

Spring 6-2008

Maintaining Hope/ Encouraging Perspective in Special Education

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DePaul University

School of Education

**HOPE AND PERSPECTIVE: A QUALITATIVE STUDY OF THE
RELATIONSHIP BETWEEN PARENTS AND PROFESSIONALS
IN SPECIAL EDUCATION**

A Dissertation in
Curriculum Studies

by

Donna Smith

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Submitted in Partial Fulfillment
of the Requirements
for the Degree of

Doctor of Education

December, 2008

We approve the dissertation of Donna Smith.

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ABSTRACT

Having a child with moderate to severe disabilities is a life-altering experience for many families. This study is an exploration of the relationship that exists between the parents of children with moderate to severe disabilities and special education professionals. It is an attempt to gain a deeper understanding of the parental perspective on the complexities of that relationship, and to investigate how that relationship is negotiated through stories told by eight parents about their experiences with the professionals in the schools their children attend. This study is also focused on how parents, school systems, and societal understandings of disability and difference intersect in the realm of providing educational opportunities and care for children with disabilities.

This is a Narrative Inquiry study, and it is influenced by feminist methodological considerations. Interviews conducted with participants generated a collection of life-story case studies. Findings were analyzed for commonality and seven themes emerged from the data. They include the impact of having a child with a disability on the family, expectations, special education placement issues, communication, the quality of interactions between parents and professionals, systemic barriers to relationships, and the process of accepting or making peace with having a child with disabilities. The conceptual framework for analysis involves the ethics of care, power relationships in school and the phenomenon of ambiguous loss. Results suggest that conflict is inevitable because parents and professionals view children through different lenses, but that thoughtful and compassionate efforts on the part of educators can develop into

relationships that provide welcome support and understanding to families during difficult periods of adjustment and transition.

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“God has furnished us with constant occasions of bearing one another’s burdens. For there is no one living without failing; no person that is so happy as never to give offense; no person without a load of trouble; no person so sufficient as to never need assistance...therefore, we should think ourselves under the strongest engagements to comfort, and relieve, and instruct, and admonish and bear with one another”

(Kempis, 1952, as cited in Gottlieb, 2002, p. 236)

Acknowledgments

Although it felt sort of lonely at times, I have not been alone at all throughout the process of completing this research study. There are so many people who have helped me along the way...

Thank you to the members of my dissertation committee, Dr. Karen Monkman, Dr. Mojdeh Bayat, and Dr. Horace Hall. Your time, energy, thoughtful encouragement, constructive criticism and faith in my ability to see this through to completion are deeply appreciated.

Thank you to Dr. Layla Suleiman and Dr. Jeffery Kuzmic. Your guidance and interest in my work in its earliest and most awkward stages was of immeasurable help.

Thank you, “Joanne” for being so generous with your time and helping me with the pilot study for this research.

Thank you to the friends and colleagues who helped me to locate the participants for this study. Chris Cayo, Johnnie Thomas, Brenda Kraber, Barbara Melman, Dr. Smith, and Arlene Brennan...thank you!

A very special thank you to Elizabeth, Grace, Rachel, Leslee, Marie, Ivy, Karen and Kathleen for participating in this study. I wish I could print your real names on the title page of this paper so the whole world (ok, ok, everyone who reads this) would know who you are. Thank you for opening your homes and hearts and sharing your stories with me. I am humbled and grateful.

Thank you to the friends who have been with me along the way, tolerated my lack of availability for fun, and helped me keep it all in perspective. Bonnie Cortez, Maria Meachum, Stacey Prange, Ann Pistone, Hedy Cohen, Lara Barros, Ali Schwartz...I think I am now free to go to the movies, shop the farmer’s market, play Scrabble, drink tea, listen to YOUR deep thoughts, and play with the kids and the dogs.

Thank you to my friends at DePaul University who have kept me company along this journey. It has been a long one, but because of you I am sad to see it coming to an end. Marjorie, Brenda, and Ravi, please know that your friendship and support have made all the difference to me.

A special thank you to Mary-Terese Cozzola, for listening, for walking, for checking the teapot and for formatting the many, many pages of this document. And for teaching me that it is unnecessary to count all the dots to get the page numbers in the table of contents lined up correctly. Who knew you could do that automatically?

I like to save the best for last. Mom, Pop, and Nathan, thank you. For your love, support, understanding, humor and infinite appreciation for each other and for me in the best and worst of times. I love you all very much. Mark, thank you. For being patient, gentle, and ever supportive of my endeavors, but also for putting up with me, for making me laugh, for cleaning up the kitchen, for taking care of my animals, and for being you and being here with me. I'm not sure how I got so lucky. I love you.

CHAPTER ONE: INTRODUCTION

INTRODUCTION

Working in special education for sixteen years as a teacher and school-based occupational therapist has deeply altered my perspective on what it means for students with special needs to be “educated.” If I had to select the most meaningful aspect of my work, it would be the relationships I have with my students, their parents and the co-workers who share my vision of creating a safer and more accepting world for those among us who need extra help. And if I had to select my greatest frustration, it would be those same relationships. Very little in special education is simple. The children are complicated, and most of the adults even more so. The rewards are small (although occasionally profound) and the frustrations are significant. While I am troubled by larger issues such as the curriculum, funding, and inclusion policies that have great impact on the system in which I work, my main interest, other than providing good therapy services for my students, is in the dynamic of the relationship between parents and professionals in special education.

Watching what parents of children with special needs go through in seeking out what they believe to be the best educational opportunities for their children is very difficult for me. Over the years, I have grown increasingly sensitive to what I perceive to be fear in their eyes and anxiety in their voices. There are the parents who amaze me with their positive energy and tireless advocacy for their children. They are fiercely protective, but maintain a clear vision of their child’s abilities and realistic expectations for school performance. They partner with teachers, connect with administrators, make important contributions and offer constructive criticism. There are also parents who intrigue me with their resourcefulness and refusal to give up hope. They understand the significance

of their child's limitations, but will try anything that might help. They may be demanding, but their intentions are clearly to make life better for their child. And then there are the parents who astound me with the inexplicable depth of their grief and the power of their denial. They are frustrated and angry. They come to meetings with advocates and lawyers to argue, intimidate and demand. They sometimes point their fingers, threaten, and blame the school staff for their child's failures. They may be hurting, but they are also hostile and litigious. Maintaining professional distance and perspective is difficult in these situations, and I often walk away from these meetings with an upset stomach and a heavy heart.

Disability, regardless of the level of severity, is incomprehensible to most people, and human response to it, although somewhat predictable, is not something that can be easily defined or explained. For me, there is no easy way to deal with it, but lessons learned from parents I have worked with over the years have been helpful. From parents I learned there are times when it is appropriate to talk and times when things are best left unsaid. I learned to acknowledge their pain quietly, and to share in the experience of being with children and their parents respectfully when invited. I learned to say "I don't know," and "I'm sorry," and to ask "Is there anything I can do to help you with this?" I stopped holding back tears and taking things personally. I know that my job is a bit difficult some days, but parenting a child with disabilities is much more difficult than I could ever begin to imagine. I am changed for all of this; as a younger teacher and greener therapist I was task-driven and goal-oriented, but my mission now is one of benevolence. I cannot make the pain go away, but I can certainly and gently offer to share in the "burden," at least for a little while. Although we have extensive and very specific Individualized Education Plans (IEP's) for each student in special education, what we need, perhaps, is a similar plan for supporting each of their families.

A confounding factor in this situation is that in our society, disability is not exactly embraced. People who look, think, act or move differently have traditionally been excluded from what is referred to as 'mainstream culture.' Up through the 1950's, children with physical and cognitive disabilities were institutionalized, and, according to Kliever & Raschke (2002), special education practices of today, especially those that remain separate from regular education, are deeply rooted in "moral traditions of control, dehumanization and devaluation" from "a presumably less enlightened past" (p. 43-44). The field of disability studies has emerged as a powerful force in educating medical and educational communities about "...how people with disabilities are viewed and the effects of those views on the life experiences of persons with disabilities" (Paul, Lavelly, Cranston-Gingras, & Taylor, 2002, p. 152) but because human nature resists change and sensitivities are slow to develop, we still have a long way to go. There is, I think, a persistent arrogance in our culture that continues to support notions of people with cognitive and physical disabilities needing to be repaired, remediated and normalized so they can fit in to a society that is intolerant of difference and frowns upon the need to be taken care of.

As a culture of educators, we are often quick to judge and label children. This is, perhaps, reflective of our society and our general discomfort with disability. According to Kauffman, McGee & Brigham (2004), denying disability exists is counterproductive because "...when we can only whisper or mime the undesirable difference called disability, then we inadvertently increase its stigma" (p. 616). Regardless of a child's potential to benefit from schooling, every child in this country has a right to be educated in a setting that meets their individual needs. They are also entitled to dignity, respect and opportunities to belong. I am biased, of course, but I think children with disabilities are reasonably well taken care of within our educational system in this country. My concern

is that sometimes we do not do as well in taking care of their families. My theory for this dissertation, essentially, is that a little bit of love goes a long way. If an ethic of care (Noddings, 1995; Faircloth, 2004) could be legislated the way IDEA and No Child Left Behind have been, the culture in our schools might look very different for children with disabilities and feel very different to their families. Bringing children with disabilities up from classrooms in the basement and out from the farthest corners of our school buildings has been a start. Including children with disabilities in the life and culture of school activity is also a welcome step in the right direction, but there is still a great deal of work to be done with children with disabilities and their families. There will always be tragedy, difficult situations, personality clashes, power struggles and inequities in special education, but as professionals we need to move beyond those conflicts and maintain our focus on what is best for children with disabilities and their families. We are trained to view *possibility* as more important than *disability*, and it is, I believe, fully within our realm of capability to make special education a more welcoming place.

Special education professionals often find themselves in the midst of a perplexing paradox. Finding a balance between what parents want and what schools can provide for children with disabilities is inherently fraught with contradiction. Professionals are forced to walk the fine line that exists between compassionate care and the reality of available resources on a daily basis. Hope and systemic efficiency are constantly at war, and no hopeful parent I have met has ever been willing to concede defeat. Children with special needs clearly need special attention, and teachers and therapists employed by school districts are trained to provide it for them. But parents also require special attention, and that is often where the relationship between parent and school begins to break down. Parents and professionals view children differently. Even the most thoughtful and considerate special education professional cannot have true

understanding and empathy for parents unless they have walked in their shoes, and we know that is simply not possible. Most of us, parents and professionals alike, do the best we can with the resources we have. This research project is my attempt to add a resource to the body of literature about relationships between parents and professionals in special education.

DEFINITION OF TERMS

- 1. Special education** is a specialized curriculum delivered by special education professionals designed to meet specific needs of students with intellectual, physical or sensory differences that impact their ability to benefit from the general education curriculum.
- 2. Low incidence disabilities** are disabilities which occur with a low level of frequency among the general population in the United States. These disabilities may include, but are not limited to cerebral palsy, autistic spectrum disorders, Down syndrome, spina bifida, moderate to severe cognitive impairments and genetic conditions and syndromes resulting in moderate to severe intellectual and physical disability.
- 3. An Eligibility Determination Conference (EDC)** is a meeting held to determine a child's eligibility for special education and related services in the public school setting. During the EDC, evaluation results are reviewed and discussed. EDC meetings occur once every three years, or more frequently upon parent request or teacher recommendation.
- 4. An Individualized Education Program (IEP)** is the plan written by teachers for every student who receives special education services. It is a legal document, and

contains present levels of performance, annual goals and short term objectives. It is updated quarterly and reviewed annually.

5. **Inclusive** classrooms are general education classrooms where children with disabilities are included for academic instruction and special activities (lunch, physical education, art, music, etc.) with the provision of appropriate assistance and support from special education personnel.
6. **Self-contained** classrooms are classrooms where children with disabilities receive academic instruction and participate in other daily activities apart from their same-age peers.
7. **Special education professionals** may include teachers, teacher assistants, speech-language pathologists, occupational and physical therapists, social workers, school psychologists and administrators.
8. **Occupational therapy** entails the use of purposeful activity to promote health and achieve functional outcomes and increased independence among individuals limited by a physical illness or injury, medical conditions, cognitive impairment, psychosocial dysfunction, mental illness, developmental or learning disability or adverse environmental conditions (Illinois Occupational Therapy Association, 1993).
9. A “**successful**” relationship may be defined by participants in this study in any manner they choose, but my expectation is that participants will define the term in either a child-based context (where they feel confident their interactions with educators have resulted in services and support that are in their child’s best interest) or in terms of a supportive, practical or friendly relationship between themselves and the educators involved in their child’s care. My intent is to begin the inquiry with a loose definition of the term “success,” in order to leave room

to discover what “successful” relationships really look like between parents and professionals and what “meaning” truly exists in those relationships for participants.

10. Please note that throughout this document, use of the phrase “**child with special needs**” is interchangeable with the term “**child with disabilities**” in order to keep wording true to cited sources, as well as to avoid repetitive use of either phrase.

CHAPTER TWO: LITERATURE REVIEW

REVIEW OF LITERATURE

Introduction

Even the kindest and most caring professionals in the field of special education sometimes find themselves unwelcome partners with parents in the education and care of children with special needs. Because parents and professionals view children through different lenses, tense and acrimonious interactions sometimes hinder the development of productive working relationships. Although trained to provide educational services for children, professionals are not always equipped to offer parents emotional support, understanding and the encouragement they might need.

In my experience as a school-based occupational therapist, I have met a number of parents who seem to be especially adept at navigating through the maze of special education services, advocating for their children and establishing strong and functional connections with the professionals responsible for meeting their child's educational needs. As a professional, I sometimes find Eligibility Determination Conferences (EDC) and Individualized Education Plan (IEP) meetings to be emotionally charged and difficult to endure without dissolving into tears or crying out in frustration and anger. I can only imagine the magnitude of those feelings parents may have, and have become increasingly sensitive to and curious about how parents feel, how and what meaning they find in their experience of raising a child with special needs and how they are able to negotiate relationships with school professionals effectively in order to get what they want for their child.

This study is focused on the relationship between special education professionals and parents of children with disabilities. There are many voices that speak to this issue,

and in the following review, I will explore some of the literature related to historical and cultural perspectives on disability and difference, exclusion and inclusion as educational practices, how some parents cope with loss and challenge, caring relationships and partnership between parents and professionals in special education. Although somewhat broad in scope, I believe these areas of research are central to understanding the relationship in question and fundamental in bringing together many of the issues professionals need to be mindful of in their interactions with parents.

Historical and Philosophical Perspectives on Disability

Problematic relationships between parents and professionals in special education may have roots in the troubled relationships that exist between people with disabilities and those without, as well as how people with varying levels of competence in physical and cognitive endeavors are viewed and understood in our culture. Many scholars are in agreement that “disability” is largely a social construction (Moore, Beazley & Maelzer, 1998; Gottlieb, 2002; Titchkosky, 2003) and “...those who find in themselves or in others a ‘loss or abnormality of a psychological, or anatomical structure or function’ are engaged in social action oriented to and by cultural knowledge, social settings and unexamined conceptions of normalcy” (Titchkosky, 2003). The fact remains that many children are excluded from involvement and participation in the activities of typically developing children because of their actual or perceived disabilities. Inclusive educational practice has steadily increased in the United States, but successful inclusion requires deep and enduring efforts beyond simply placing children with disabilities in classrooms with their typically developing peers. Although the language used to describe children with special needs today is “...often gentler and framed around metaphors of dependence and support rather than personal incompetence or immorality” (Ferguson,

2002, p.29), the way we ‘see’ children with special needs and provide for their care and education is still largely informed by residual from outdated cultural understandings of disability (Neville & Pankratz, 2001; Titchkosky, 2003).

Philosophical perspectives on human experience and social interactions over time may serve to situate existing views of disability historically as well as to shed some light on current situations and encourage institutional and individual change. In *Discipline & Punish* (1979), Foucault examined how rituals of exclusion may be traced back in history to efforts to contain the plague, isolate people infected with leprosy, enclose the insane in psychiatric asylums and control criminals by locking them away in prisons. These practices eventually evolved into “...a whole set of techniques and institutions for measuring, supervising and correcting the abnormal...” (p. 199) that still persist today as mechanisms of power which function to brand and alter the individual perceived as ‘abnormal’ (p. 199). Neville & Pankratz (2001) used Bourdieu’s theory of symbolic violence (where power is disguised while being exercised) to describe the special education practices that continue to contribute to the devaluation of people with disabilities in our culture. Varenne & McDermott (1998) found the cultural context within which we view schooling and ‘see’ people with disabilities to be problematic. In their examination of disability, “...the subject shifts from THEM to US, from what is wrong with them to what is wrong with the culture that evolved a THEM separate from an US” (p. 144). As a part of their discussion of people with vision and hearing deficits, Varenne and McDermott noted,

...their problems stem only incidentally from what they cannot do and much more radically from the ways others further limit their movement and participation...and from the way they are treated by others in relation to the designation, assignment and distribution of more or less temporary or partial difficulties interpreted as success or failure... (p. 134-135)

Oberski (2003) took the “us and them” case a step further. He used Goethe’s “way of seeing” as a tool to examine inclusive educational practices. He described how some “...children who are technically or physically included may remain excluded within the mainstream...” because they are perceived as “...somehow fundamentally different from ‘normal’ learners” (p. 339). For children with special needs to truly be “included,” Oberski indicated what we need to do is change the way we ‘see’ schooling; our vision of all human beings needs to become more holistic so we can “...develop a way of seeing ‘them’ as a part of ‘us’ and ‘us’ as a part of ‘them’ (p.339).

Learning to see children with disabilities as a “normal” component of our educational community has been a long, slow process for all involved. Perceptions of fundamental difference are very difficult to overcome, and in spite of what we know to be best practice, some of our current practices have not changed much in the last fifty years. Rituals for testing, sorting and segregating in special education have been viewed by some as practices placing too much social power in the hands of those defined as “normal.” Kliewer & Biklen (2001) cautioned that “...the person perceived as defective and the person perceived as competent are both social constructions. People in whom resides the power to define the capacities of other human beings are making moral decisions...” (p. 11) that can have a profound effect on quality of life issues for an individual child and his or her family. But these rituals persist. In special education, children are basically categorized according to their level of academic need via comparison with their same aged “normal” peers. Although we know education is not an exact science, using test scores as a basis for placement and program planning offers a scientific legitimacy to educational practices. It is also an extremely effective method of turning children into abstractions. As Apple (2004) pointed out, categories are social constructions which emerge from specific social situations and conform to specific social

institutions (p. 127). Essentially, we evaluate and label children so they can fit into one or more eligibility category to justify the provision of services. These services may appear to be benign, but they also function to perpetuate existing institutional practices that maintain social and academic stratification between children with disabilities and those without. For example, if a child has autism, he or she gets a special education teacher, speech and occupational therapy. If the diagnosis is cerebral palsy, the services are a special education teacher, speech, occupational and physical therapy. If testing reveals a learning disability, a resource teacher is assigned and if a behavior disorder is recognized, the service provided is generally social work. And if a child is cognitively impaired, he or she is frequently transported on a special bus to school and spends a majority of the day in a classroom separate from other children of the same age. Apple also suggested that children who are perceived as (and I would add “actually are”) different are threatening to the pattern of daily life in a school. Labeling and separating these children from their peers, although done in the name of helping, is actually a strategy of deception and functions

...to preserve the tenuous nature of many interpersonal relationships within schools on which “adequate definitions of situations” depend. But even more important, it enables people like teachers, administrators, curriculum workers, and other school people to confront stereotypes rather than individuals... (p. 137).

Perhaps part of the hidden curriculum in special education is to maintain the status quo, and to keep the children who look, think, act or move differently marginalized and away from the community of more capable learners while placing them, strategically but for short periods of time, in the very same spaces as their typically-developing peers. In a profound masking of our discomfort with difference and disability, we claim to be holding a place at the proverbial table for children with disabilities by including them with their typical peers for lunch or art or maybe in gym. The message we send is one of

tolerance, but certainly not one of acceptance. This is a problem. It is a problem for children with disabilities, a problem for educators and school administrators, and problem for parents who want their children, regardless of their disability, to have the same educational opportunities as their typically developing peers.

