, evidence from this study did not suggest that advocacy always worked. Sometimes advocacy was effective, and sometimes access to certain resources was beneficial, but this was not always the case. Instead, it appears that until there is significant change within the system, there will be limits to what parent advocacy can accomplish no matter what resources parents have at their disposal to do this.

### **Implications for School Professionals**

From the perspectives of the parents who took part in this study, there is much change needed in the way that many, though not all, schools and school professionals address the literacy needs of children in their schools who have intellectual disabilities.

First, it is important that school professionals realize that students with labels of intellectual disability may be marginalized in schools when it comes to opportunities for literacy instruction. Common goals and instructional setting recommendations for students with labels of intellectual disability may be based on faulty assumptions concerning these students' aptitudes for literacy development. For example, the idea that children with intellectual disabilities cannot benefit from literacy instruction and, therefore, must be taught only functional sight words appears to be ubiquitous, as evidenced by the numerous studies that exist concerning this particular skill and student population (e.g., Burns, 2007; Collins, Branson, & Hall, 1995; Didden, de Graaff, Nelemans, Vooren, & Lancioni, 2006; Mechling & Gast, 2003; Mosley, Flynt, & Morton, 1997; Van der Bijl, Alant, & Lloyd, 2006). However, there is research that shows that children with intellectual disabilities can benefit from higher-level and/or more comprehensive forms of literacy instruction (e.g., Al Otaiba & Hosp, 2004; Allor, Mathes, Roberts, Jones, & Champlin, 2010; Cologon, Cupples, & Wyver, 2011). Unfortunately, the former view is more wide-spread and is often assumed to be best practice despite the evidence that calls this view into question.

It is important, therefore, for school professionals to understand that although individuals with a particular disability label may have some strengths and needs that are similar by virtue of the label that they share, these individuals are not identical persons with precisely the same abilities and needs. They will not respond identically to instruction (Al Otaiba & Hosp, 2004). Equating one's label of disability with the ability to gain certain knowledge and skills without actually giving that person an opportunity to learn and without making adjustments through assessment is unacceptable. When

devising goals and instructional setting recommendations, school professionals should consider all recommendations, including those recommended by parents, to be certain that students with labels of intellectual disability are being given appropriate access to literacy instruction and resources.

Next, it is important for students labeled as having an intellectual disability to be instructed in print-rich and language-rich environments (Copeland & Keefe, 2007). In addition, these students should be instructed in all major areas of literacy, including, but not limited to phonics, sight words, reading and listening comprehension, fluency, and written communication which is authentically connected and not reduced to isolated, decontextualized sub-skills (Katims, 2000). Whenever possible, children with labels of intellectual disability should take part in this instruction alongside their nondisabled peers so that all children have the opportunity to learn from each other and benefit from the individual talents, skills, and perspectives that each brings. As Copeland and Keefe state, “Access to language- and print-rich environments is negatively affected by the segregation of students with moderate to severe disabilities from their general education peers” (p. 104).

Granted, students labeled as having an intellectual disability may have impairments that make it more difficult for them to gain certain skills and to express what they understand (Copeland & Keefe, 2007). Further, some students may not become conventional readers and writers (Copeland & Keefe). However, this is not a reason to deny these children access to literacy instruction. Instead, teachers and therapists should envision these students as capable of learning literacy and provide rich and motivating literacy instruction and opportunities to meet this goal, making use of modifications and

augmentative and assistive communication technology when appropriate (Copeland & Keefe). Such instruction may require teachers to be creative in finding ways for struggling students to access the instruction in non-traditional ways.

Also, in designing literacy goals for the IEPs of children with intellectual disabilities, schools should consider inviting the school literacy specialist (and literacy coach if the school has one) to the children's CSE meetings. Traditionally, children with intellectual disabilities have not received services from the school literacy specialist, perhaps due to inaccurate, yet persistent, notions of what children with intellectual disabilities might or might not be able to achieve in regard to literacy. Despite this fact, the person in a school building with the most expertise in helping struggling readers is likely the school literacy specialist, and he or she would also be likely to have a number of ideas about how to help a child improve in the areas of literacy that seem to be causing him or her the most trouble. Similarly, literacy coaches could work with general and special educators in helping them to devise and implement literacy lesson plans that would best meet the individual needs of such children.