Obtaining Special Education Services

Given the passive but pervasive resistance that exists in our society to children with disabilities (Davis & Watson, 2001; Kearney & Griffin, 2001), negotiating the massive bureaucracy of a school system to obtain appropriate special education services for a child can be a daunting task for many parents. The layers of administration and piles of papers that need to be filled out at every meeting are not especially parent-friendly or likely to encourage the development of healthy or happy working relationships. Federal legislation provides guidelines for the provision of special education services. The Individuals with Disabilities Education Act of 1990 (IDEA) states that all children with disabilities are entitled to receive a free and appropriate education in the least restrictive environment. Eligibility for services may be established under various categories of disability, including visual, hearing or motor disability, emotional disturbance, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability or speech/language impairment. The 1997 reauthorization extended the categories to include children with traumatic brain injuries and autism. In addition, students with attention deficit disorders are eligible for special education services under the category of “other health impairment” and students with issues related to transience, homelessness and limited English language proficiency are also afforded services (Altshuler & Kopels, 2003). Mandates from the 2004 reauthorization are

currently being implemented as well, but do not significantly change direct services to children.

Having a disability and being deemed “eligible” does not mean services are readily available at the local school. Because the language of the law is vague, implementation is subject to interpretation by individual school districts and is often the source of confusion and controversy between parents and professionals (Yell & Katsiyannis, 2004). Contention and litigation are most frequently centered on placement in the least restrictive environment and understandings of what entails an appropriate level of service (Ryandak & Downing, 1996). Parental opinions vary greatly in regards to where and how they want their children educated. Some support full inclusion models (Gartner & Lipsky, 1998; Kauffman, McGee & Brigham, 2004) while others prefer programs separate from the general education curriculum (Fuchs & Fuchs, 1995; Hall, 2002). Although parents are supposed to be equal partners with educators in the IEP process (Spann, Kohler & Soenksen, 2003) many report feeling angry and frustrated when their input is met with resistance from administrators or when they arrive at an IEP meeting to find decisions about their child’s needs and placement already made (Zaretsky, 2004). IDEA implies child-centered decision making, but in reality, placement decisions are often made according to the range of available options for service provision. To some extent, parents and educators agree that “...schools do not necessarily serve *all* children equally well” (Zaretsky, 2004, p. 63). Every child in special education presents with different strengths and needs, and it would be ideal if all schools were able to effectively support each child with a continuum of available special education services. Some children benefit from self-contained classroom environments, while others do best with support in classrooms with their typically developing peers. As Zigmond (2003) noted, “...effective teaching strategies and an individualized approach are the critical

ingredients in special education, and neither of these is associated solely with one particular environment” (p. 198).

Placement in special education has additional implications and stigma for children and their families. Stigma is defined by Goffman (1963) as a “disgrace,” an “undesired differentness,” or an “attribute that is deeply discrediting.” Characteristics that stigmatize may be physical, racial, mental or religious (p. 4) as well as inborn or acquired (p. 32). Goffman wrote of the common sense assumption that “what distinguishes an individual from all others is the core of his being, a general and central aspect of him, making him different, through and through” (p. 56). Clearly, it is not “normal” to be disabled and some deep and enduring prejudices exist in our society against individuals who possess physical, sensory or cognitive characteristics that fall outside the realm of “typical.” According to Greene (1993), “there are ways of speaking and telling that construct silences, create “others,” and invent gradations of social difference necessary for the identification of certain kinds of norms” (p. 4). Notions of ableism, or the devaluation of disability, are apparent in pervasive societal attitudes that assert it is preferable for a child with disabilities to do things in the same manner as his or her typically developing peers (Hehir, 2005). And outside of school, according to Erevelles (1997), “...disabled people have been historically located at the margins of the margins of our social world in spaces that have been construed as irrelevant to the economy, society...and culture” (p. 1). Our modern antidote to stigma is to claim to see a child or person first and their disability second, but at this point in time, that is still just a claim. Parents of children with disabilities are keenly aware of the isolation and marginalization associated with disability, (Fialka, 1997; Kroth & Edge, 1997; Murray, 2000; Hall, 2002; Robb, 2003; Green, 2004) making it even more important for special education

professionals to demonstrate sensitivity to how parents experience the process of placing their child in special education.

Special Education Placement and Service Options

Special education placement and service options for children with disabilities are a primary source of contention between parents and professionals (Lake & Billingsly, 2000). Since approximately half of all cases that go beyond mediation to due process hearings are actually personality conflicts rooted in that disagreement (Whitted, 2001), it makes sense to look closely at issues related to the inclusion of children with special needs in regular education classrooms. Proponents of full inclusion claim all children belong together, and when inclusion is properly instituted, it functions "...like a rising tide that lifts all the boats..." (Gartner & Lipsky, 1998). Some believe inclusion promotes the acceptance of children with disabilities by non-disabled peers, resulting in social, emotional and academic benefits for both groups (Garrick & Salend, 1999). Others with strong beliefs in the ideals of inclusion regard it as a civil right for children with disabilities (Henderson, 2001; Hall, 2002) and consider implementation of inclusive educational practices to be the moral obligation of educators (Kliewer & Biklen, 2001; Kliewer & Raschke, 2002).

Reservations among parents, teachers and people with disabilities about placing children with special needs in regular education classrooms are also documented. Some of the concerns are related to teacher expertise, educational methodology and the implementation of IEP goals (Garrick & Salend, 2000), but others are focused more on the child and his or her social and emotional well-being. Parents have expressed concerns related to their child's ability to benefit from the regular education setting without adequate attention and support, along with fears about how their child might be treated by

teachers and peers. In response to the idea that children in regular education may benefit from the presence of children with severe disabilities in their classrooms, one parent stated,

...No matter the benefit to “regular students,” severely handicapped children should NOT be used as “examples” to better the “regular students” life. Severely handicapped children have a tough enough time just living and should be given additional support NOT additional ridicule! (Palmer, Fuller, Arora & Nelson, 2001, p. 477)

The voices of children are largely absent from the literature on inclusion (Davis & Watson, 2001). Though there are certainly children with special needs who achieve academic success while included in regular education settings, there are also some who pay a high price in their social lives and with their psychological health for that inclusion. This alone highlights what might be the greatest challenge in special education; that of bridging the *theory* of what we hope for with the *practice* actually occurring in classrooms where real children work and play. Meyer (2001) conducted a study on the impact of inclusion on children’s lives, with special attention to friendships between children with disabilities and their typically-developing peers. Because the children with special needs were constantly being “helped” and never expected to help anyone else in return, she found inclusion actually created a “special status” among children with disabilities that fell short of what might be considered true friendship and appeared to interfere with the growth of social connections between the children. According to her research, in some of the interactions between children with and without disabilities, it “...almost looked as if the nondisabled [sic] child was playing with a pet...” (p. 18).

From the literature one can see there are people who believe all children with disabilities should be educated alongside their typically developing peers and there are those who believe some children are best and most compassionately served outside of the general education curriculum. There are many facets to both arguments, and for families

of children who require assistance to access activities across the curriculum, it is a difficult and personal decision. It might serve both parents and professionals well to acknowledge that while inclusion policies may be established with the best interests of children in mind, in reality, there is within them the potential to create social experiences for children that are less than desirable. While striving to meet a child's educational needs, professionals in special education might also benefit from mindful attention to the social and emotional impact that having a child who requires special education services can have on parents.

Facing Loss

Little doubt exists that most parents who have a child with special medical or educational needs have experienced a loss that warrants grieving (Moses, 1987; Fadiman, 1997, Fialka, 1997; Abrams, 2001; Bruce & Schultz, 2002; Gottlieb, 2002; Hughes, 2003; Ross, 2004). Regardless of onset or etiology, diagnosis is often "...like a bolt of lightning out of a clear blue sky..." later reflected upon as the experience "...that shattered our expectations of a controllable life and rocked the foundations of our world" (Green, 2004, p.22). Kubler-Ross (1969) identified sequential stages of mourning (denial and isolation, anger, bargaining, depression and acceptance) that have been applied to families in the process of adaptation to life with a child with disabilities. While these stages may hold true and represent common experiences for some parents, they may be inadequate in explaining the experience of loss for many others. Blacher (1984) questioned the reality of an ordered progression through specific stages of adjustment to the birth of a child with special needs, and reviewed a fairly extensive body of literature which indicated most parents do not progress through stages of grief and adjustment in any particular order. Schall (2000) pointed out that because childhood disability impacts

the structure and system of family life in a "...pervasive and extreme way," living with and providing day to day care for a child with disabilities may preclude opportunities for parents to mourn and move forward through increasingly adaptive stages of adjustment.

Moses (1987) discussed the "devastating and continuing loss of having an impaired child" as being one of the most painful experiences a person can live through. He noted that grieving, for most people, does not actually progress in a step-by-step process. Instead, he described the fluidity with which the "stages" of grief are experienced by parents and explored the adaptive function of each stage of the grieving process. Denial, for example, can be used to buy time to gather internal and external resources. Anxiety may serve to mobilize energy needed to make major lifestyle changes, and according to Moses, fear may actually function as a medium to help a parent "reattach" to the child who presents with a level of impairment the parent was not expecting. Moses disagreed with the idea of this type of loss eventually being accepted, and stated that in his practice, he has "...never seen anyone achieve acceptance of loss, only acknowledgment" (p.8). Other research disagrees with Moses; some parents of children with special needs have described the emotional resting place they eventually arrive at as one of "tenuous emotional compromise," or, essentially, an acceptance of the child and his or her impairments (Roll-Pettersson, 2001; Green, 2004; Larson, 1998).

Bruce & Schultz (2002) described the diagnosis of disability in a child as a "personal, quiet tragedy..." that is without an associated social ritual for grieving. They used the term "non-finite loss" to describe the extensive loss faced by many families, and defined it as a grief that is "enduring" with a constant physical and/or psychological presence. Doka (1989) described this type of grief as "disenfranchised," and noted that healing is especially difficult when the loss is not openly acknowledged and there are no socially sanctioned rituals in which the bereaved may take comfort. Olshansky (1962)

suggested that parents of children with special needs experience “chronic sorrow” in varying degrees of intensity throughout their lives. More recently, Pauline Boss (1999) coined the term “ambiguous loss” to describe the loss family members face when a loved one is physically present but emotionally unavailable or cognitively unable to engage in typical family-based interaction. Although her work focused on caregivers for those suffering with chronic illness, Alzheimer’s disease, traumatic brain injuries and strokes, her theory is also relevant to parents of children diagnosed with the most severe forms of cerebral palsy and autism, or who have experienced other traumatic events and illnesses which result in moderate to severe childhood disability.

Often by the time children with disabilities reach school age, their parents have come in contact with a multitude of professionals who possess varying levels of both expertise and compassion. According to Robb (2003), many parents benefit from continued support from caring professionals who not only understand the process of grieving and the means by which parents and families cope with the challenges associated with raising a child with disabilities, but who also consciously act on that understanding in their interactions with them.

Coping with Challenge

The way parents who have children with disabilities cope with challenge often has an impact on the quality of the relationships they have with school-based professionals. According to Walsh (as cited in Abrams, 2001) “...highly resilient people reach out for help when needed, turning to kin, social, and religious support systems, as well as helping professionals” (p. 290). How an individual experiences difficult circumstances is often very personal, but there is, for many parents, some comfort in connection with professionals who are knowledgeable about providing care and

assistance to children with special needs as well as with other parents who face similar family circumstances. Many variables have the potential to influence parental coping. These include, but are certainly not limited to, socioeconomic status, available support services, level of severity of the child's needs, parental experience with physicians and other medical professionals during diagnosis, single or two-parent family, presence of siblings, religiosity and the appearance and personality of the child with special needs (Blacher, 1984; Judge, 1998). Gathering large amounts of information is often an early step in coping with a child's newly diagnosed disability and it is one that can help a parent feel qualified to make important decisions regarding their child's care (Gerlach, 2002). Insistence on participation in normal early bonding rituals, attributing culturally valued qualities ("he's a fighter" or "she's a spitfire") to the child and maintaining faith in the child's potential to defy medical predictions also function as positive coping strategies (Landsman, 2001). Some families have described a feeling of living on a roller coaster; there are calm periods where hope, waiting and wondering outweigh fear, and then there are intermittent deep plunges into fearful and unforgiving despair. To cope requires taking "...one day at a time and hoping for a better future" (Schall, 2000).

Many parents turn to religion and faith to make sense of the experience of having and caring for a child with special needs. Parents may choose to view the child as a blessing, a gift or a test of their faith (Fadiman, 1997; Hughes, 1999; Poston & Turnbull, 2004). Some parents report an increased ability to cope with the challenges presented by life with a child with special needs as a result of the strength they find grounded in their faith (Hughes, 1999; Camper, 2002). Gottlieb (2002) wrote about his need for spiritual resources in order to avoid bitterness, envy and despair when caring for his child. He found his strength by submitting to the will of God and maintaining belief in the infinite worth of each human soul. He discussed the development of two virtues that, for him,

were the most emotional aspects of parenting a child with complex needs. The first involved finding the courage to see his child and her disabilities clearly. The second involved "...a kind of surrender in the midst of never-ending labor..." (p. 234) as he struggled to accept that his child's limitations did not, in any way, diminish the value of her life or his efforts as a loving parent. Gottlieb acknowledged his use of both spiritual and intellectual coping strategies, but others have reported virtues to have a different function. Hope, love, faith, patience, perseverance, fortitude, and generosity are some of the many human virtues. Some people use them regularly for the common good, while others do so more when placed in situations where forced to exercise them. In exercising them, these virtues become stronger, and as they do, parents of children with special needs may surprise themselves with abilities to demonstrate a strength and power above and beyond what they might have considered within their capacity before the birth of their child (J. Smith, OSB, personal communication, November 5, 2004).

The experience of raising a child with special needs may also become a unique aspect of a parent's personal identity. Parents may identify themselves as advocates for their child, motivated to make sure that people do not miss out on the lessons their child may teach about love, simplicity, priorities and what really matters in life (Landsman, 2001). Finding meaning in this identity and from the experience of parenting a child with special needs is also a coping strategy for some parents. Landsman (2001) described the two types of stories some parents of children with special needs tell; one where they hurt for their child and their own losses, and another where they acknowledge that their lives are enriched by the experience. If given the chance, most parents would choose to make their child's disability go away, but in several comprehensive studies of parents of children with disabilities (Larson, 1998; Landsman, 2001; Barnett, Clements, Kaplan-Estrin & Fialka, 2003; Green, 2004), few expressed willingness to "...give up what they

learned from the experience.” As one parent in Larson’s study stated, “The child with a disability enables, perhaps forces, the family to grow layers of unconditional love, selfless consideration and quiet strength around this unusual person” (p. 872). Of caring for her child with a severe seizure disorder and intellectual impairments, another mother (McGowan, 1997) said,

I am, in a strange way, happier now than I have ever been in my life. It is a happiness laced, edged and knitted through with sorrow, however, and that, too, deeper than I have ever known. I have, sure enough, found the purpose for my life that gives it meaning, excitement and a real joy, but at the same time there is an aching sense of loss for the life that might have been (p. 65).

There is, essentially, no way for school personnel to truly comprehend the emotional, intellectual, family, financial or organizational turmoil parents of children with disabilities experience. There are, however, multiple means by which professionals can communicate respect and the desire to provide care, understanding and support in school for both children and their families.

Professional Perspective and Partnership with Parents

It is understood by professionals in the field of special education that parent involvement in the educational process leads to academic and social benefits for children (Henderson, 1988; Garrick and Salend, 1999). Turnbull and Turnbull (1997) noted that although the Individuals with Disabilities Education Act calls for parent participation and encourages collaboration between parents and professionals, in practice, professionals continue to be the primary decision makers in educational planning for children with disabilities. According to Kroth & Edge (1997), this is unfortunate in that it causes many families to feel alienated from the schools their children attend. Research has demonstrated that parents commonly report communication problems (Mitchell & Sloper, 2002), feeling excluded from decision-making processes (Pruitt, Wandry & Hollums,

1998) and being disrespected as team members with valuable input regarding their child's capabilities (Garriott, Wandry & Snyder, 2000; Hughes, 2003).

This alienation and disillusionment with the school system may result in an "advocacy" more confrontational and adversarial than collaborative in nature (Shapiro, Monzo, Rueda, Gomez & Blacher, 2004), resulting in interactions between parents and special education professionals that are complex (Pruitt, Wandry & Hollums, 1998) and delicate. Lightfoot (2003) described the conflict between parents and teachers using terms from Willard Waller's 1932 book entitled *Sociology of Teaching*:

Parents...have a "particularistic" relationship with children, where the bond is deeply passionate and individualistic. Parents necessarily speak from a position of intimacy, advocacy, and protection for their child. Teachers, on the other hand, have a "universalistic" relationship with their students, which is more distant and dispassionate. They work hard to find a balance between responding to the needs and capacities of individual students and supporting the development of a classroom community in which children learn to be responsible and accountable to the group (p. 43).

The relationship between parents and professionals has been compared to a dance, one in which both partners are not always willing participants (Fialka, 1997). Where parents enter into the world of special education out of necessity, most professionals in the field do so by choice. This can potentially lead to misunderstanding or resentment, and conflict is often inherent in the relationship between the two, largely because each views the child through a different lens (Shapiro et al, 2004). The medical model in which many rehabilitation and education professionals are trained is deficit-based and tends to consider disabilities as inadequacies residing within a person (Davis, 1995; Oliver, 1996; Hall, 2002; Paul et al, 2002; Titchkosky, 2003; Shapiro et al, 2004) while parents more often see their child in a more holistic light as both normal and disabled, with both strengths and weaknesses (Shapiro et al, 2004). While parents grapple with the paradox of wanting to embrace their child "as is" and simultaneously cling to

hope for a miracle cure (Larson, 1998) professionals tend toward the practical, and may not always be responsive to the sense of ownership many parents feel for their child's deficits or to the fragility that feeling of ownership engenders. When looking to improve these relationships, it is important to take the emotional connections that both parents and professionals have to the child into consideration. Both care about the child, but in very different ways. According to Katz,

Teachers are responsible for...children for a specific period confined to the school setting and therefore the teacher's role is more objective, detached and rational, using insights, techniques and abilities to support each child. The teachers' role is shaped by professional knowledge about 'all children'. Parental relationships, on the other hand, are shaped by their own child for whom they are responsible 24 hours a day and are likely to demonstrate intense partiality, attachment and even irrationality in their interactions about their own child (as cited in Keyes, 2002, p. 181).

Given that teachers and parents may have different expectations, cultures, styles of communication and varying personal attributes such as openness, flexibility, reliability and warmth (Keyes, 2002), finding common ground is both a challenge and a necessity for partnerships between parents and professionals to grow. Parents require respect and trust to feel supported, and as Schall (2000) reported, many families place as high a value on the relationships they develop with educational and therapeutic service providers as they do on the actual service being provided for their child.

By the time a child reaches school age, parents have often been exposed to more negative information about their child than they can tolerate. Many develop a fear of the "knowledge" professionals in schools are so eager to share. Lightfoot (2003) described encounters between parents and teachers as "loaded" (p. xxi) and discussed the "complex and treacherous subtext" that exists within dialogue between them that "...is defined by both autobiographical narratives and generational echoes, and by resonances from the broader cultural and historical tableaux" (p. 39). Conversations between parents and teachers almost always contain more than what is actually verbalized, but this subtext, according to Lightfoot, is just barely hidden. As she stated,

I believe that communication between parents and teachers is enhanced when there is an awareness of this subterranean content, when the adults begin to understand the forces within them and around them that shape their views of one another, their perceptions of the child, and the values they attach to education. This subtext should be seen as a legitimate and critical piece of the parent-teacher dialogue (p. 39).

In conversation with parents about their child's needs or progress, educators are often so focused on specific skills or activities that they neglect to attend to the emotional impact their words may have on parents (Bruce & Schultz, 2002). Educators, trained to rejoice in each small increment of progress, need to be mindful of parents who appreciate minute changes and gains, but continue to grieve the fact that their child is still not, and may never be, at the same functional level as his or her peers (Bruce & Schultz, 2002).

Research in the area of special education is extensive and "collaboration" is a buzz among buzzwords in many recent studies. Friend and Cook (2003) defined collaboration as "...a style for direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal" (p. 5).

Although widely accepted, this definition is vague and subject to interpretation. What if the parties are not equal? What if they are not voluntarily engaged? What if, as Turnbull and Turnbull (1997) asked, the decision making process is not actually shared? What if the parties speak different languages or come from different racial, ethnic or socioeconomic groups? These are not rhetorical questions. When there is no common goal, it is very difficult to find common ground. According to Lightfoot (2003), "...families and schools are overlapping spheres of socialization and...the successful learning and development of children depends, in part, on building productive boundaries between and bridges across them (p. xxiii). True collaborative practice between parents and professionals in special education is not an option. It is necessary and it is our responsibility as educators.

Finding Common Ground for Caring and Connecting

There are many means by which educators can strengthen their communication and better their partnership with parents in special education. According to Noblit, Rogers & McCadden (1995), "...caring must be embodied in interpersonal interactions

and in the everyday life of the classroom” (p. 5). Noddings’ (1995) statement about incorporating “themes of care” into the curriculum might also be considered applicable to the field of special education.

Care is conveyed in many ways...It is not just a warm, fuzzy feeling that makes people kind and likable. Caring implies a continuous search for competence. When we care, we want to do our very best for the objects of our care. To have as our educational goal the production of caring, competent, loving and lovable people is not anti-intellectual. Rather, it demonstrates respect for the full range of human talents. Not all human beings are good at or interested in mathematics, science or British literature. But all humans can be helped to lead lives of deep concern for others, for the natural world and its creatures, and for the preservation of the human-made world. They can be led to develop the skills and knowledge necessary to make positive contributions...there is more to life and learning than the academic proficiency demonstrated by test scores (p. 676).

Within the educational system, children with disabilities are largely reliant on the compassion and professional expertise of teachers trained to enable access to the same learning opportunities afforded their peers in general education. Caregiving is a component of educational service provision taken seriously by many special education professionals because “...real healing,” according to Hulnick & Hulnick (1989) “...occurs in the presence of genuine caring” (p. 167). The idea that many “contemporary problems faced by caregivers (today) are rooted in historical obligations to care in a culture that does not value caring” (Lashley, Neal, Slunt, Berman & Hultgren, 1994, p. xvii) is not likely to be disputed in the field of special education. In *Being Called to Care*, Louise Berman described being “called” as “a profound way of being in the world,” (1994, p. 169) and related human service professions to sacrament and “a search for deeper reality (p. 171).” She quoted Fenhagen’s definition of caring as “...a way of actively using our lives in the service of others...” and discussed the “...quest for wholeness, which involves softening our edges and strengthening our center. Soft edges allow the crossing of boundaries into worlds different from our own. Strengthening our center allows creative responses to ideas and situations that might (be) threatening” (p.

174). Those in caring and healing professions (teachers, nurses, doctors, therapists, social workers) often consider themselves "...privileged to have the ongoing, daily opportunity to affect the lives of others" (p. 57), but recognize that this privilege comes with a great deal of responsibility. According to Berman, meeting that responsibility requires "...a sensitive blend of observational, analytical and normative skills that allow what is hidden to emerge. It is wisdom in the midst of complexity, meaning finding in the absence of hope, and clarity in the valley of shadows" (p. 11).

Without sounding too dark and dreary, I think it is only fair to acknowledge some of the many shadows that loom over special education. Given the importance of caring about and collaborating with families, one of them is the fact that many teachers in both general and special education receive very little, if any, specialized training in their teacher education programs related to working with families. In Lightfoot's (2003) comprehensive study of parent-teacher conferences, participants indicated the following three concerns: First, that "...their education did not offer a *conceptual* framework for envisioning the crucial role of families in the successful schooling of children," second, that there was "...no central *value* put on the crucial importance and complexity of building productive parent-teacher relationships," and third, that "...their training never gave them tools and techniques, the practical guidance that is helpful in communicating and working with parents (pp. 7-8).

Without formal training, maybe teachers cannot be expected to have a complete sensitivity to and understanding of all the issues parents of children with disabilities face, but I would argue that a great deal of learning takes place and sensitivities develop over the span of a teacher's career. Certainly pre-service teachers can learn how to demonstrate caring behavior, but is it actually possible to teach people to care? It takes time and experience to learn how to work with children who have moderate to severe

disabilities, to maintain hope and to interact with parents in a supportive and compassionate manner as they make sense of and find meaning in their experiences with their child in special education. It requires a grace that should be discussed and contemplated as a component of the teacher preparation curriculum, but there is no way around the years of practice required for any level of proficiency to be achieved.

Special educators can increase the possibility of developing strong and healthy emotional connections with parents in a variety of ways. One is to encourage teachers, therapists and administrators to engage in what is known in both the medical and educational communities as “reflective practice.” Reflection, according to Birmingham (1991), is “...not something a teacher does, not a form of knowledge or a thought process...but a moral way of being” (p. 189). Reflective practice can serve to remind us that “...the roots of our profession lie in service to people rather than to systems ...” (Wellington, 1991, p. 5). According to Epstein (1999), reflective practice allows physicians (or other professionals) to “...attend in a nonjudgmental way to their own physical and mental processes...” and allows them “...to listen attentively to patients’ distress, recognize their own errors, refine their technical skills, make evidence-based decisions, and clarify their values so that they can act with compassion, technical competence, presence and insight” (p. 833). Reflective practice also requires “mindfulness,” which Epstein described as being present, humble, welcoming of uncertainty, compassionate based on insight and willing to set aside prejudices. It also requires that the practitioner do some “thinking about thinking and feeling about feelings” in order to “...become flexible...recognize bias and judgments and thereby act with principles and compassion” (p. 835). According to Epstein, “mindlessness accounts for many deviations from professionalism, which seem to occur more often in emotionally charged situations, during situations of uncertainty, and under pressure to

resolve problems” (p.837). This describes the environment in special education perfectly, and explains how easily communication may be soured and relationships damaged when school professionals behave without taking the feelings of parents into consideration. Much of the conflict that exists between parents and professionals in special education could be reduced if professionals made their “...teaching decisions on the basis of a conscious awareness and careful consideration of the assumptions on which the decisions are based, and the technical, educational and ethical consequences of those decisions” (Yost, Sentner & Forlenza-Bailey, 2000, p. 41). Thoughtful decisions are necessary in the classroom, but they are also especially helpful in negotiating relationships with families.

A considerable body of research exists in relation to building collaborative relationships between parents and school personnel. According to Lake and Billingsley (2000),

Attention needs to be paid to the whole child, and his or her abilities, strengths, aspirations, and needs. Educators also need to provide opportunities for parents to describe their children and their dreams for their children, and to include parents’ perceptions in educational planning. This sharing of parent and school perspectives and viewing the child as a whole person provides a firm foundation for good parent-school partnerships (p. 249).

According to Oyler (2001), educators must “...view all learners as active constructors of knowledge, and seek to uncover their capacities, rather than their deficiencies” (p. 29). A focus on what a child brings to the learning situation can set up opportunities for professionals to collaborate with parents, and numerous studies have indicated a variety of ways in which professionals can increase collaborative spirit in the school environment. Demonstrating sensitivity to the multiple challenges (emotional stress, financial strain, time limitations, unfamiliarity with educational processes, general anxiety) faced by families of children with special needs (Ross, 2004) are helpful. The adoption of a family-centered approach and use of language driven by themes of

opportunity and possibility rather than limitations and deficiency (Rogers, 2002; Christenson, 2004) can alleviate tensions between families and professionals. Conflict can be avoided when professionals refrain from pathologizing the child and instead focus on his or her strengths and abilities (Shapiro et al, 2004). Respecting the integrity of the family, in terms of available time and resources for meeting the needs of the child with special needs (Dinnebeil, Hale & Rule, 1996) can also enhance collaborative relations. It is important for parents to sense compassion in order to enter into a partnership with professionals, as well as to trust that their perspective and the knowledge they possess about their child will be respected rather than judged. Finally, establishing trusting relationships associated with security and predictability can help parents tolerate smaller negative events without losing faith in the school community as a whole.

Conclusion

Review of the literature indicates that deeper consideration of families in special education is key to relationship building. I think demonstrating understanding and sensitivity are the most direct routes to healthy relationships between educators and parents, but in-depth analysis of this relationship from the perspective of the parent appears to be scant in the literature. Certainly, as special education professionals, we cannot make all parents of all children with low-incidence disabilities happy all the time. But if strong relationships between parents and educators are necessary for successful school experiences for children with special needs, then we, as educators, owe it to both parents and children to recognize and honor the complexities of that relationship. This qualitative study used interviews to elicit stories from parents about the experience of their relationships with professionals in special education.

THEORETICAL FRAME

An Ethic of Care

Caring is a complicated concept. It has been trivialized and marginalized by some and held up as a legitimate practice that should be acknowledged as a valuable and worthwhile endeavor by others (Noddings, 2003; Rauner, 2000). Few would deny caring environments facilitate social adjustment and academic learning for students in regular education settings, and even fewer would argue against including care as a component of policy and program planning in special education. The problem, as it relates to this research study, is that while the value of caring relationships may be undisputed, definitions of “care,” and how it should be provided vary widely among individuals who maintain different positions of power and authority in the school setting.

What does it mean to care? According to Rauner (2000), it is an “endlessly cycling process comprised of three interrelated components” (p. 20). They include:

1. Attentiveness, which involves concern for others, awareness of other people’s needs, desires and suffering, and the ability to consider others’ point of view....It is both a state of being receptive to others and of mental clarity, or awareness, that allows one to see not only what one expects to see, but what is truly there. Attentiveness is not merely a passive state of readiness for whatever might come along; it is the active seeking of an understanding of the other.
2. Responsiveness, which impels us to act: to call out to a stranger who has unknowingly dropped his wallet; to reach out to a woman who has fallen and appears to need help; to embrace a child who begins to cry. With attentiveness, we go beyond ourselves to the other in our state of mind; with responsiveness, we extend ourselves to act to help another, (and)
3. Competence, which is a skill that has both cognitive and affective qualities. It is knowing what to say and how to say it, or what to do and how to do it. It is knowing, and being able, to refrain from action when one’s strongest affective impulses are to action. It is knowing, as well, the *value* of the care one can offer to its recipient...Competence in care can be taught and cultivated, and it is certainly a product of experience (p. 21-22).

There are rules and reciprocity in caring relationships; when we give care, we usually get something in return. It is not, as Rauner noted, “a free-floating sentiment: it is bounded by the needs of the one cared for, the capabilities of the caregiver, and the circumstances of their relationship (p. 37). The circumstances of relationships between parents and professionals in special education often defines the degree of partnership between them. Fisher and Tronto (1990) noted the difference between *taking care of* and actual *caregiving*. *Taking care of* involves assessing and planning, investigating available resources and assuming responsibility for outcomes and consequences. *Actual caregiving* is the “...concrete (sometimes called hands-on) work of maintaining and repairing our world” (p. 43). It seems important to acknowledge that students with moderate to severe disabilities require levels of care above and beyond what typically developing children require in school and that the people responsible for that caregiving, especially those in paraprofessional roles, are often afforded the least recognition, respect and compensation by the educational community. As Fisher and Tronto indicated,

Bureaucracies also separate caregiving from taking care of. The levels of responsibility in bureaucratic organization increase as one goes higher in a bureaucracy; the levels of caregiving increase as one goes lower in a bureaucracy. Thus, at the bottom, individuals are expected to engage in caregiving according to routines whose procedures and logic were derived at some distance from the actual caregiving itself (p. 49).

Parents and professionals have different long-term responsibilities to the partnership that exists between them (Murray, 2000), and clearly “...in organized care situations, practical considerations make limits to care essential” (Rauner, p. 43). Teachers cannot care equally well and with equal intensity about all students and their parents all the time. Every once in a while though, parents and professionals are able to take a step back from one another, acknowledge each other’s incompleteness and begin to listen to each other in a way that allows each to hear more than what is simply being said.

It is a generous and risky gift (Todd, 2003) from both sides, and what emerges from it is, I believe, a tentative type of friendship. It "...entails a joint promotion of common ends" and is characterized by kindness, reciprocity, care, sympathy and solidarity (Porter, 1996, p. 57). I have not found this friendship documented at length in the literature on care or collaboration between parents and professionals in special education, but it is something that I have witnessed and personally experienced. When parents and professionals have "friendly" feelings toward each other, the dynamic of the relationship is changed. The tone of face-to-face interactions are no less professional, but there is a less somber, more lighthearted quality to conversation and an ease between people that makes talking about difficult or sensitive information both possible and productive. It is something to strive for, to treasure and to learn from when it happens. In light of its impact on special education practice, it is also something that warrants further exploration.

I think this friendly connection can only happen when power is equalized, parents and professionals know each other well and both parties come to the table with care and respect for the other. They do not always have to agree, but when each believes they are cared about both emotionally and practically as a person by the other, collaboration is most likely to occur. As Gilligan (1982) noted, "...moral judgment proceeds from an initial concern with survival to a focus on goodness and finally to a reflective understanding of care as the most adequate guide to the resolution of conflicts in human relationships" (p. 105). Unfortunately, care, in and of itself, is not always reflected in interactions between parents and professionals in the school setting.

Power Relationships in School

In the school setting, parents and special education professionals interact most often during formal meetings. Time may be limited and there is often a significant

amount of information that needs to be reviewed. Educators are generally in control of these meetings and their agenda tends to dominate the proceedings. In *Transforming Power: Domination, Empowerment and Education*, Kreisberg (1992) looked "...deeply at how specific relationships of domination are situated within a web of supporting ideological and structural forces that form a pattern so pervasive and persistent that...people believe relationships of domination are inevitable, unchangeable, appropriate and natural"(p.15). Two notions of power are central to his theory. He described the forceful or coercive imposition of will in attempting to control others as "power over." Alternately, he explained "power with" as action rooted in human connection and conceived as "...a developing capacity of people to act and do together" (p. 71). It revolves around mutual caring, respect, trust and collaborative efforts.

In his writing, Kreisberg drew on Fromm's concept of "humanistic communitarianism," where work, decision-making and resources are shared in a spirit of love, respect and dignity (p. 62) between human beings. Kreisberg noted how use of "power with" can reduce and eventually diminish the need for "power over" (p. 62) tactics and result in the development of a relationship characterized by collaboration. These relationships of co-agency (p. 85) are ideal in education, but hold even greater potential in special education where successful partnerships between parents and professionals are known to result in greater student achievement (Turnbull & Turnbull, 1997).

Kreisberg recommended seeking out "...new modes of relationship which are not based on domination and submission and are not organized into hierarchies of the powerful and powerless" (p. 18). He also encouraged alternative visions of relationship in schools between parties traditionally thought of in hierarchical terms; although he referred mainly to administrator/teacher and teacher/student relations, extending the

metaphor to the relationship between special education professionals and parents of children with disabilities makes sense. For the most part, educators are more powerful than parents when it comes to decision making and program planning for children with disabilities in school. There seems to be a pervasive message of expected submission woven throughout the IEP process. School administrators prefer compliant parents to those who arrive at meetings armed with knowledge, demands for special treatment or an attorney. It may be subtle, but I believe there is violence embedded in the coercive nature of professional conduct in special education. When we make decisions about children and then attempt to convince parents our decisions are best for their child, we are imposing our will in an attempt to control them. It is aggressive and coercive, but it also might be considered an abuse of the power held by many school professionals.

When relationships between parents and professionals turn adversarial, they consume an enormous amount of time and energy that could be better spent in a more productive and meaningful manner. It is imperative for school professionals to pay attention to issues of loss and to take the reality of life with a child with disabilities into consideration when interacting with families. While we cannot change the anger or pain families bring with them into special education, we can, on an individual basis, change how we respond to them. As special educators, we do not have the power to make cerebral palsies and autisms and retardations go away. We might acknowledge this, and then begin to imagine our students as if they were our own children and their parents as if they were our sisters and brothers. I am certain that our treatment of them would change accordingly; we might quiet our attitudes, soften our voices and extend our definition of “best practice” to include simply being with families as they cope and learn and grow. It might not be easy or efficient, but it would be just, inclusive and extraordinarily compassionate.

Ambiguous Loss

In the earliest stages of formulating what would eventually become this research project, I came across a book written by Pauline Boss (1999) called *Ambiguous Loss: Learning to Live with Unresolved Grief*. Boss described two types of ambiguous loss; one in which a loved one is physically absent but psychologically present, and another in which a loved one is physically present but psychologically absent. Boss focused on caregivers of those with Alzheimer's, dementia and other chronic mental illness. Her research was narrative and attentive to the lived experience and meaning embedded in the stories people told. She wrote about how ambiguous losses are highly stressful because of their complexity, how they often continue for many years and how they are rarely treated as "real" losses that warrant participation in socially sanctioned rituals for grieving. She also wrote about the stigma attached to some ambiguous losses, the resilience she observed in families, and the need for the professional community to recognize and validate this experience.

In the process of conducting this research, I read many books and articles about how parents of children with disabilities make sense of their experience. Many refer to the partial and ambiguous loss without calling it that by name, and most, like Boss, are quick to point out that loss does not, by any means, preclude or distort the joy associated with parenting and caring for a child or loved one, regardless of his or her level of need. I did not expect any one theory to be able to shed light on all the stories that are contained in the narratives from participants in this study, but I found Boss' theory of ambiguous loss to be a unifying theme in the analysis of many of the stories. Boss (1999) spoke of families who, in the absence of clarity, cling to hope that their loved one will, at some point, return or recover (p. 30). Parents of children with disabilities often cling to that

same type of hope for their child to outgrow or overcome their disability. Hope is an understandable and necessary thing, but when it is unspoken and nurtured silently for many, many years, it can become somewhat immobilizing. Boss described her therapeutic goal of helping families celebrate a loved one's presence while providing the support they need to mourn the part of them that is lost (p. 24), and I believe that should also be a relevant goal for special education professionals. If we could simultaneously help parents celebrate their child's progress while supporting them in any sadness they might feel about their child's disabilities, our relationships might become stronger and more cohesive. Stories from participants in this study served to support this belief.

PLAN FOR STUDY

Problem Statement

As stated at the beginning of Chapter Two, even the kindest and most caring professionals in the field of special education sometimes find themselves unwelcome partners with parents in the education and care of children with disabilities. Parents and professionals often view children through very different lenses, which at times can result in tense and acrimonious interactions that hinder the development of productive working relationships. Although trained to provide educational services for children, professionals are not always equipped to offer parents emotional support, understanding and encouragement toward empowered participation in their child's educational program, which can place additional stress on an already strained relationship. Clearly, the relationship between special education professionals and parents of children with disabilities is a complex one.

There are many issues in special education that make me uneasy. Most of them are large, systemic, and beyond my ability to fully understand or hope to change.

Relationships though, are negotiated on an individual basis and can always be improved upon. This research project is, essentially, a personal one. It is based on my own dissatisfaction with and concern for the tentative and troubled relationships created and maintained by many professionals in the field of special education with the parents of the children we serve. After sixteen years as a witness to and participant in some amazing and some truly awful attempts at collaboration with parents, I might know a few things about what works and what is guaranteed to fail, but I (and we, as special education professionals) have much yet to learn, and I believe it is parents of children with disabilities who can teach those things best. The intent of this study was to use stories parents tell of their experiences with professionals in special education to increase awareness of the complexities of that relationship. Residing within the stories is, I believe, a framework for looking at this relationship in a positive light. With that light, I hope my readers will see themselves as agents for positive change with parents and other professionals in their own lives, schools, and personal narratives.