Further, students with intellectual disabilities should be given the right to participate in the interventions being provided by school literacy specialists. In the same way that students with reading disabilities need much the same literacy instruction and interventions as struggling readers without labels (National Research Council, 1998), the same is likely true for children with intellectual disabilities (Kluth & Chandler-Olcott, 2008). That is to say, to improve in areas of reading, many children, despite disability labels, will likely benefit from appropriately delivered, research-based literacy instruction, as the newest studies on literacy education for such students have begun to



show (e.g., Alfassi, Weiss, & Lifshitz, 2009; Allor, Mathes, Roberts, Jones, & Champlin, 2010; Flores & Ganz, 2009; and Hua, Hendrickson, Therrien, Woods-Groves, Ries, & Shaw, 2012). Students with intellectual disabilities may need additional repetition, more time to grasp a topic, and/or creative delivery of new ideas among other modifications, but the concepts and skills to be learned are the same. If children without labels of disability and children with learning disabilities are eligible for the specialized lessons and interventions provided by such teachers, children with intellectual disabilities should not be denied the opportunity and benefit of working with these teachers either.

Another implication of this study is the importance for school professionals to realize that parents of children with intellectual disabilities may be excellent sources of information when it comes to devising literacy goals and instructional activities for their children. Parents often have “local understanding” of their children, meaning that they have intimate knowledge of their children and are often able to interpret understanding in their children who may not portray their understanding in conventional ways (Kliewer & Biklen, 2001). That is, parents may be aware, for example, that their children understand plots when chapter books are read aloud to them by certain gestures or facial expressions that the children make. Such understandings may not be as clear to teachers or professionals who do not know the children as intimately and who require an oral or written response to a story for one to convey understanding. Parents in this study, for example, were often aware of skills that their children possessed when school professionals were not. If parents and school professionals work to share their information, and if parent input is valued, it is likely that the literacy instruction afforded

to students with labels of intellectual disability can be improved by tailoring instruction more so to each child's specific needs.

Finally, school personnel should be aware that parents interact with school personnel in different ways and with different styles of communication. Parents enact these styles in an attempt to achieve what they feel is best for their children educationally. Parents displaying particular styles of communication may be an indication of how they are feeling regarding the meetings, the decisions being considered, and their positions in taking part in such decision-making. Recognition of their styles might lead to a further understanding of such parents and their needs during meetings with school personnel. For example, a parent employing Present Listening may feel overwhelmed at meetings and/or be unsure about how much information or what kind of information to share with the committee. These parents might benefit from reassurance from the school professionals that their perspectives are important.

On the other hand, parents employing Steadfast Advocacy likely aim to be integral parts of decision-making taking place (as is their right by law). Though not necessarily the case, they also may have had harrowing past experiences in trying to procure appropriate services and/or education for their children within a school setting. These parents may benefit from an honest expression from school personnel that the school personnel have the children's best interests at heart and that they intend to listen to the parents' concerns and wishes so that they may work as a team to achieve the best literacy outcomes for the children. Of course, it is also important not to essentialize these patterns and treat all parents displaying particular styles of communication in the same

way without further understanding of the parents and their needs and wishes through careful listening and an effort toward collaboration.

### **Implications for Teacher Education**

According to a number of participants in this study, teachers appeared unprepared to teach literacy skills to children with intellectual disabilities. While this was not true for all teachers discussed in this study, a number of teachers, both special and general educators alike, to their students' parents, seemed to lack the knowledge needed to help children with significant types of disabilities to improve in literacy. Additionally, and, again, in the parents' views, some teachers appeared to enact beliefs that indicated that they did not believe that children with intellectual disabilities could benefit from literacy instruction, at least literacy instruction that moved beyond the very basics of letter recognition, word copying, and sight word reading.