Purpose Statement

The primary purpose of this study is twofold: to explore parental perceptions related to healthy working relationships between parents of children with disabilities and special education professionals, and to explore how the experience of parenting a child with disabilities impacts the relationship parents wish to form with those professionals. It is also an attempt to examine how parents, school systems and societal understandings of disability intersect in the realm of providing educational opportunities and care for children with disabilities, to obtain more comprehensive understanding of how raising a child with disabilities may impact parental relationships with special education professionals, and to explore and reflect on the multiple meanings healthy working

relationships with special education professionals may have for families of children with disabilities through the stories they tell of their experiences. In addition, it was my hope that this collection of life story case studies (McReynolds and Koch, 1999) would help me answer my research questions and that those answers might eventually be of benefit to the special education community as well as useful as teaching tools for pre-service professionals in the field.

Research Questions

1. How might the experience of parenting a child with disabilities impact parental relationships with educators?
2. What are the pertinent issues identified by parents of children with moderate to severe disabilities that relate to successful working relationships between parents and educators?
3. How do organizational structures and practices support or impede effective and meaningful relationships between parents of children with moderate to severe disabilities and educators?

Rationale for Study

My intent was to fill what I perceive to be a gap in the literature with the narratives of parents who have met the challenge of raising and educating a child with special needs with grace and fortitude, a willingness to embrace and adapt, and the courage to engage in the give-and-take required to build and maintain working partnerships with educators. I believe the field of special education can benefit from in-depth qualitative study of the parent experience in special education, especially when that study is focused on positive ways in which we, as professionals, can make relations

between ourselves and the parents of our students better. The participants in this story are extraordinary parents who have persevered through intense but diplomatic negotiations with school teams to obtain what they believe is best for their child. Their stories deserve to be told. And as Lightfoot (2003) indicated, "...we-parents and teachers-can learn a lot more from examining examples of "goodness" than we can from dissecting weakness and pathology" (p. xxvii).

My plan was to seek out parent participants who have children with moderate to severe disabilities, because this is the population of children who are most often excluded from general education classrooms. I targeted parents with children who are included in general education classes for either one or more academic subjects or non-academic activities, because parents of children with disabilities who are included have to communicate and build relationships not only with special educators, but also with general education teachers who may or may not have an understanding of or sensitivity to their child's special needs. I initially limited the study to participants with children between the second and seventh grades because a majority of the children I have worked with over the years have fallen into this grade range, and I am familiar with the social, academic and functional skill expectations for children this age in both special and general education settings. I thought this would allow me to feel more comfortable probing for information during the interview process and more able to extrapolate and explore the common themes that emerge from the information participants shared with me. As potential participants contacted me, I decided to expand these

limitations to include children in Early Childhood and primary grade levels as well.

CHAPTER THREE: RESEARCH DESIGN

METHODOLOGY

I am interested in learning about how I, and we, as educators, can better relate to the parents of children with whom we work. Given the complex nature of the relationship between professionals in the field of special education and parents of children with disabilities as well as the depth of my personal and professional connection to the subject, I completed an interpretive study which utilized narrative and feminist methods of qualitative interview research. I invited the participants in my study to share stories of their experiences with special education professionals and examined those stories in light of power relations in education, ethics of care and the phenomenon of ambiguous loss.

Feminist Inquiry

Several components of feminist inquiry were significant in this research study. According to Spender (1985) feminist inquiry is "...based on the premise that the experience of all human beings is valid and must not be excluded from our understandings," as well as that there is "...no one truth, no one authority, no objective method that leads to the production of pure knowledge" (cited in Reinharz, 1992, p. 7). Honoring lived experience is central to feminist inquiry (Olesen, 2000), as is being attentive to the context in which that experience occurs (Sutton, 1998). As "...feminist epistemology is concerned with reforming or reconstructing scientific practice in a manner that equalizes power between social scientists and the people they study," (p. 13) feminist researchers often seek to create an environment within the study where participants are viewed as knowledgeable experts with experience that is considered

valuable (Reinharz, p. 25). These notions were especially important to me in the context of this research project, as it was my intention to become a student to the participants in my study and to recognize them as experts of their own realities. My status as a researcher and special education professional was of little importance as I collected data for this study; regardless of the fact that I was the one reading, interviewing, analyzing and writing, the participants were, without question, the authorities on their experiences.

Personal interest and experience have come to be accepted points of departure for feminist research studies, but like other researchers conducting studies in their own fields, I come to this project with bias and preconceived notions. According to Patton (2002), personal connection to the subject can “either enhance or reduce credibility depending on how it has enhanced or detracted from data gathering and analysis” (p. 566). Reinharz (1992) wrote about the role of the “knowledgeable stranger” (p. 27) and described the “epistemology of insiderness” (p. 260) that allows a researcher with knowledge about the topic of study the ability to more effectively understand what participants say during interviews than someone with a less intimate understanding of the topic might. Initially I was not sure how much disclosure of my “knowledgeable stranger” status would be needed during the interview process, but as I progressed through the interviews I found it mattered very little. The participants were all used to talking to school personnel about their children and seemed to me to find my interest in them and their stories about their children either odd, refreshing, or mildly amusing. Compassion grown from professional expertise may have served me well during this research by allowing me to be less intrusive than someone outside of the field might, but I was cautious, listened more than I talked and tempered my responses to participants during interviews with the perspective that while the experience the participant was describing was not completely foreign to me, it was also not one with which I was personally familiar.

For this study I sought out participants who maintain a caregiving role and who were interested in talking about their relationships with the professionals in their child's school. Although the study was open to both men and women, I anticipated that a majority of the participants would be women, and I was correct. If one believes that women and men perceive and relate to the world differently (Crotty, 2003, p. 174), then it makes sense to privilege the voices of women in matters specifically pertaining to their lives and their work. Without diminishing the important contributions any male participants might have offered, I think it needs to be noted that women, as mothers and teachers, are usually the primary caretakers for children with disabilities in our society.

Narrative Inquiry

Narrative inquirers, according to Clandinin & Connelly (2000) "...tend to begin with experience as lived and told in stories" (p. 128). My own lived experience as an occupational therapist in the public school setting was the *narrative beginning* (p. 70) for this research, the root of my curiosity and desire to understand, more deeply and effectively, the lived experiences of the families connected to the children with whom I work each day. Just as with typical children, children with disabilities and their families experience joys, triumphs and pleasures, but there is also an undeniable undercurrent of emotion unlike anything I have known families of typical children to describe. It would not be quite accurate to label it anger, frustration or loss, and it is deeper and more subtle than sadness or disappointment. What it is, in many ways, defies description and is best explored through the stories told by people who know and live with it daily. Within Ellis & Bochner's (2000) definition of narrative inquiry is, I believe, a very accurate description of the lives of many of the families I have come to know and, essentially, the heart of this research project. They defined narrative inquiry as

...stories that create the effect of reality, showing characters embedded in the complexities of lived moments of struggle, resisting the intrusions of chaos, disconnection, fragmentation, marginalization, and incoherence, trying to preserve or restore the continuity and coherence of life's unity in the face of unexpected blows of fate that call one's meanings into question (p. 744).

Narrative inquiry has also been defined as a conversation composed around a particular wonder or puzzle (Clandinin & Connelly, 2000, p. 124) that begins "with experience as lived and told in stories" (p. 128) and carries more "a sense of continual reformulation of inquiry than it does a sense of problem definition and solution" (p.124). Phillion (2002), described narrative as having

...a close-to-life, intimate quality, a reflective, reflexive quality, a flexible, fluid quality, and a contextualized, historicized quality, which enables inquirers to explore and portray the shifting, evolving, often paradoxical nature of experience. Narrative is about understanding the complexities of experience, honoring the subtleties of experience, and understanding the dynamics between individual experience and contexts that shape experience. Narrative reaches out to the past, is rooted in the present, and turns an eye to the future; narrative evolves with changes and shifts in time, place and interactions. Narrative, as both phenomenon and form of inquiry, is a perspective that provides illuminating ways of viewing the world (p. 20).

Given the nature of this study, a narrative form of inquiry was the most appropriate methodological option available for a number of reasons.

The first, although not the most important, is that its use allows me to acknowledge myself as a participant in the inquiry. Clandinin & Connelly (2000) noted the strong autobiographical nature of narrative work and how our research interests grow out of and are guided by our experiences. This study is about the stories participants tell, but it is also about my journey into their lives. I conducted this research, but I am also, in many ways, in it. My perspective had an influence on the questions I asked participants, the stories I heard in the descriptions of their experiences, and the in formulation of the analysis. The stories will always belong to the participants, but they were used to inform me of the reality of their lives. Some of these stories affirmed my ideas and opinions, but

others served well to counter my perceptions. It was my challenge to become informed purely through interactions with participants and their stories, to let the stories speak for themselves, and to present the data in a manner that authentically represents the participants and their experiences. It is my hope that these stories and this work will perhaps prove useful to a larger audience at some point in the future.

Entwined as I have been for many years with the people this work is about, it was impossible for me to engage in the research process without “a cascade of ghostly memories of people and happenings flooding into [my] consciousness” (Clandinin & Connelly, p. 66). Every child and every parent I have worked with in my professional life has left an impression and a story in my mind. They were with me, for better or for worse, as I progressed through this project. Clandinin & Connelly refer to these impressions and stories as *memory boxes*, and describe how they are best used to support the dynamic interaction between people and events that have touched the researcher’s life and their current research texts. This allows for “movements back and forth through time and along a continuum of personal and social considerations” (p. 66) that contribute to both the flow and authenticity of the narrative. Using a narrative form of inquiry allowed me to acknowledge that it is my experience and my narrative that brought me to this point. Rather than apologizing for my intrusions into the stories the participants shared, it was my hope to quietly and respectfully join in the “conversations” that comprised this research project.

A second reason for selecting narrative inquiry for this study is that it allowed me to access the lived experiences of participants through the interview process. Participants were initially strangers to me, but because I understand the highly personal nature of their stories and appreciated their willingness to share them, I made the effort to get to know them. Looking back, I think I was able to do this more effectively with some participants

than with others. I remain convinced that the only way to obtain the information I was looking for was to sit down and listen while the participants talked to me. Reinharz (1992) noted that interviewing allows "...access to people's ideas, thoughts and memories in their own words" (p.19). Weiss (1994) indicated interviewing also

...rescues events that would otherwise be lost. The celebrations and sorrows of people not in the news, their triumphs and failures, ordinarily leave no record except in their memories. And there are, of course, no observers of the internal events of thought and feeling except those to whom they occur. Most of the significant events of people's lives can become known to others only through interview (p. 2).

Harvey-Kolpin (2006) noted that qualitative methods such as the interview can provide the researcher with thick descriptions, multiple perspectives and a deeper understanding about the issues being studied (p. 122). Surveys and questionnaires have their purpose, but it is face to face encounters with participants during interviews that can sharpen the powers of both observation and empathy (Luttrell, 2003, p. 153). These qualities are necessary for understanding, but also allow for a research study of this nature to yield a level of detail beyond what a survey or questionnaire might. Bourdieu (1996) described the interview as a "...special kind of social exchange" which "...implies understanding [of] what can and cannot be said, the forms of censorship which prevent the voicing of certain things and the promptings which encourage the emphasis of others" (p. 19). He discussed ways to reduce social distance between researcher and participant, using the interview as a "...sort of spiritual exercise, aiming to obtain...a true transformation of the view we take of others in the ordinary circumstances of life" (p. 24). It was my hope that the data obtained from these interviews would be rich, personal, complex and emotional, and I was not disappointed. It was also my aim in this research project to use these "...narrative fragments, enacted in storied moments of time and

space” (Clandinin & Connelly, p. 17) to produce accurate and meaningful descriptions of these narrative accounts. I hope my readers will not be disappointed.

Story is a powerful tool for transmitting knowledge, shaping beliefs and adapting attitudes and that is the third and final reason I selected narrative inquiry for this study. My parents are prolific readers and creative writers, and the stories that graced my childhood have remained with me as a framework for understanding and being in the world as an adult. For reasons that do not require an explanation to those familiar with Dr. Seuss, the story of *Yertle the Turtle* is inextricable from my understanding of how dangerous a little bit of power can sometimes be. Like a faithful imaginary friend, Yertle crawled beside me as I wandered the Holocaust Museum in Washington DC two summers ago, and he often sits quietly under my chair during meetings where I watch school administrators and parents lock horns in the gruesome and ongoing fight for authority and control. In a similar manner, the *Lorax* peers over my shoulder with every trip to the recycling bin, reminding me, with his pointed furry finger and wheezy voice, that I am a visitor here and have a responsibility to do my part in taking care of the earth and its inhabitants. There is no better way to learn, as far as I am concerned, than from the storied experience, factual or somewhat transformed, of others. A well-told story creates space for thinking and growing. It connects us to people and events we may not otherwise know and finds a way, when worded just right, to reach hidden places in our hearts. Stories can open our minds, restore our faith or provide us with a reason to take action. According to Ellis & Bochner (2000),

...the stories we write put us in conversation with ourselves, as well as with our readers. In conversation with ourselves, we expose our vulnerabilities, conflicts, choices and values. We take measure of our uncertainties, our mixed emotions, and the multiple layers of our experience. Our accounts seek to express the complexities and difficulties of coping and feeling resolved, showing how we changed over time as we struggled to make sense of our experience. Often our accounts of ourselves are unflattering and imperfect, but human and believable.

The text is used, then, as an agent of self-understanding and ethical discussion (p. 748).

Stories the participants in this study shared were difficult, at times, to hear, to read, and to think about. There were some pleasant and kindly pictures of events unfolding between parents and professionals in special education, but there were just as many stories rife with dissatisfaction, criticism and pain. Emotion is uncomfortable sometimes, but it is, I believe, necessary for growth. Again from Ellis & Bochner (2000),

...that's where the learning is. We lose our innocence and our lost innocence validates some good values. We gain tolerance and humility. Sometimes we're ashamed of how much we've excluded from our experience, tried not to see, hidden from. And we should be. We don't need to run from the fear or anxiety we feel. We need to learn from it. Racism, sexism, poverty, homophobia, disability- these issues touch all of us. We can't hide from them. We're all complicit in some way. No one's immune, invulnerable. So it's important to get exposed to local stories that bring us into worlds of experience that are unknown to us, show us the concrete daily details of people whose lives have been underrepresented or not represented at all, help us reduce their marginalization, [and] show us how partial and situated our understanding of the world is (p. 748).

While a degree of discomfort may be integral to the learning process in the context of stories, throughout this research study I remained conscious of the responsibility associated with taking on the telling of other people's stories. Aside from the potential for discomfort, disagreement and conflicting feelings about emotional experiences and social distinctions that Luttrell (2003) wrote about, there was the concern that I would fail my participants by simply not being able to do justice (p. 166) to their stories as told to me, or that once re-told, they would be subject to unkind scrutiny or misinterpretation. According to Reissman (1993), "...our narratives about others' narratives are our worldly creations...meaning is fluid and contextual, not fixed and universal. All we have is talk and texts that represent reality partially, selectively, and imperfectly" (p. 15). It was my intent to represent the stories participants in my study told with both honesty and reverence. I believe they are important and worthy of the risk

taken on my part to share them. According to Behar (1993), "...there is no *true* version of a life, after all. There are only stories told about and around a life" (p. 235).

Using story in research is a way of bringing readers into other personal and social worlds (Luttrell, 2003, p. 43) for a shared learning experience. Students with low-incidence disabilities comprise a very small percentage of the population in our nation's schools and rarely qualify for media mention aside from an occasional tragedy, crisis or feel-good story. What goes on in the lives of families who have children with disabilities and in special education classrooms is largely unknown, and mostly misunderstood by mainstream society. Stories though, have the power to provide information which can break down barriers created by a lack of information or limited exposure to a specific population or phenomenon. A few years ago when a book called *The Curious Incident of the Dog in the Night* hit the best seller list, autism became a topic of popular curiosity and book group conversation. People who read the book got a brief glimpse into a world different from their own. In this sense, the story can be seen as an important narrative form for establishing connections and understanding between people with very different life experiences. Ellis & Bochner (2000) described the value of using stories to build bridges between people who do not understand each other well:

The usefulness of these stories is in their capacity to inspire conversation from the point of view of the readers, who enter from the perspective of their own lives. The narrative rises or falls on its capacity to provoke readers to broaden their horizons, reflect critically on their own experience, enter empathically into worlds of experience different from their own, and actively engage in dialogue regarding the social and moral implications of the different perspectives and standpoints encountered. Invited to take the story in and use it for themselves, readers become coperformers, examining themselves through the evocative power of the narrative text (p. 748).

In *The Enlightened Eye* (1991), Eisner cited Elie Wiesel and Truman Capote as writers with the ability to "...put you there" (p. 37). Effective use of truth and emotion provides readers with the opportunity to develop empathy by standing for a moment in another

person's shoes. This empathetic regard for strangers is the foundation for understanding between human beings. Instilling some of that in my readers is, above all else, why I wanted to write faithful accounts (Luttrell, p. 42) of the stories told to me by the participants in my study. These are important stories. They are thoughtful, inspiring, heartbreaking and real. Within them, I believe, rests the prospect of hope for improved relationships between parents and professionals in special education.

METHOD

Information was gathered for this study using informal, semi-structured interviews (Seidman, 1988). Because I was more concerned with depth and detail than generalizable results, I aimed for relatively few participants. Studies closely related to my field commonly use qualitative narrative inquiry research involving between three and ten participants (Philpott, 2003; Das, 2006; Faber, 2006; Foti-Gervais, 2006). Using these studies as models, it was my aim to interview at least six individuals, and I completed the research with a total of eight. The selection process was purposeful in that I sought out individuals who reported having positive relationships with the special education professionals in the schools their children attend. It should be noted, however, that I did not define the word "positive" in my solicitation flyers and expected that the "positive relationships" participants would discuss were likely to be varied. Possible participants were identified through professional colleagues, which led to some snowball sampling (Bertaux, 1981, as cited in Seidman, 1988, p. 47) and participants voluntarily lead me to other people who were willing to participate in the study. Criteria for participation in this study required individuals to have a child with a moderate to severe cognitive, physical or emotional disability currently attending school. Age range for the child was indicated as between three and thirteen years of age. Although there were several families known to

me through my work that I am certain would have enhanced this study with their participation, it was my thought that I would be able to remain more objective in analysis with the stories of participants who were not known to me on a professional or personal basis. As noted in Chapter Two, it was my plan to seek out individuals who have children with moderate to severe physical, intellectual or emotional disabilities who have a history of successful working relationships with staff at their child's school. I selected this population because these are the children most often excluded from general education classrooms.

A brief letter (Appendix A) and flyer about this research study for parents (Appendix B) was distributed to teachers, school administrators and occupational therapists known to me through my education and work in order to locate potential participants. Initial contact with potential participants took place over the phone (Appendix C) or by e-mail where I explained the purpose of my study. I asked them if they would be willing to participate in an interview focused on their experiences in special education and their relationships with the professionals in their child's school. I informed them that the interview would be conducted at a location convenient for them and that it would likely last between sixty and ninety minutes. Although I anticipated one interview session would be adequate to gather sufficient information, I also informed potential participants that talking more time or breaking the interview up into two parts would be an option available at their discretion. Although I offered to reimburse participants for child care during the interviews, it was not necessary for any of the participants, all of whom scheduled the interviews for while their children were at school or invited me to their homes.

Following verbal agreement, interviews were scheduled. Prior to beginning each interview I asked each participant to sign a letter of informed consent. During each

interview, I followed the semi-structured interview guide (Appendix D) as closely as possible. As expected, I sometimes deviated from the guide to probe participants for additional information about aspects of their experience as they spoke. I also changed the order in which some of the questions were posed and skipped over some of the questions that were spontaneously answered in the course of the interview. Interviews ranged from one and a half to six hours in length, and the total time spent in conversation with participants was approximately twenty-five hours.

I used a digital recorder (and a tape recorder as a back-up) to record all of the interviews. I manually transcribed each interview and I de-identified the data as I transcribed. The transcripts were reviewed multiple times and initial broad emergent categories for coding were identified. Line by line coding of the interview transcripts was then completed and the data were arranged according to thematic content. After the data was sorted into general thematic categories, I organized block quotes of text from individual participants to create the “stories” about each theme that are located in Chapter Four.

I considered asking participants to share archival data, including Educational Determination Conference (EDC) and Individualized Educational Plan (IEP) reports to be reviewed and coded for inclusion in the analysis; however, as it was possible that they would not provide useful data and because I was concerned about what asking for them could potentially do to the dynamic of the interview, I decided against it. Many other studies have explored the actual EDC and IEP process and because my interest is more in relation to how parents make sense of that process and how it either supports or inhibits their relationships with special education professionals, those documents were less relevant to the research questions. During the interviews, my aim was to function as a researcher, not as a special education professional, and I wanted to set parents at ease so

they might open up about their experiences. I was concerned that asking for this type of documentation may have created tension or have been perceived by participants as an alliance with the professionals in their child's school. During the interviews, one participant retrieved a copy of a recent IEP from her file to show me one of her concerns about labels and goals. We examined it together briefly. Another participant offered a copy for perusal, which I politely declined.

RESEARCH CONSIDERATIONS

Credibility/Trust

According to Patton (2001), the credibility of a qualitative study is highly dependent on the credibility of the researcher as well as on the use of rigorous methods for collection and analysis of data. Patton indicated the importance of disclosing any "personal and professional information" that may have either negative or positive impact on "data collection, analysis and interpretation..." (p. 566). I made my personal and professional connections to the topic of this research explicit in the proposal for this study, and I was open and honest with the participants about these things during data collection. Regarding my profession, I disclosed to all participants that I am an occupational therapist and that I work in a school setting. Regarding my personal life, when asked, I disclosed that I am a married woman and that I do not have children. Additional details were disclosed with discretion, depending on the circumstances of particular interviews.

During analysis of the data, I took the following steps to assure that results of this research would be credible. Following transcription of each interview, I read over the transcript while listening to the tapes again to check for accuracy and to "stimulate analysis" (Lofland & Lofland, 1995, p. 88). After accuracy was established, I read

through the transcripts to document commonalities and emerging themes among participants. At that time I also noted non-verbal information obtained during each interview. This information included general impressions, speed and fluency of speech, emotional expression and body language used by participants. As planned, I maintained a journal throughout the research process, and after each interview I recorded my questions, thoughts, feelings and any connections I sensed between my participants and individuals or families I have known. Within the written analysis that follows, there is reference to direct quotations from the interviews.

Internal Validity

Patton (2001) described participant review as an effective means of triangulating findings (p.560). Member checking (Cresswell, 2003; Lincoln & Guba, 1985) to confirm the accuracy of coding and as a guide for my analysis and interpretation of the data was one option for assuring the internal validity of the study. According to Riessman (1993), the validity of a researcher's interpretations cannot always be affirmed through the process of member checking because "...human stories are not static (and) meanings of experiences shift as consciousness changes" (p. 66). In light of this, at the conclusion of each interview I asked participants if it would be acceptable for me to call them at a later date to briefly discuss coding of categories and themes emerging from the data in order to verify that my interpretations were authentic. Some of the participants agreed, and as I wrote my initial draft of the results of the study, member checking was conducted with those individuals who were available and willing to clarify areas of ambiguity.

I also utilized peer review as a method of ensuring the internal validity of the study. Peer review is a process by which a qualified peer reviews work and offers critical feedback on analysis and interpretations in order to ensure quality of the final product

(Taylor, Beck & Ainsworth, 2001; Tuckett, 2005). Two peer reviewers were utilized as I wrote the initial draft of the results of this study. Both are colleagues from DePaul University who are familiar with my work and my research interests. Both completed the human subjects training prior to discussing or viewing any data from this study. Participants were not known to peer-reviewers.

Both member checking and peer review were valuable exercises for me during this study. Both contributed to the learning process, increased the depth of my thought about various issues and validated my analysis.

External Validity

“Purposeful sampling,” according to Patton (2001), “involves studying information-rich cases in depth and detail to understand and illuminate important cases rather than generalizing from a sample to a population” (p. 563). Given the small and purposeful sample size that was sought out for participation in this research project, I do not anticipate that the results will be applicable to the general population. It was not my intent to present a biased sample to support preconceived notions about the experience parents may have with professionals in special education, but to make explicit my bias so as to thoroughly and thoughtfully explore and highlight aspects of the participant’s experiences that might be most useful in expanding current knowledge and obtaining a greater understanding of the experiences of families who have children in special education. Participants in the study were not only people with first hand knowledge about the subject, but also people with an interest in sharing their stories. It remains my hope that through the use of “rich, thick description to convey findings” (Cresswell, 2003, p. 196), the final written form will have what Lincoln & Guba (1985) referred to as “transferability.” This will hopefully provide readers with the opportunity to relate to the

participants and learn from their experiences, but I recognize this is a decision that rests in their hands; it will be up to them to decide what aspects of this study will have value or be useful to them in other, perhaps similar, settings.

Ethical Issues

In spite of the obvious time constraints, it was my intention to establish a caring and compassionate relationship with the participants in my study. I hope that my appreciation of their time and respect for their stories was evident. I informed participants that all data obtained for this research would be held in confidence. Pseudonyms, largely of their own selection, were assigned to each participant and his or her family to assure anonymity. Transcriptions were completed by the researcher. Involvement in the study was voluntary and participants were free to withdraw at any time. Potential risks associated with participation were therefore deemed to be minimal.

CHAPTER FOUR: RESULTS

Introduction

One strength of qualitative research is "...its ability to illuminate the particulars of human experience in the context of a common phenomenon (Ayres, Kavanaugh & Knafl, 2003). Although all eight of the participants in this research project shared the commonality of having a child with disabilities, each of their circumstances and subsequent experiences were very different. Certain aspects of an experience that are unique to one individual may or may not be applicable to the interpretation of a similar experience for another individual. For this reason, prior to considering their stories as sources of data, it is important to me to introduce each of the participants and the stories they shared with me about their children.

As a novice researcher, my interviewing technique was certainly not flawless. Initially I was very nervous, and although with practice I became slightly more comfortable with the process, I think there was a tentative quality to my interactions with each participant that may or may not have worked to my advantage. In spite of the fact that the interviews ranged in length and depth, none of these stories are complete. All of them strike me as little snapshots, barely scratching the surface of very complex lives. Each one could fill a dissertation in their own right, but woven together it is my hope these stories will provide a powerful and readable lesson in how we, as educators, might improve the quality of our interactions and strengthen our relationships with families in special education.

Interviews

Elizabeth

Elizabeth was the first person I interviewed. I found her through an occupational therapist I know who owns and operates a private clinic in Wisconsin. We met at the clinic and sat in little chairs in a speech therapy room while her son was with his occupational therapist in another area of the clinic. Elizabeth is fifty-two years old and has been married for fifteen years. She and her husband have three sons; twins James and Peter are eleven and Brendan is seven. The twins were born prematurely via cesarean section because James was not growing properly. Peter remained in the NICU for three weeks and James stayed for five. According to the doctors everything was fine at discharge, but James did not achieve developmental milestones at the same rate as his twin, and when he was six months old the pediatrician at the developmental follow-up clinic recommended therapy services. They started physical and occupational therapy first and speech therapy later. James made progress, but he did not catch up with his twin. When he was a year old he was diagnosed with cerebral palsy.

The diagnosis was difficult for Elizabeth as a first-time mom, but because they were already involved in therapy services, nothing in their day-to-day life changed drastically. He continued to receive therapy services through the birth-to-three program and when he was two he attended a child care center that provided special care for children with disabilities. When he turned three he entered the public school system and was placed in a cross-categorical class with other children with disabilities. He did well academically and socially and eventually joined his peers in a general education program. Cognitively he is able to keep up with the class, but motorically he needs extra time and occasional assistance to do what his peers are doing. He uses a quad cane in school and

fine motor activities like writing are time consuming for him. Outside of school, James does everything his family does. He hits golf balls with his dad and loves to ski and go tubing. He has three therapy sessions and karate lessons outside of school each week, which can be a transportation challenge for his mom and dad but they are helpful for him, and so, according to Elizabeth, they are worth it. The most important thing to Elizabeth is that James is happy and healthy and in almost all ways except for his mobility, he is very much a regular eleven year old boy.

Grace

Grace was the second person I interviewed. She was referred to me by the principal of a school in the area who had received one of my solicitation flyers. Grace invited me to her house for the interview, and we sat and talked in her son's room while he played and his two year old brother napped in the other room. Grace has a Master's Degree in theology and came to the United States with her husband from Poland in 1991. She is in the process of earning an early childhood education certificate from a local university and is currently working part-time as an interpreter. Grace realized that something was wrong with George when he was about three months old. He did not turn his head and his body seemed very floppy and weak. The pediatrician gave them the number to call for an evaluation from the state birth-to-three program, but was otherwise unhelpful. When George was six months old Grace took him to see a neurologist. He had a CAT scan and an MRI and some genetic testing done, but Grace said even that doctor did not really know why George was developmentally delayed. She was told that sometime early in her pregnancy the connections in his brain "didn't develop properly" and that he was functioning at about half of his developmental age. George continues to function at that particular level for now. He is very little for a six year old boy and his

attention span is very short. He does not have discipline problems, but he needs a lot of help with everything he does. He is able to walk, but his balance and coordination are not good. He makes sounds and approximates some words, but is not able to speak in a manner that allows people other than his family and some of his teachers to understand him. He is not toilet trained and his interactions with children his own age are minimal.

George received early intervention services from the time he was nine months old until he turned three. At that time he entered an Early Childhood Special Education Program. The program has children with very severe physical and cognitive disabilities needs mixed in classrooms with typically developing children and Grace has been happy with the program as well as with George's progress. She is very concerned about the transition to kindergarten though, as George will have to transfer to a different school and the options that have been presented as possibilities so far have been inappropriate or unacceptable. Grace told me that in the future she would like for George to become "just a regular kid" but she knows that is "...a dream even more than a hope." She would like for his school program to help him be prepared to exist in society and be as independent as possible, even if he is unable to do complex things or live on his own.

Grace feels lucky to be in the United States, where she perceives people to be much more tolerant of individuals with disabilities. The immigrant experience is something that Grace does not take lightly. Being educated and able to understand and speak English has given her an advantage in seeking out medical care, therapy services and educational opportunities for her son that many other immigrant families do not enjoy.

Rachel

Rachel was the third person I interviewed and the only one who elected to come to my house for the interview. She dropped her boys off at school and took the train over for the visit. Rachel was born in England and lived in Canada. She came to the United States twenty-six years ago to study aerospace engineering at the Illinois Institute of Technology, where she met her husband. Albert was born eleven years ago and her younger son Gerald is eight. Rachel's husband runs his own computer programming business and works long hours. She is a stay-at-home mom.

Rachel described Albert as very "different" kind of child. He never crawled and he never played with a toy the way you would expect him to. He would just turn it over and start taking it apart. When he was three he developed an intense interest in numbers and learned to add. He liked to sit in the lobby of their apartment building and watch the number display on the elevator bank. He could multiply by the time he turned four. Rachel said he was a smart and easy toddler. He talked like an adult when he was three and she could take him anywhere, like on airplanes and to nice restaurants without a problem; he would just sit and look around and listen to the conversation and eat. He had some unusual habits though, like asking her the same question over and over and getting very upset if she didn't give him the answer he expected. And his fine motor skills, for a child of his obvious intellect, were delayed.

Rachel told me she thought he was unusual, but that her family is full of people who are different and so she did not think his behaviors would become problematic as he got older. Albert attended a park district program for pre-school and entered the public school in his neighborhood for kindergarten. Albert was tested for the gifted program and placed in the 99th percentile on all of the tests. He attended a gifted program at a school

on the other side of they city for a year, but he had difficulty with writing, completing his work within the given amount of time and getting along with his peers. Second grade went well, but in third grade Albert was struggling and so Rachel again requested testing with the hope that he might qualify for some special services. A school psychologist who never actually saw Albert decided he had Attention Deficit Disorder (ADD) and told Rachel he needed to be medicated. Rachel talked to Albert's pediatrician, who sent them to Children's Memorial Hospital for an evaluation where he was eventually diagnosed with Asperger Syndrome, seizures, ADD and Obsessive Compulsive Disorder (OCD). Some of the medication he was given for the seizures actually helped his attention, but he continues to struggle with his work at school, even though he is given extra time, a reduced work load and can use an AlphaSmart (which is a small, portable keyboard) or the computer for writing. Albert has difficulty with organization and some significant social skill deficits; Rachel said that in spite of his intellect, he does not know how to approach other children or join in a conversation or play activities. When he talks to people it sounds as if he is reading a book to them, and he is sort of uncoordinated so the other children do not want to play ball or tag with him on the playground. He does not tolerate frustration well and will sometimes just start shrieking when he gets upset or overwhelmed. Albert is in fifth grade now and academically (according to his test scores) he is doing well. He is learning to use the computer for writing and the volume of his written work has been increasing. But he is still socially and emotionally dysfunctional, and Rachel is very worried about the future for him.

Leslee

Leslee was the fourth person I interviewed. We connected through a friend of mine from the gym who is a distant relative of hers. I drove to her house in the far south

suburbs for the interview and while we sat in the kitchen talking her children were in and out of the room and their big black labrador let me scratch his ears while we talked. Leslee has been married for seventeen years. Her background is in biology and her husband is an air traffic controller. She and her husband have two children. Andy is thirteen and a straight A student, and Jeff is ten years old and has autism. He was diagnosed when he was three, and over the years since Leslee has explored a wide range of therapeutic and educational options for him. His first school experience was an early childhood special education program, and he has also been in a cross-categorical classroom and in self-contained rooms for children with autism. Jeff was in general education classes with the help of an aide between second and fourth grade, but according to Leslee, it was increasingly difficult for him to follow along and not all of the teachers were willing and able to include Jeff in the activities along with his peers. Leslee spoke of both positive and negative interactions with teachers and administrators regarding Jeff's academic, social and life skill needs. She talked about her disappointment with the range of available placements and services and her frustration with individuals in the school system who were not knowledgeable about autism, did not understand Jeff's strengths and made decisions based only on their perceptions of his deficits. Leslee and her husband eventually made the decision to move Jeff to a program at a different school where he will receive the services he needs. That school also has a residential program, which may be an option for Jeff when he gets older.

Marie

Marie was the fifth person I interviewed. I found her through one of my classmates at DePaul who is an administrator in the south suburban school district where she lives. Marie invited me to her home for the interview and we sat in the backyard with

the family dog and big glasses of lemonade to talk. It was a lazy summer afternoon, and in between short bike rides and playing ball with the neighbor kids in the front yard, her son Roger also joined us for the interview. He answered some of my questions and offered additional information about his interests and things he likes and dislikes about school. Marie's background is in social work and she worked for the local police department for many years. She and her husband have three children. Roger is fourteen, Jacob is eleven and Lisa is seventeen. They are a close family and maintain many connections with extended family, friends and their church community. After Jacob was born Marie decided to stay at home with the children, and for the last eleven years she has worked part time at their church preschool, tutoring and for a local real estate agent.

When Roger was six months old their pediatrician noted some developmental delays and by the time he was a year old she was concerned enough to refer the family to Easter Seals. Roger received physical, occupational and speech therapy in the day care program there until he turned three and qualified for the early childhood special education program at their local school. He spent a year in a developmental kindergarten class and then went to self-contained classes for first through fifth grades. When Roger was six the school did a case study evaluation and Marie also had some evaluations done privately to confirm the findings. He does not have any medical issues or neurological or genetic abnormalities, but his IQ is low enough that his eligibility for special education is a cognitive impairment. Marie has been pleased with Roger's program. Meetings went well, occasional problems were dealt with in a kindly and efficient manner and Roger's teachers and aides have all been wonderful. Roger has also been involved in Boy Scouts, which has provided him with additional opportunities for growth and friendship. He is, according to his mom, an easy kid to be with, friendly and happy most of the time. They need to maintain high expectations and push him, and while he may resist some of the

pressure, he has also demonstrated a great deal of progress. After initial difficulties with early literacy and phonics he can now read at the fifth grade level. He is learning to keyboard and has developed a wide range of independent living skills that Marie hopes he will carry with him into adulthood. He interacts well with peers and adults and has a best friend who is not in special education. Roger's disability has had an impact on the family, but Marie feels lucky that his issues are, in many respects, easier to cope with than those many other families face.

Ivy

The sixth interview was with Ivy. She and I have been acquaintances for several years, and she volunteered to participate in my study because of the experiences she has had with her daughter. Ivy was the only African American woman to participate in this study. She was also the only one actively working as a professional in the field, the only one whose child's disability could be considered "mild" and the only participant known to me from outside of this research project. When I asked her if any of these issues were of concern to her she waved her hand, rolled her eyes and told me that she was happy to share her story. She felt that it was important for me to hear about her experience, especially from her perspective as a professional in the field. Ivy is a young mother of four. Her background is in special education and she has recently moved into an administrative position. I have always been somewhat awed by how clear-thinking and articulate Ivy is. I appreciate that her administrative philosophy is grounded in classroom experience, and the fact that she can function so smoothly with four children at home is nothing short of amazing to me. As an assistant principal, Ivy is responsible for overseeing special education services in her building and we talked quite a bit about the challenges associated with that before we discussed her daughter.

Gabriella is in seventh grade. She was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) of the Inattentive Type when she was in third grade, but the signs were apparent when she was in kindergarten. Ivy was resistant to initial efforts to test Gabriella because she felt the school was trying to say something was cognitively wrong with her daughter and she knew that was not the case. At her doctor's recommendation, Ivy did not share the initial diagnosis with the school because she wanted the opportunity to see if a trial of medication would be helpful for Gabriella. It turned out to be, and has continued to work well for her, but she still presents with a variety of organizational deficits and some social difficulties.

Ivy has to make sure every year that the proper accommodations are noted on Gabriella's IEP. She benefits from re-teaching, extra time and the use of graphic organizers, but Ivy is adamant that the work load and expectations not be lowered for her. Administrators and teachers have, for the most part, been helpful and Ivy feels fortunate that they live in a district with an excellent school system. But it is a continuous battle to get the right help at the right time for Gabriella. Similar to some of the other children described in this study, Gabriella's disability is invisible to the untrained eye and unfortunately, in our current system, a child often has to fail before their need for support is recognized. Ivy told me that she goes into meetings for her daughter now with boxing gloves on and that in spite of her position in the field she still, at times, is haunted by the feeling she got as a teenaged mom in those very early meetings about her daughter. For now though, things are improving. Gabriella is doing well academically and she is a creative writer and talented flute player. She is learning to manage her challenges, and with the right support from home and school Ivy is hoping that it will be a good school year. She is, however, keeping the boxing gloves handy.

Karen

Karen was the seventh participant. Her children attend or attended a school where one of my friends from DePaul has been teaching for many years. I went to her home for the interview while her children were at work and summer school, and we sat in the backyard to talk. Her garden was beautiful, green and full of flowers and her friendly and very large dog kept sticking his head in my purse to snuffle for treats. Because of her schedule we had a limited amount of time to talk so we spent a few minutes reminiscing about the neighborhood we both grew up in and then she told me about her family. She has been married for twenty eight years. Her oldest son Ryan would be leaving for college in the fall. Her youngest son Phil is twelve. When Phil was eighteen months old he was hit by a car, in the driveway, by someone in the family. He suffered a severe closed head trauma and his brain injury is what is described as a diffuse axonal injury.