Based on these findings, it appears that some changes need to be made in the preparation of teachers, including general education teachers, special educators, and literacy specialists. Since it is federal law that students with disabilities receive instruction in the least restrictive environment, all teachers need to be knowledgeable in the education of students with diverse needs. While teachers of different subjects and grades will have certain areas of expertise and will certainly not be able to be experts in all types of education, at all levels, they must at least be instructed with diverse learners in mind. To assist with this, it would be helpful for inclusive education and ways to make it work to be at the forefront of education for all teachers. In doing so, all teachers can be encouraged through their courses of study to think more deeply about the needs of those individuals with intellectual disabilities. According to Titone (2005), "inclusion

should be a philosophy that permeates a program and stresses the importance of collaboration, differentiating curriculum and pedagogy, and continuing professional development” (p. 27).

Once inclusive education becomes an important topic, it can begin to be addressed naturally, at any given time in any given course because a central question then becomes, “How do we support all learners in gaining ‘such-and-such’ an idea, concept, or skill?” As teacher candidates are learning about teaching phonics, for example, they should be encouraged to do so with a diverse student body in mind. They should be invited to investigate how different students with diverse needs might be hindered in their development of such a skill and investigate multiple, perhaps creative, ways to teach the concept. No longer should discussions of the learning needs of children with “special” needs, including those with intellectual disabilities, be dismissed as belonging only to the realm of the special educator.

While many colleges and universities have begun to address the importance of inclusive education as evidenced through the many inclusion-focused courses available in various schools of education around the nation, much of the focus on teaching children with special needs to read remains on students with high-incidence disabilities, such as learning disabilities and ADHD (Copeland, Keefe, Calhoun, Tanner, & Park, 2011). Ironically, instruction regarding the literacy educational needs of children with intellectual disabilities, therefore, is often marginalized even among instruction specifically focused on disability. To address this problem, teacher preparation courses should include classes that focus on the literacy needs of children with more significant

forms of disability to assure that when teachers leave their preparation programs, they are competent in delivering such instruction.

Furthermore, parents in this study frequently mentioned the problems surrounding teachers' preconceived notions regarding literacy instruction for children with intellectual disabilities. Parents often felt that certain teachers did not engage their children with such disabilities in literacy learning because they did not believe such children could benefit from literacy instruction. Such mindsets appear to be widespread (see discussion in Copeland, Keefe, Calhoun, Tanner, & Park, 2011), and can have a devastating effect on the eventual literacy learning opportunities afforded to children with intellectual disabilities. Schools of teacher education, therefore, should consider combating this mindset when present by encouraging new understandings of individuals with intellectual disabilities. For example, it would be helpful to show such students in the light of being able to use literacy and benefitting from instruction in the area. One way to do this might include encouraging prospective teachers to read excerpts from primary sources written by individuals with intellectual disabilities (e.g. Hunt, 1967 or Seago, 1964).

In general, there is a need for more research in the area of literacy instruction for students labeled as having an intellectual disability. Literacy instruction for these students is in need of improvement. According to the parents interviewed in this study, many teachers and school professionals continue to believe that individuals with an intellectual disability are unable to benefit from literacy instruction, and, therefore, such students are relegated to the literate margins of their schools.

### **Conclusion**

The more dominant societal views of disability have not offered all that there is to know about the capacity of children with intellectual disabilities to develop literacy skills. In fact, such views have too often led to the opinion that children with intellectual disabilities cannot become literate (Kliewer & Biklen, 2001). For this reason, other perspectives are important in gaining a broader understanding about what happens for children educationally in school systems that may have been structured around such hegemonic views. By speaking to parents about their children's experiences with literacy instruction in school and the opportunities such parents have had to take part in decision-making regarding this instruction, a different way of conceptualizing some of these opportunities comes to light.

This study has the potential to heighten school professionals' understanding of parents' views on ways of thinking about their children. For example, the parents' views have suggested some alternative ways for teachers to understand children's competence and give further insight into ways to instruct students with intellectual disabilities. In addition, the critical perspective of this study has the potential to encourage change in schools that might marginalize individuals with intellectual disabilities. This study also has the potential to illuminate some areas regarding literacy instruction for students with intellectual disabilities that may need to be addressed in teacher education.

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