His survival was questionable initially, and because his brain swelled, surgery was required to relieve the pressure. The damage was extensive, and the neurosurgeon ended up removing approximately 40% of the frontal lobe in an effort to prevent further damage. Phil was in the hospital for a long time and then went to a pediatric rehabilitation hospital. He stayed there for ten days and then went home. Karen took him to therapy five days a week and in about six months he was walking and talking again, but shortly after that he started having seizures, which is a common occurrence after traumatic brain injury. Medication did not help the seizures, but he responded well to a vagal nerve stimulator.

Phil never, according to Karen, progressed developmentally beyond the age he was when the injury occurred. He can see and hear, but he is almost completely non-verbal. He wears braces on his legs and can walk a little bit, but his movements are ataxic

and he is not safe on uneven surfaces or near stairs without assistance. Phil is dependent for all hygiene and self-care needs and is fed through a g-tube. At school he has an aide with him at all times. He is in a life-skills program, and he loves going to music, drama and gym. He enjoys it when kids and teachers say “hi” to him in the hall.

Karen described him as having a sweet and happy disposition, but he cannot follow simple directions and has not made any academic progress. He communicates some with facial expressions that register pleasure or displeasure, but he is unable to indicate a choice or when he needs a clean diaper. Karen picks him up early from school for therapy several days each week and in the summer she takes him to the beach to walk in the sand and look at the boats. Phil never tires of this ritual, and will start screaming with excitement when he realizes they are en route to the beach. At home he will walk around the yard and say hello to the flowers. He loves the dog and will grab his ears and squeeze his head.

Phil had a strong connection with his grandmother who passed away recently at the age of eighty eight. She would come over every day on her way home from work and sit on the couch with Phil and sometimes they would nap together. Phil waited at the window for her daily for months after she died, often with tears in his eyes. Karen talked briefly about one negative experience with an insensitive and incompetent social worker, but otherwise had only kind words for the educators who have been on Phil’s team since his enrollment in school. Karen was dismissive of a few who gave her a hard time about pulling him out of class for therapy (“What is he missing, organic chemistry?”) and those who have failed to acknowledge that his schooling is more about caretaking and exposure to interesting things during the day (“Sure he likes art, but as soon as he takes someone’s paper and crumples it up or breaks something, in my opinion, he’s done with art. Because it’s not fair to everyone else.”) than it is about academic content. At the end of the

interview Karen mentioned how at the last IEP meeting a transition coordinator was in attendance to talk to her about planning for the future. She understands the reason why she is being encouraged to look into residential options and put him on the waiting list for Misericordia and Lamb's Farm. But Phil is her baby, and, for the rest of his life will remain the eighteen month old child she let out the front door and into the path of her brother's car. So for now, she is not ready to take that step.

Kathleen

The final interview was also the most extensive. Kathleen was referred to me by the principal of a school in the area who had received one of my solicitation flyers. She is from the South and went to college in the Midwest. After finishing her PhD, she and her husband came here together. She is an historian and professor of history at a local university and he works in the educational publishing field. They have one child, and her name is Anna. Kathleen's pregnancy was typical until the seventh month, when during a routine ultrasound an abnormality was noted in the baby's brain. After further testing Kathleen and her husband were told that the baby had agenesis of the corpus callosum (ACC). At the time there were only two options. The first was simply to wait and see what might happen. They were told that some children with this diagnosis are fine while others are not but there is no way, really, to determine the outcome in advance. The second option was essentially not an option for Kathleen and her husband; they were not interested in terminating the pregnancy for any reason. So Kathleen and the baby were monitored very closely for the last two months of the pregnancy.

Anna was delivered by cesarean section because Kathleen's labor did not progress. The historian in Kathleen found the experience to be an odd one; on one hand she was grateful for the medical intervention that brought her daughter into the world, but

at the same time she was wary of it because of what she felt Anna might be trying to tell her and her knowledge that maybe a hundred years ago it was likely they both would have died during childbirth. But when Anna arrived she was beautiful. She was colicky but otherwise healthy until she was three months old and the seizures started. Seizures are a common complication in children, especially girls, who have ACC, but none of the doctors talked about that with Kathleen and her husband. She suspects that they knew but consciously avoided mentioning it because they assumed early on it would not have been helpful. But it is the seizures, sometimes up to forty of them each day, not the ACC, which have become what Kathleen described as “a fixture” in their lives.

Anna is four years old now, and her intellectual and motoric development is severely delayed. She can roll a little bit but is otherwise not very mobile. She can make sounds but cannot yet say words. She cannot control her movements enough to feed herself or manipulate toys in a manner that is functional for sustained exploration and play. She can see and hear, but she has difficulty processing sensory information and often becomes startled or disorganized by visual and auditory stimulation. Anna received early intervention services at home and entered a special education program at a school that is on the far northwest side of the city when she turned three. Kathleen has been happy, for the most part, with the school program for Anna but recognizes that she sees her child in a much different light than the teachers and therapists at school do. They do not expect as much of her as Kathleen would like and seem too willing to concede to what she is unable to do. She is disillusioned with how the system functions and angry that she, and other people like her, have to fight so hard to obtain appropriate care and services for their children in the public schools.

The following is a chart containing basic information about each participant in this study.

Table 4.1 Chart of Participant Information

Interview	Mother	Father	Child	Child's Age	Child's Condition	Siblings and Age
1	Elizabeth	Not Named*	James	11	Cerebral Palsy	Twin Peter, 11 and Brendan, 7
2	Grace	Not Named*	George	6	Congenital Brain Anomaly	Alex, 2
3	Rachel	Not Named*	Albert	11	Asperger Syndrome, ADD, OCD, ODD, seizure disorder	Gerald, 8
4	Leslee	Not Named*	Jeff	10	Autism	Andy, 13
5	Marie	George	Roger	14	Cognitive Impairment	Lisa, 17 and Jacob, 11
6	Ivy	Not Named*	Gabriella	12	ADD	Two sisters, one brother, ages not indicated during interview
7	Karen	Mike	Phil	12	Traumatic Brain Injury	Ryan, 18
8	Kathleen	Not named*	Anna	4	ACC, intractable epilepsy	

* Indicates fathers who were referred to as “my husband” or “Dad” during the interviews so a pseudonym was not required throughout transcription of the narrative.

The Major Issues

Although the stories told to me by each of the participants in the study were very different, it was not difficult to identify many of the common themes running through each. After thorough review and examination of written transcripts from the interviews, eight common themes emerged from the data and were used as an organizing framework

for the narrative. They include the ways in which children with disabilities impact family life, expectations, school and classroom placement issues, challenges to effective communication, the quality of the interactions between parents and school staff members, problems with the school system, how families ultimately resign themselves to, accept or make peace with their child, the school system and their family situations, and parents' recommendations for change. Each theme is presented below. The voices of multiple participants are woven together in each section and followed by my analysis to create a coherent story for each theme.

The Family

For families who have typically developing children, many common sense notions about how they learn and grow and behave (most of the time) can easily be taken for granted. Children are supposed to get bigger, develop interests and personalities and have an occasional temper tantrum as they become increasingly independent. While they require a considerable amount of care, feeding and frequent washing, most also provide their parents with a great level of return on their investment. They smile, play, talk, toddle from room to room, and then move on to school and work and usually, eventually, out of the house.

Families who have children with disabilities often follow a different path; when your child's developmental trajectory does not include independence in matters small (such as playing with toys) or large (such as toileting, feeding, walking or expressing him or herself verbally) life as you know it changes drastically. There are practical considerations to attend to, and there may be financial issues and altered family dynamics. Activities that were once simple, such as a trip to the store or stopping at a restaurant for a meal may become time consuming and complicated. For many of the

families in this study, even those who consider their lives to be quite “normal,” it is a challenge to keep the family running smoothly. This section is divided into six parts. They include practical considerations, financial concerns, tension between significant others, sibling relationships, grandparent involvement, and the process of redefining what it means to be a “normal” family.

Practical considerations.

Having a child with disabilities frequently requires that an extended amount of time be allowed for most daily activities. It can also add a number of activities to the daily schedule, such as therapy and extra doctor visits. According to Elizabeth,

When could I just sit and read a magazine if I wanted to? When James has his therapy, maybe. It’s busy, you know. After school he’s got four outside therapies each week and karate, with two kids in baseball, one in soccer...after school is a nightmare. It’s just busy, you know. It changes your life.

Grace talked about how necessary it is for her to be patient with her son. There are many things he can do for himself with support and it is her hope that as he gets older and practices his routines more he will develop independence. She said

George, um, he needs more time and um with feeding, with dressing, with taking the bath, he basically needs more care, and I have to be careful and just watch him. He needs more care, more attention, but we take him everywhere we go...we travel a lot and we go to Wisconsin and he likes to go there, we have a travel trailer...he likes to fish and biking. So even if he is afraid of something we try to explain it and push him a little, so we push him. And he needs pushing and he needs to be challenged, to be in different situations.

Many of the participants spoke of particular aspects of their lives that have become more challenging. Leslee, however, responded that

It is not just one thing. You know what, honestly, everything. Some disabilities aren't like this, but when it is autism it is social and communicative and academic, everything from not getting landscaping done to not going certain places for vacation, to not, he won't get in a boat, my husband has a boat. We have never tried a plane. "I would not could not on a plane..." just like Dr. Seuss. Disney we did when he was much younger and still in a stroller, but it affects what you do as a family. We always have a backup plan and sometimes we drive two cars because sometimes he's ready to leave you know, and the rest of us are not, that's especially important if Andy [Jeff's older brother] is involved. We used to have parties here and now we worry about how Jeff will take people playing on his swing or with his train...or family parties are no problem, everybody is wonderful and accepts Jeff, but our friends, we don't get all the kids together anymore...it affects going to the grocery store and it affects me having a job.

Daily living activities with a child who is active and mobile are very different than those same activities with a child who has physical limitations. Karen described some of the altered routines in her home:

We have a step-in shower, I am the only one who does it because my husband gets nervous, or my big one will hold him up in there for us to wash him. We only have six steps up and he does it once a day. And he does walk. He wears braces, is not real steady, he's got a lot of ataxia. And of course if he is off balance...most of the seizures are noise-triggered...we have a noisy house, a dog, that stuff doesn't bother him, but a door banging, somebody dropping something on a desk, a high pitched scream he wasn't expecting if it comes from behind him. If we go out to eat to a restaurant, we always try to sit facing toward the kitchen so he can see rather than have the noise come from behind him.

In spite of the extra time and energy involved, several of the participants spoke of keeping their lives in perspective and acknowledging the range of difficulties many families face. Elizabeth shrugged her shoulders and talked about her life being good but

...different. He does everything we do. Our attitude is we're not going to not do things. We're going to do everything and he does it right along with us. He might do it differently but he still does it. He goes golfing with his dad and he has water skied. He loves swimming. He's had horseback riding therapy and he's, he's pretty active and involved.

Karen echoed Elizabeth's sentiment and tried to find something positive to share. She sees Phil as a part of the family, a variation of everyone else in the house. Phil's head injury occurred when he was very young, and according to Karen,

The good news is that he doesn't remember. Everyone said under the age of two is the best time to have a brain injury. Future learning? How do you restore that? He talked, he walked, he ran. How do you get that back? Teachers and social workers ask me about his favorite toys...the kids around here carry golf clubs, that's what you do in this house. Stuffed animals? I said he has a 150 pound dog, that's his toy. We have a house full of toys, he doesn't play with them.

Leslee though, was blunt in her acknowledgment of how family life has changed as her son has gotten older. It is never simple, and

It affects everything! I don't want people to feel sorry for us, but I want them to understand. Why aren't you going here or there? Well...we can't get a sitter. My mom and dad help a lot, but it is very expensive to get an adult to baby-sit. They might interact with him a little, but we can't just pay some fourteen year old from down the street to come over.

In spite of the challenges and uncertainties her family is facing related to Anna's medical condition and developmental delays, Kathleen talked about how amazed she is every day by the love and support she receives from her family:

My sister lives here. She moved here after Anna was born in part because she was sick of Los Angeles but also in part to help with her and us. My mom lives in Memphis still, my mom and dad were divorced when I was in college and my dad lives in New York and he's gay and has a partner there and they are awesome and totally supportive. All of our family has completely embraced Anna and we are so lucky. I can't believe the stories I've heard about how families freak out. But maybe because our family went through this whole thing with my parent's divorce and my dad's sexual orientation, maybe we kind of had a lot of our sort of notions about normalcy challenged in that way, so in a way Anna came into a family that had already adjusted to how would we be kind and good to one another despite, you know, some pretty profound misunderstandings, right?

Financial concerns.

As Leslee indicated, financial concerns can be considerable for families who have children with disabilities. An occasional babysitter may be a luxury when it becomes necessary to budget for specialized medical care, supplies, equipment and therapy. Many of the parents who participated in this study spoke about how careful they need to be with their finances in order to ensure the best possible care for their child with disabilities while providing for siblings, other family needs and attempting to save for college and their own retirement. Financial planning to make sure that the child with disabilities will be secure once they are no longer available to provide care and attention is also something that weighs heavy on the minds of many parents.

Having a child with disabilities often forces two-income households into becoming single-income households, and that can be stressful, emotionally and financially for both parents. Karen said after Phil got hurt she just couldn't work during the day because it was too hard to manage his appointments and be there quickly if something happened at school. Other parents spoke of how costly alternative and supplemental activities and therapies can be:

Lovass [a behavioral program for children with autism], horseback riding, a little Greenspan [a program designed to improve relationships and social interactions through developmentally appropriate play in children with autism], some Therapeutic Listening [another program for children with autism, focused on improving auditory processing and sensory integration]. They will tell you it helps everything from toilet training to handwriting (rolling her eyes) but there is other stuff, craniosacral and the hyperbaric oxygen thing...I mean, you can spend thousands and thousands of dollars. There are also all those supplements, and I don't believe a lot of it but I try to keep an open mind and we even went to a chiropractor who claimed he could help the autism and I wasn't sold on it but...I also have to think about the hour driving back and forth and I really have to think about our family. You know, is there a better way to use our time?

Sometimes alternative treatments can be a source of contention in the family. Karen said her husband

...doesn't believe in any of this alternative stuff I ever did and he told me that right from the beginning. If you want to do it, fine. I'm not going and I'm not paying for it. You want to do this, go and do it but don't ask me to go to craniosacral or acupuncture.

Tension between significant others.

When two people live and raise children together, some degree of tension is inevitable. Responsibility to and for another person or multiple people can be stressful. Families who have children with disabilities are often forced to adapt to their particular circumstances quickly, and all of the participants in this study spoke of adaptations they have made over time to preserve the integrity of the relationships they have with their significant others.

Mothers and fathers often have different caretaking roles with children, as well as inner resources for coping with the challenges and stress. Marie was very thoughtful about how her relationship with her husband George has evolved over the years:

Um. You know, you go through your ups and downs and there are certainly...there has been a process we have gone through together and then also separately. Just in your own mind. Yeah. We could probably write books on it. George has been to almost every IEP, which I think is amazing. He takes the time off and that is one way I think he shows his support. He's always looking for things in common with Roger, but that is hard sometimes...it took time for him to realize that it is ok to just go to the movies, you know, you don't have to talk...just go to the movies. It's more than enough.

She also talked about how she and George have helped each other out and learned, together, to cope with the more difficult aspects of raising Roger:

We've been married more than twenty years so we're kind of in a pretty good groove now. We've gone through a lot of the ups and downs together, maybe I'm doing too much, let him grow, you're not doing enough, come get involved.

Marie also talked about how Roger has changed their plans for the future. At first she looked a little bit sad but then she brightened:

Marie: This is my kid that I thought was going to grow up, move out, get married and do all that stuff. And you're still trying to grapple with the idea that when I retire I'm going to have someone with me still. You know. My husband and I used to daydream about when we are old and retired we are going to buy motorcycles and travel across the country. Well now we're going to have motorcycles, but...
Donna: One will have a sidecar?
Marie (laughing): Exactly!

Mothers and fathers also often have different caretaking styles, and depending on the child's level of need, one or the other may take over in certain situations. Karen talked about how in spite of the fact that she is the one who takes care of more day to day things, she respects how her husband has coped with Phil's injury over the years. When the kids are sick he offers to stay home but Karen always tells him to go to work. I asked her why, and she said,

He doesn't deal well with a crisis, was never a real flexible kind of guy. I tend to be more reactive and I don't get in a panic. I mean...I'm high strung but I don't get nuts in a crisis. A little blood doesn't bother me and whatever. My husband is totally different than I am. We're married twenty-eight years. He's very quiet, doesn't talk just to hear himself talk, deals with it very well but doesn't like...would rather stay home with Phil. Quite often if you say we are all going somewhere he will stay back with Phil. Part of it is him, part of it is because he can't deal with all the hauling and the taking and...he's also a guy. It's probably not that different, just his way and with something like this people become a little exaggerated at whatever they are. He's sad. And sometimes he just shakes his head.

Karen acknowledged that she and her husband understand and act on their sadness in different ways. She also talked about being surprised every once in a while by the things her husband has decided to take part in. Although he doesn't do well with blood and the need for stitches really upsets him,

The one thing he really got involved in is the stomach tube which is funny because if the kids ever throw up he would throw up. For some reason that is what he took on. Didn't like the neurologist, didn't want to deal with all that, I think it's just overwhelming. And my husband is also very black and white. I still have pictures that they drew for us at the hospital when they did Phil's surgery and he asked how much (of his brain) they were going to take out and the doctor's didn't know exactly and what's he going to be like? We don't know. And when they finished I remember he asked, "How much did you take out?" And they said "Somewhere between 30% and 40%." Well, that's a big difference to someone who is so black and white and kind of anal...there's only yes or no answers. That's all there is. He's awful when Phil gets hurt, he hovers. And he goes back and forth between thinking that he should be in a wheelchair for safety.

To Karen none of caretaking issues really impact the quality of the relationship between her husband and her son. The kinds of things they do together are different from what other fathers might do with their boys, but when he comes home from work he "loves to sit and have Phil climb up in his lap and nap for ten minutes and then play."

Denial about either the magnitude or long terms implications of a child's disability can also result in tension within the parent partnership. Rachel noted,

I think that my husband has a lot of the same things that Albert does, probably milder. And I think it is too overwhelming for him. He won't admit that Albert has a problem probably because Albert is a lot like him and that would be like saying he has a problem so he thinks it should just be more about discipline. My husband, he does not believe in psychiatrists or psychologists and he doesn't believe anything they say so it doesn't matter what any of them say, I don't want them to see him and I don't want medicine...so we battle over that kind of stuff.

The force of the denial can often leave the other parent feeling unsupported and second guessing their decisions. Ivy talked about the issue of medication for her daughter:

Up until now in certain areas, I feel like it created a struggle between me and my ex-husband because we disagreed on how to help her. He was more of the mindset nothing is wrong with her, she doesn't have a disability. All I need to do is...or all she needs to do is...and it will go away. She doesn't need the medication, I was a bad person for putting her on it...so there was a lot of fighting that way, and even this time, when I put her back on, he made a comment. She told me *you* put her back on that medication...and you know, it is just really hurtful because it is hard enough to acknowledge that something is wrong with your child in terms of how they process and I have to be honest, being a highly intelligent person myself, and being able to manage a thousand things at once, you really struggle when your own child is having difficulty.

Even when parents are generally in agreement about larger issues, one or the other may fail to connect or respond to the child as efficiently or effectively as the other at times. This can be especially difficult when one parent spends more time with the child (or children) and can take a great deal of what might be pleasure or fun out of the time the family spends together. Leslee expressed some frustration with her husband related to how he deals with Jeff when he is having a hard time:

When it gets bad, he, he just had a meltdown last week, kicking, punching, headbutting, and then I am the only one who can calm him down. My husband starts yelling and I'm like no, you have to use an even-toned voice to soothe him, you can't even tell him it's all right anymore...he's just agitated and yelling ALL DONE ALL RIGHT ALL DONE ALL RIGHT...he's very verbal and I know some kids are not but he isn't understanding at that point and then so it's kind of...it just all comes out.

Rachel expressed a similar frustration with the fact that her husband works long hours and when he is at home is easily exasperated by the children. She spends almost all of her time with the children and would appreciate a little bit of time to herself when her husband comes home. It is common for him to

...arrive home at two or three in the morning, like a second shift. He works in offices on the computer systems when everyone else is gone for the day. He might be there during the day to answer questions and go to meetings but then he has to be there when they are not there so he can do the work. When he is at home he just gets frustrated with the kids. Like five or ten minutes and then he's screaming at them. He likes to tell them how to play or eat or just control everything they do. The younger one, he gets really angry and will go off to his room to be alone and it will just go downhill with Albert from there. So no, we do not tend to do a lot of things together as a family.

Sibling relationships.

Some of that frustration and hostility can carry over into the relationship that exists between the child with disabilities and his or her siblings, but just as often it does not. Aside from the occasional interlude of hostility that naturally occurs between brothers and sisters, most of the participants described extremely positive relationships between their children with disabilities and their typically developing siblings.

Grace's children are both little and when I asked her how George gets along with his brother she said

They play together. They like to jump on the bed together and just play. Sometimes the little one gives him a hard time and he cries or calls for mommy to help him, but sometimes they want each other's toys so I buy them both the same. They, I don't see them fight.

Karen talked about the very complex nature of the tragedy in her family for both of her boys. She reported that they get along well, that Ryan treats Phil like he is fine but that she always has to keep in mind that

Ryan saw it happen. It was my brother that hit him. So it became a really complicated tragedy...I mean, if you could just keep adding one more thing to it, it just got worse and worse. My dad was already gone at the time and my brother lived with my mom...I opened the door. No one ever came up our driveway and so my brother was backing the car up to put Ryan's bike in, he had a flat tire and my brother was going to take it to the gas station. And we were inside and Phil kept pounding on the door and pounding to go out to see his brother and his uncle and I said "In a few minutes!" and he said "Outside now!" and so I opened the door and of course didn't holler that he was coming and that's how it happened. And I remember that for Ryan, you know.

It is difficult to know what to say to a young child after a terrible accident and Karen turned to the teachers at Ryan's school for help. While Phil was in the hospital, she

...went to the school and said "You guys tell me." I called the pediatrician and I went to the school and I said I don't know what I am looking for. He's talking about it and he's writing about it in his little first grade journal. I don't want to not talk about it but I don't know that we need to run to four hundred therapists, we're living in a hospital. And the school was great, the teachers, social worker, the principal, they were all great. And we went to meet with them on, he got hurt on a Thursday, I had called the school on Friday because at that time we didn't know if Phil was going to live and asked them if I could come in on Monday and explain it to them so not knowing what was going to happen. And we sat down and talked and they all eventually said that he [Ryan] seemed to be fine, that he was adjusting well and they would watch him and it was always the same thing, wait and see what happens when he gets older.

Karen spoke easily of the closeness between her boys, how they grew to need and depend on each other over the years. Inevitably though, siblings grow up and move on and away from home. When he was young, Karen said, Ryan

...did write a lot about it and some he shared and some I snooped. I'll be honest because...he said we never missed a soccer game, we never missed tennis, but what we did miss was for some time was all four of us being able to go together for things. Maybe Phil would have a seizure and need to stay home, but no one ever said no to Ryan. He's really good about it. He so wanted a brother, and, so, it's sad. And it's going to be hard for Phil when he leaves. Because Phil is very attached to Ryan and to his friends.

Leslee talked more about her sons getting along with each other on a day to day basis and about making sure she divides her time as equitably as possible between the boys. Because it can be difficult to communicate with Jeff, it is sometimes hard to determine how he feels about the people who are around him. Leslee said Jeff's older brother Andy

...gets along with him usually, but he's not like the super sib. They kind of ignore each other at times. Things will go fine until he crosses the line, but Jeff likes him to be around, likes people, familiar people to be around, even though he doesn't always interact with them, you know, he still wants everyone to be together. And Andy, it's hard, but he understands and you know, we totally make time for him. We always have tried to do that, especially at the beginning when Jeff was so young, we spent a lot of time with speech and therapies and all that. But my mom and dad would take Jeff sometimes, and they still do, and then we go out or just spend the time with Andy. So...I mean he's definitely affected, but I don't think it's ruined his life or anything like that.

Ivy described some of the ways in which the nature of sibling interactions can be altered by differences in ability among them. She knows her girls love each other but also how competitive sisters can be. It has been helpful for her to think about Gabriella's learning disabilities in terms of the life lessons they can teach all members of the family about respecting difference, taking time to understand each other and setting aside your own frustration to be gentle and helpful when needed. Gabriella's challenges in school absolutely

...has had an impact on her siblings. My middle child is in a gifted program and the oldest, she has felt like...why is everything so hard for me? And it's hard for me, too, when she will say why is everything so hard for her? Why can she not just get those A's when everyone else is able to? Sometimes when they are having their little sibling spats it will come up and that is something that her middle sister will throw out because that's all she has.

Marie also talked about the challenges between siblings and the challenges she and her husband have faced in treating all three children fairly while taking into consideration that Roger understands things differently as well as navigating the emotional responses the other children have had to having a brother like Roger:

Wow. All in all, he's a great kid, thank goodness. He's so easy to get along with and that's a huge help. He loves learning...that's half of it right there, but, so I think compared to a lot of other families we have it pretty easy in regards to that, but the difficulties are dealing with his younger brother who has no patience with him at all, expects him to be...he's so in-between. He doesn't have such a disability that you go OK, that's not going to work, but lots of times they are great together. The biggest challenge is helping them both learn to deal and play and or not play with each other, and to give each other space, because they are three years apart. It's certainly been a lot for my oldest. You never know, you don't have a crystal ball...but we do believe that she pushes herself and that's part of her personality, but her experience of having a little brother who was someone who was always going to the doctor, for years...that's all we did was try to find out what was going on, and going to Easter Seals for therapy and all of that. She is a straight A student and we have always felt our job as parents was to say "It's OK if you get a B, it's really OK" and she is kind of a perfectionist, but I think having her little brother has really pushed it along. Further. And then with Roger's younger brother, you know, he doesn't need to be disciplined in the same way. To say "I'm disappointed in you" brings tears, where as the other ones, we have to get a lot tougher with. And so they see the discrepancy and we try to balance it out, like any parent with any children but...it's difficult. They do a lot of things together, and yet, Roger's mentality is not like his brother's and he also knows he is a teenager...so he wants to sometimes do teenager things and he doesn't always want to be with his brother and his little brother doesn't always understand that. So those are some of the things we struggle with.

All of the participants in the study also spoke of the long term relationship they hope their children will have. Although all are making provisions as best they can for the future, they also all acknowledged that their typically developing children may eventually become caretakers and/or decision-makers for their siblings when they are no longer able to do so. This is a serious responsibility, one that parents can hope for but not demand of their children. Marie put it bluntly:

I don't know what I see in the future for him. There's certainly, we've talked to his brother and sister. She understands his disability, but I am not really sure yet if his brother does, if he has that awareness yet. Our hope is that when we're gone they will keep very close tabs on him.

Grandparent involvement.

Several of the participants in the study also talked about their own parents and how having a grandchild with disabilities has affected them. While they expressed a profound appreciation for the love, support and efforts their parents made, they also acknowledged some of the tensions.

Karen's situation is, as she described it, "tragic," and while her brother was traumatized, her mother was, for a long time,

...in denial. She told everyone it was a friend of mine. And when Phil was at rehab, they came out one day and I had this huge bag of card that came from everyone...we live in a neighborhood, there was school, Ryan's baseball and soccer teams, you know, we know a lot of people and people hear about it and it could have been anybody. We all slam on a brake for a kid, I don't care who you are and I finally sat down with them and said, "This is not about you or about me. This is about Phil. I want you to open every card. And the first thing they all said? "I'm praying for you and your brother." "My heart goes out to you and your family." I'm like you don't get it. People care. But it was very hard for him and it was very hard for my mother. And my dad had died shortly before it happened, which is probably a good thing that he wasn't around to see this happen. But they have gotten a lot better.

As her denial faded, Karen's mother became more and more involved in daily family life and grew closer to both boys. She was eventually able, according to Karen, to "accept it for what it is" and was glad to spend the time at Karen's house. Because of the frequency, intensity and duration of Phil's seizures, Karen is always cautious about who can stay with Phil when she is not in the house, and for years, her mother would watch him on Friday nights.

So, my mother would watch him on Friday nights when I'd go to work. My mom was eighty-eight when she died, she still worked and was wonderful...so when she would come over Ryan would say he would stay home with Grandma and so I'd say maybe Grandma doesn't have to come and he's say no, Grandma likes to be here. But Ryan would stay home to be with them and undo the tube and stuff for Phil's feeding...

Kathleen's mother lives far away, but they talk on the phone frequently, and she will often ask for updates on Anna's progress. Anna's progress is slow, and while she is growing, maturing and gaining skills, she is not meeting the developmental milestones that would be expected for a child her age. For this reason, her inquiries about progress can be difficult for Kathleen. As she stated,

And my mother, for instance, has really struggled with Anna because she really needs that achievement. That's really hard for her, it's been really hard for her. She's very, she loves her. She's totally supportive but she frequently still wants progress reports. How's she doing with her walking? How's she doing with her talking? It's like well mom, if she started talking today, I would have been on the phone with you, right? Right? That's going to be a big day. And she actually is improving and she does do some, but it's still...and my mom always takes a day or two to get into Anna groove when she visits. You know, that sort of thing.

While Karen and Kathleen recognize the relationships their mothers have with their children are different from what they may have planned on or hoped for, both are appreciative of the fact that they have those relationships. Karen summed it up well when she was talking about her mother. She said,

...so we all did what we had to do. Because that's what you do.

Redefining the "normal" family.

Words people use to describe family life often include adjectives like "busy" and "crazy" or phrases like "never a dull moment." Most people would also describe their lives as "average" or "normal" in that the things they do on a daily basis (work, clean, cook, drive children to activities) do not stand out as especially unusual. For people who have children with disabilities, it may appear to outsiders as though nothing could possibly be "normal" about their family life, but that is, according to the participants in this study, simply not the case.

Depending, of course, on your feelings about what exactly “normal” means, adjusting family life to accommodate to the needs of a child with disabilities can pose different kinds of challenges. Kathleen and her husband found out early on in her pregnancy that Anna would have medical complications, but they did not know the extent to which those complications would lead to disability. Looking back, Kathleen noted

...it's definitely a process of...it's weird, being so far on the other side of it now. I feel so much more comfortable with everything than I did then and it's interesting to remember how many distancing things there were. Like how I distanced myself from various aspect of it as a way to keep some modicum of sanity together like OK, I am not going to just lose my shit completely. You know, I'm going to try to lose it a little bit and not just fall down on the job here. Just that I am going to have to have this baby and like...be her mother! And by the end of the 8th month, we sort of went into like OK, we're just normal now, we sort of reasserted some sense of normalcy and kind of went through the rest of the pregnancy like we expected everything to be normal. And it kind of was except we kept having ultrasounds.

Kathleen described herself as an optimistic person, and like most mothers, spent a considerable amount of time during her pregnancy thinking about and imagining what life with her baby daughter might be like after she was born. They bonded, connected, and got to know each other in that way, until the diagnosis that almost changed everything. Coming to terms with it took time, and Kathleen found herself avoiding information about ACC for this reason:

When it's that close to you and when it could dash all your hopes, frequently you don't want to know. And if you're an optimistic person, I think, by nature, it's particularly hard to do because it's like I knew my optimism was the thing that was going to keep me going through this and I didn't know that I was strong enough to sort of shore up my optimism in the face of sort of unrelenting bad prospects. And I think too, I've had a very hard time, from the minute the diagnosis was made I had a very hard time reconciling my sense of who my baby was and not those words. And I had this distinct sensation when I was pregnant of being like oh, who are you now? I thought I knew you. And now you're an alien. Now you're disabled. Now you're different. And I definitely had that moment of having to say wait a minute, you know, just sort of reframing it. You just lost a sort of mythic solidity we all think we have about our future. That's all that happened; nothing really has changed except that you now know you can't count on some idealized future for your child. And nobody really knows that, we just feel like we do.

Letting go of the "mythic solidity" of a "normal" future in your own mind is one thing, but coping with the reactions of those around you is something completely different. Karen was moved by the compassion and support she and her immediate family received from family and friends after Phil got hurt, but the one place she liked the least

was the waiting room at the center where she took Phil for therapy after he left the rehabilitation hospital. It was there that she described just wanting to be alone, not wanting to reciprocate the inquisitive questions or superficial conversations with other parents at the center. They meant well, but it was stressful for her because

...you had to sit in the lobby or in the waiting room and of course we had Ryan with us and we, people kind of look at you and ask you questions and you are overwhelmed and you don't want to hear some monkey's asshole's uncle had the same thing. I don't need to hear that story, I've got enough of my own friends that I don't get to see, I don't want to deal with this [other people's problems].

Waiting is a hard thing to do and waiting rooms can be very difficult places to be. Sitting there among other families waiting for their children to come out of therapy made it all too real and obvious how far from "normal" Karen's life had strayed. And yet, even with all of the complications, doctor appointments, therapy visits, heartache and chaos, when asked, Karen still describes life in her house as "Normal. For us."

Elizabeth also described an intense schedule of appointments and activities, not only for James, but for everyone in the family. Although it requires cooperation, organization and occasional help from friends, Elizabeth spoke calmly and said,

Well...we just...you do what you do. And it's normal for us. Yeah. It is. You know, I remember talking to someone early on, I was, you know, a basket case in the beginning and I was talking to her and she said you know, she could probably feel I was in panic mode, like what am I going to do here? And she listened and she told me this isn't bad. It isn't horrible. It's just different.

Leslee was in agreement with the others and summarized her thoughts well:

We're not the people we would have been otherwise, thinking we have the perfect life. It's not anybody's normal family life, but it's all we know.

Summary and analysis.

Multiple points for analysis emerged from the data collected in relation to how raising a child with disabilities can impact a family. Participants described numerous practical considerations, and all noted that everything takes more time and requires careful planning. Family habits and rituals, as well as the dynamics between individual family members are often altered, and the level of care a child with disabilities requires may sometimes preclude time spent with other children or in activities previously enjoyed collectively as a family. Participants described financial concerns and how the cumulative stress of raising a child with disabilities can increase tension between significant others. Some participants noted the negative impact of having a child with disabilities on sibling relationships, while others described how loving and understanding their other children are toward their brother or sister with disabilities. A few discussed additional roles grandparents and other family members have taken on and how adult friendships with people outside of the family can either become family-like or go by the wayside. All of the participants talked about how their idea of what constitutes “normal” family life has been altered and expanded by their experience of raising a child with disabilities.

Denzin and Lincoln (1998) caution of the tension inherent in attempting to reconcile the particular and the universal in the analysis of qualitative data. Doing so may shift focus from concrete to more abstract commonalities, and there is a danger, then, that “multiple cases will be analyzed at high levels of interference, aggregating out the local webs of causality and ending with a smooth set of generalizations that may not apply to any single case” (p. 194). Given the varied experiences of the participants in this study, it seems wise to heed this warning here. Every child and every family in this study is very unique, and it would not serve the research purpose well to smooth over their differences

in an effort to pull generalized findings from the data. But reading through the interview transcripts is a bit like finding myself in a random gathering of runners who can share stories of lost toenails and dehydration or an informal assembly of dog owners with stories bemoaning chewed shoes and strange wet spots on the rug. It is almost impossible to not see the commonalities and connections and feel the sense of the camaraderie that grows out of a familiarity of experience, even among people who have never met.

That familiarity is the most essential thing here; in spite of their differences, it appears to me as though their stories can be generalized on a level useful or helpful for those seeking to understand their perspectives better. At the core of each story is a child, and having a child who requires special care is much more common than most of us would like to think. The bottom line is that it can wreak havoc on a family, and while the families represented here in this research are able to function and thrive, there are others who struggle and have a great deal of difficulty coping. It is certainly much easier to think of the children in special education as other people's children, but as educators, we need to keep in mind that they could just as easily be our own. Schostak (2006) described listening to the lives of others in the interview process as "...a curious kind of voyeurism," and wrote about the momentary thrill of the "images, the personas, the actions of others fill(ing) my imagination with lives I might have led had I been luckier or less fortunate" (p. 1). But he also wrote of the hope that "...somehow by listening enough, something might be learnt and something might be changed" (p.1). And one thing that can certainly be changed is the level of understanding and sensitivity teachers and administrators bring to their interactions with families in special education. We do not need smooth generalizations that apply to all children to do this. We need compassion, consideration and local understanding.

Expectations

Parents often view their children through different lenses than other people. Some individuals are very critical of their own offspring, while others may see talents and gifts that teachers, coaches, neighbors and friends might not be aware of. It goes without saying that parents know their children best and are most familiar with their strengths and deficits, but in special education there are frequent disagreements between parents and professionals about the expectations that each hold about a child's potential for academic, motoric and functional skill growth. This in turn can lead to disagreement about what children should be learning in school and the methods with which they are taught. There are three parts to this section. The first is about how some of the parents in this study view their children, the second is about how parents are often frustrated when the expectations operating at school are lower than those at home, and the third is about how both parents and professionals in school can streamline their expectations and work together toward common goals.

Parental perceptions and expectations.

Among the participants in this study, Kathleen spoke the most vehemently about the differences between how she views her daughter Anna and how many of the professionals she has encountered at Anna's school seem to view her. It is a source of frustration and anger, but it is also representative of the very painful process many parents of children with moderate to severe disabilities go through as their children age out of Early Intervention Programs and in to the Early Childhood Special Education system in the public schools. Kathleen's perceptions of Anna are complicated by the knowledge that seizure medications Anna needs to take blunt both her affect and her arousal level significantly, and for this reason, most of the professionals in Anna's school

have never really seen or had the opportunity to get to know “the real Anna.” Looking back at her initial evaluations for both Early Intervention and her current school placement, Kathleen expressed her disappointment. Both evaluations were completed when Anna was heavily medicated for recent seizure episodes, and it seemed to Kathleen as though

...none of the people who were encountering her, once her seizures began, knew who she was. I felt like...she was so sedated and so unresponsive and so out of it and it was so imperative to me that she had the possibility to be a full complete person. And I didn't like, especially the eval team, I felt they were just judging her in seeing her as this very limited individual and I knew this little person already and I'm like she's not...she's just on Phenobarbital!

Kathleen also talked about how she initially expected the teachers and therapists to understand how Anna's medical condition would impact her performance, but that was not the case:

And that's I think what's interesting for me. I can't make people not look at her with that lens. Either they will see her clearly, for all she is and all that she represents and all the awesome things she is, or they will filter her through the achievement lens and say well, she can't do X, Y, or Z. And there is a real difference in how people interact with her and that's pretty much it. I mean, it basically comes down to whether or not you need someone to do certain things to connect with them, whether or not you can connect with somebody just for who they are.

Kathleen had no difficulty describing Anna's strengths. The first one she described as

...her determination. She is incredibly determined. She is amazingly resilient. She's strong. She can work really hard. She's not afraid, she is really brave, very self possessed. She's um...independent, and I think she's got a really great sense of humor. She doesn't laugh a lot because of the seizures, they sort of compromise her ability, the meds can mess with your ability to do that but when she is not having them she smiles and laughs a lot more. I can tell if she thinks something is funny and she definitely has a sense of when she has pulled one over on us, you know what I mean?

Then she described her weaknesses, as she sees them:

Her weaknesses are, um, that she can't independently access very much. Like she can roll and when helped she can walk around and is very, she wants to do things, but she has a very hard time transferring desire into bodily movement. So she'll get really frustrated and need something to do and not be able to roll over to the toys and pull down a toy and entertain herself. Some days she can do it, but most of the time she's just going to get frustrated and really angry and yell. Or perseverate. So that's a major weakness. Another major weakness is her ability to initiate conversation or let you know she needs something which is still at a really, really sort of basic level. Um, and it's hard to discern because frequently during the day I'll start to tune out some of the sounds she is making just to go do my thing...I've got to do laundry or...and she talks to herself a lot and sometimes I'm just not paying the right attention and she may have been wanting me to help her. She doesn't say "Mama," instead it's "Ungugh," and if I'm not watching her I'm not going to get a lot of it. So for her I feel like that's a big weakness. But I don't feel it translates into her not having a thought. She has thoughts all the time.

Kathleen continued to talk about two other major weaknesses that are even more pronounced when Anna is in the school setting than they are when she is at home:

Her communication is extremely difficult and frustrating for her. We've been seeing a lot improvement of late and she is doing a lot of responsive talk so back and forth, not so much mimicking although she is trying more and more to make the sounds that we make but there is definitely some sensory input processing thing that just does not work for her. And there is some affect that you see with a lot of kids with ACC that's autistic-like in that she doesn't really mirror emotions. When I say something I am very exaggerated in my visual cues to her and it still takes her a couple of beats to get it and even then I'm not sure she's really getting it...Like I'm not sure what she reads in terms of emotions, but she has a range of emotions herself and she expresses them...In that sense she's not what I would call a classically unemotional child because she is very loving, she thinks things are funny, she thinks that they are interesting, she's not just in herself, right? But, so, a lot of the things you might think of as very basic, sort of fundamental emotional markers of development are extremely delayed. And I think that's a problem. And another major weakness is that she doesn't interact with children. Partly because children don't interact with her. Because the children she is with at school, many of them are less able to interact than she is. But also she doesn't look at them. Her visual focus is very fragmented, sometimes it is very hard for her to look at you in the eye. When she does, she's great, but sometimes she's just like this (eyes darting around) a lot. And sometimes she moves a lot, her body moves a lot, so there is a kind of control piece that makes it hard for other children.

Five other participants in this study also talked about how their child's strengths and weaknesses are perceived differently in school than they are at home. Grace indicated George's language and fine motor skills as being most problematic for him, and also noted that in school, these things

...are the most important. So when he tries to do things, it is frustrating. When he eats he doesn't want to use a spoon and fork, but he is doing it much better. It has been pretty messy, but at least he knows how. He can scoop his cereal, and his speech, I can understand him what he wants to say, but I think he would talk more if he was able to tell more...it will be hard for the teacher to find out what he wants to do and sometimes I don't know what he wants so I try to think what is his favorite toy or what he wants and make connections with the past to find out what he wants from me.

Rachel described how Albert can quote long passages from books he has read and how his general presentation can easily lead to misinterpretations of his abilities:

...he is always thinking about what he was reading and reliving it in his mind. So he needs quiet and he needs someone to keep him focused. If you put him somewhere quiet and there isn't someone checking on him every minute or two, then he isn't going to be doing anything. He does so well on tests, it was so hard to get an IEP for him because he tested above grade level in everything. So while he's not doing any work, he's not missing any education according to them.

Leslee had difficulty containing her irritation when she talked about how Jeff sometimes comes home with crafts or activities that a teacher assistant has obviously completed for him. She wondered out loud what Jeff might be doing while the adult is doing his work, and wished they would understand how much

I would sooner have him do half his own way than have someone else do it for him. We always know he didn't do it and we throw it out.

Marie talked about how well Roger can follow directions and do concrete things on his own when he is provided with the right type of instruction and adequate support. Her perception of him is that

...he is still pretty much working on one step directions, if you give him two or three he kind of forgets and has to ask again. But he is very cooperative, he's a pleaser, you can tell. But we have to really push him to do things, or he is content to just sit and talk.

Marie also talked about how she and her husband push Roger at home, but are well aware that he is not always pushed to capacity at school for a variety of reasons. A similar situation is unacceptable to Kathleen, who is angry that the things she is working on at home are not being reinforced at school. As she stated,

...even with her teacher who is awesome, they aren't going to push her, they are not going to. You know, I have to push them to accept that she needs to be challenged. You know, at home, I can tell that she needs to sit on the potty and I put her there and she goes. It's a pain, but she doesn't want to poop in her diaper. She knows. She doesn't know how to tell you the way you want her to tell you, but she will tell you and you have got to pay attention to her.

Elizabeth spoke with a resigned tone when she talked about the difference between how she sees James and how he is viewed at school. Perhaps because she has been dealing with the issue longer than Kathleen, she has almost given in to the fact that

...this is what they are going to do. I have been told that the services are good in (this area), you're not going to get better services anywhere. I guess I was sort of prepped about what to expect. So I feel comfortable that he's gotten good services, but in the same vein, I've always understood that it is going to be limited and it is going to revolve around James getting through his school day, not about the big picture like here in the clinic. So my expectations were, I don't want to say they were lower, but they were realistic, let's say. And he's been cut back, but we make up for it in other ways, he's always had outside therapy.

Grace stressed that she is not displeased with George's current IEP. It is an accurate description of his needs, which include things such as breaking tasks down for him, providing simplified directions, assisting him with use of his communication device, giving him extensive verbal and visual cues, assisting him with peer interactions and gathering materials for activities. But what she does not like about the IEP document in general

...is that they focus on really what he can't do instead of what he can do and he can know, it just, it should be focused more on strengths.

Grace was hopeful that this might take place in the future for George, but Leslee sounded more defeated. According to her,

...it's their mindset. You can't make people change their mind about somebody. Or make people do their jobs.

Perceptions and expectations at school.

Several of the participants in this study who have older children talked about how it took them some time to realize how different their views of their children were from the views held by teachers, therapists and administrators at school. It was a painful lesson across the board, and during the interviews, all of the parents were thoughtful about the process. As the mother of the youngest child in the study, Kathleen's pain appeared to me to be the most newly-inflicted. Although she was complimentary of many of the individuals in Anna's school, her frustration with the system was raw. She was blunt about the fact that

I think she can do a lot more than they do. And that is partly because I'm her mom but I also know that they don't, what I think happens is that they don't understand. I think some will know better than others, and I think her teacher does get this, but I think therapists who see her less frequently than the teacher don't understand the degree to which she is like this on a given day if she has had a bunch of seizures she is not going to be able to do some things. But if you get her the next day when she hasn't had any seizures, than she'll be able to do a lot more, and that's something I've tried to communicate to her teachers. So I think that is what is missing there, they don't understand how variable her ability is because they don't see her that often and they don't really understand what it means to have intractable epilepsy. This is historically true of epileptics; they have been consistently understood to be retarded or to have inabilities of varying sorts. That if their seizures are under control, those things will disappear. And Anna will never, even if she wasn't having seizures she would be having trouble. But part of what I struggle with, is that I feel it is very hard to separate out what I see is a part of, as a consequence of this chaotic brain and what her potential is and what to try to do with her.

Leslee's frustration was also with the system; she realized early on that the resources for effectively working with children with autism were not available in her local school. It was awkward and uncomfortable for her to encourage the district to obtain outside consultation, but it was what she needed to do because Jeff was not making the kind of progress she knew he could be making with appropriate interventions.

I think he could be more independent. He doesn't always do it, he is beyond the pictures but he follows the directions with words. I have always thought the verbal stimming was getting in the way but that has never been addressed in school consistently. They don't stay with things and two months later move on to something else. His communication skills are low, but there are things he can do, and if they give him jobs to do, like shredding, and he has it written down so he knows what is expected of him he will do it and he likes it. The social issues are a problem, the nose picking and hands in the...those are things we work on. Any independence he shows an interest in we are trying to encourage. At home now we are working on him making his sandwiches. School always saw what he could do and it is good because they are also looking at what he can't do. Maybe that is good, because early on, the speech and the OT did not get him at all. At the mapping we talked about how he is doing and well, they said they really see him as non-verbal. And we were like really? They said he doesn't answer questions and they went on and on and you could just tell they didn't understand autism, but it was an eye-opener because it was the system, they really didn't know him. And that is when they finally agreed to call in an autism consultant.

Rachel expressed a similar frustration with the large urban system that has repeatedly mislabeled her son. It was obvious early on that he needed additional support, because even though he is smart, he is emotionally and socially unable to navigate the world his peers are in. His academic progress is at risk, but Rachel has been unable to secure additional support for him at school. Her suspicion is that

...they are running their school like a business. I think our principal's main job, in his mind, is to raise money and then make sure he doesn't spend any more than he has to. And in my guess, for a lot of kids, that is a very short-sighted view of accommodations, not to fix the problems but to just move them along and keep them going. And when he gets to high school? And when he has to go and get a job? He's not so disabled that he will...you know, he's not going to get a boss who will come and remind him every five minutes to do this or that. He is going to have to

be able to pay attention and interact with people and I think they should be working on that with him more than on academics.

Kathleen explained an ongoing conflict with Anna's speech therapist at school as a perfect example of the difference between family and professional views of the same child. It has long been a source of frustration for Kathleen that this particular therapist is not really working on actual talking.

Right now at home we're working on talking, like I'm just like OK, let's just talk. Let's try to talk. And she does talk. She doesn't say words, but she talks back, she gives me vocalizations in response to questions or you know. So she's trying. And like yesterday we were working on "dog." I said to her, "Let's say dog. It's a good easy word." She knows them from outside and we talk about them and we were... and I had her in my arms and she was looking at me and I was looking at her and I said, "Let's do dog. Dog. Dog. Dog." And she would just go like this (facial motions) and I'd say, "This is really hard, isn't it?" And she would just look at me and then she went "Og." And I went "Good! Now we work on the "D" part." But you know she's having the, you can see on her face how incredibly frustrated she is and she wants to talk. She knows what I'm asking her to do and so it's like what's inside of her? There's this great person who is trapped. And what I worry about in school is that they kind of concede to what she can't do. A little bit. And maybe that's what it has to be. But I never hear anything about that, I never hear about them working on trying to get her to mimic or working on that consistently. And I think part of it is that they don't want her to fail her learning goals. They want to set outcomes that she can reach. I get that. They want to cook the books a little bit for her sake and for theirs and also for mine. But I don't care if she passes it or not. I know that if you sit there and actually work with her on saying a word again and again and again, she's actually going to get something from that. That she's learning something all the time, whether she can give it back to you or pass a test, that doesn't mean she's not learning.

All of the participants in the study struggled on some level with the perceptions school-based professionals held of their children, but with the exception of Karen, those whose children were the most severely and globally impaired expressed the greatest level of frustration with this issue. All of the others reflected on how, over time, they were able to come to a consensus of sorts with the school staff regarding their child's needs and abilities. Along the way and in spite of their differences of opinion, almost all of the

families found teachers, therapists and administrators who were willing to push their children toward the goals they set together.

Establishing common goals.

In the middle of a stressful IEP meeting or when your child comes home, yet again, with an art project he or she clearly did not paint, the distance between you and the professionals in your child's school can seem vast and impossible to bridge. Although it required a significant amount of patience and a willingness to give up or give in on issues that were of lesser consequence in the grand scheme of their child's education, many of the parents in the study looked back almost fondly on how the process unfolded for them and the individuals who made it happen.

Marie remembered sharing information from Roger's pediatrician in an effort to help the school staff remain open to alternative placement options. She said,

When he was like four years old or so, the pediatrician said something to me and I'll never forget it. We didn't know what his disability was. And the doctor said, "I don't know when the light bulb will go on, but it's going to go on, maybe when he is four or ten or twenty." And we held on to that and we've seen it in middle school. He is reading at the fifth grade level! And the more he is exposed to, the better he does. And the school staff has been with us on that and they arranged for him to be out of the self-contained classroom for some classes. The way they arranged it was different, it was just different from anything I had seen or read about. It wasn't written into his IEP but they just did it because it provided him with more stimulation and more challenge and they couldn't do that in the self-contained classroom, even though he still needed that level of support for other things. So it was wonderful that they allowed him to do that.

Elizabeth talked about several of the teaching assistants who have been assigned to James over the years. Most of them were wonderful, caring people, and with the exception of one situation (an assistant assigned to James who had back problems and therefore would not be able to assist him to safety in an emergency) she had no

complaints. His most recent assistant has been particularly helpful; Elizabeth trusts that she will remain close but not help him with things he can do on his own. As she stated,

She's tough on him. But she loves him, too. We are crossing our fingers that she will be able to follow him to middle school. She's just so good. A godsend. She looks out for him, and pushes him, too. They all want the best for him and really are, we haven't had anyone who has tried to hold him back or say "you can't do this." Once people get to know him, I think they are impressed by him.

Leslee described how some of the assistants would stay with Jeff for more than one year at a time and how helpful that was for his progress. When people assigned to assist him are less familiar with his abilities and moods it can be difficult for them to read his behaviors and intervene at the most appropriate time. Their interactions with him tend to be more isolative and may actually prevent, rather than facilitate his interactions with peers. Leslee noted that

...sometimes they miss the signs that he is going to escalate. His assistants used to know, uh-oh, this is not good, when he starts talking in a high-pitched voice or whatever. But if he is always kept separated, that's one of the drawbacks of special ed, would be the lack of socialization with typical peers...but I also think when they finally see what he can do, they get excited about it and when you think about how they view him differently, in first grade he was flopping all over the place, wouldn't keep his shoes on, all over the place but in fifth grade, he kind of acts appropriately most of the time. But unless they have known him all along, they don't know what, how much work went in to that.

Elizabeth also brought up a concern about the school staff really getting to know James and developing a familiarity with his strengths and needs so that they can most effectively enable him to meet his goals. Because her boys are twins, people tend to compare them to one another and often use James' motor limitations as a gauge for his cognitive abilities. This is inappropriate, but it is also inaccurate, as James' academic abilities are actually superior to his brother's in some areas. There was some discussion one year about holding James back, but Elizabeth has always felt strongly about keeping the boys together. She described the situation and said,

...but we did not, because he has a twin, we did not want to go that route. I said to move him ahead and if he can't do it then we'll talk about it. But I don't want him to live, to go through school and have this stigma of being one year behind his brother. It paid off, and I feel like now, as an eleven year old, he might feel inadequate in certain ways so I'm just really glad we did that. He totally kept up with everyone else.

Marie also talked about how working closely with teachers and assistants over the years has also helped her come to terms with the process of accepting Roger's academic and functional strengths and limitations and letting go in small increments as he becomes more and more independent. When asked if she and the school staff are in agreement about where Roger is most capable and where he needs the most help, she laughed a little bit and said,

I think so. A little anxiety about high school. As he gets older, I feel I'm less and less involved and I'm not used to that. I know for him to get more independent I have to back away. I joke with people at school sometimes that I have an IEP and the goal is to back off!

Summary and analysis.

All of the participants in this study expressed some level of angst about the discrepancy that exists between the way they view their own children and the way they perceive many of the educators in the schools their children attend seem to regard them. Some of the participants spoke of their frustration in trying to reconcile their own perceptions of and expectations for their children with those perceptions and expectations held by educators as well as of the pain that comes along with realizing your child may not be as bright, as capable, as social, or as independent as you thought when viewed among typically developing peers. These differences of opinion between parents and educators can strain communication efforts and damage relationships at times, but participants in this study also described many of their interactions with school

professionals that were supportive and helped them come to terms with their child's needs. These interactions, according to participants, often laid the foundation for more effective communication and strengthened relationships.

In the introduction to his text on discourse analysis, Gee (2005) wrote:

Human communication, especially across social and cultural divides, is a very difficult matter. We humans are very good at finding meaning. In fact, we are so good at finding meaning that we often run off too quickly with interpretations of what other people mean that are based on our own social and cultural worlds, not theirs. Too often we are wrong in ways that are hurtful (p. xi).

School-based professionals should certainly expect parents to believe in their children, to hope for positive educational outcomes and to advocate for services and supports that are in what they perceive to be in their child's best interest. At the same time, parents should not expect school staff members to view their children in the same light they do all of the time. Consideration needs to be given, from both sides, to the contradictions that arise from each person's perspective. It is not hard to see how the space between parents who have children with disabilities and educators might be considered a cultural divide and how easily that divide might contribute to misunderstandings between individuals. Negotiating interactions with school staff is complex for many parents because parents and professionals look at children through different lenses. They also have different emotional attachments to children, come to the negotiation with varying expectations and possess disparate levels of knowledge about a child and his or her potential. Communication in this situation is often a challenge for all parties involved, and the challenge is frequently intensified by the context of the situation. The information I obtained from participants about their expectations being different from those of school staff members and how they, in some situations, were able to work things out together speaks to a number of considerations related to bridging that social and cultural divide

that exists between parents and professionals in special education. It also speaks loudly and clearly to the hurt inflicted on families by the educational system.

Placement options, therapy services, inclusion and instructional assistants are sources of contention most often discussed among parents according to the literature. These are things that are relatively easy to talk about, especially if a parent believes that better or more of these things will make a difference in their child's life. It is harder, in my experience, to talk openly about the levels of cognitive, emotional or physical impairment that impact academic performance and have long-term implications for severely compromised independence. While it is difficult to determine the trajectory of development for a child, medical professionals and experienced educators can often venture an informed prediction about the future for some children early on. Sharing that information with parents is a responsibility that all individuals in schools do not fulfill equally well, and an optimistic parent may perceive a teacher's realistic assessment of their child to be unfairly pessimistic. The IEP meeting where that conversation first occurs may go well on occasion, but more often, even though the parents have the most at stake, it is painful and uncomfortable for everyone.

While keeping my occupational therapist hat off was necessary in the earlier phases of this research project, putting it back on briefly has helped me to realize how the language we use to describe children is a complicating factor in the way expectations are communicated between parents and professionals. While not indicative of a lack of depth of understanding, teachers and therapists tend to rely on more clinical definitions of words, while parents tend to use the same words in a more affective manner. The clearest examples from the study can be found in Kathleen's narrative. When she used the word "independent" to describe Anna, it was clear to me that she was talking about Anna's spirit, not her ability to use physical or intellectual skills to get something done on her

own. Kathleen's discussion of her frustration with Anna's speech therapist also provides a good example of this communication problem. In this discussion, Kathleen described the sounds and facial gestures Anna demonstrates as "talking," while the speech therapist describes her as "non-verbal." From the perspective of an outsider, I can see that as a parent, Kathleen interprets Anna's attempts to communicate with her qualitatively as "talking," while the speech therapist looks for quantitative skills Anna does not have yet. To Kathleen, the fact that Anna is trying might be the most important thing. To the speech therapist, it is all about functional performance and outcomes. And because their communication is not particularly effective, it is easy to see how their relationship might break down even further over this issue.

On a deeper level, these arguments are really not about academic expectations or minutes of service. They are about the unavoidable pain associated with the way we categorize and label children in our schools based on what they are able or unable to do, and our willingness, as a society and especially in school, to concede to what a child is not able to do. There is no way around the fact that in order for schools to provide appropriate educational services to those who need them, a systematic method for determining eligibility is necessary. Although dated, the method currently in use is deficit-based. If you are unable to talk, you become eligible for speech therapy. If you are unable to ambulate safely through the school, you become eligible for physical therapy. If you are unable to decode words and demonstrate adequate comprehension, you become eligible to spend time with a reading specialist. And so it goes, with services constantly hinged on that which a child cannot do. We cannot seem to find a way around this.

Labeling children for school services is also emblematic of how children with disabilities are labeled and stigmatized in our society, and a portion of the disconnect between parents and professionals in special education might be attributed to the issue of

investment that was discussed in the literature review. Schools are not required, by law, to provide children with the best services and supports money can buy. They are required, by law, to provide educational programming that is adequate. Unpleasant as it is to think about, the children who receive the highest level of service in the public school setting are most often those who will require intensive care and support throughout their lives. The likelihood that increasing the number of instructional or therapeutic minutes will alter that outcome is slim, and so within reason, schools need to establish and maintain eligibility criteria as well as limit the amount of service that can be offered to individual children according to available resources.

I found it interesting that Karen was the only participant in the study who quietly acknowledged the fact that “education” for her son is more about the stimulation he receives from exposure to the activities in school and caretaking than it is about academic progress. She spoke little of any discrepancy in the expectations she holds for Phil and the expectations of the teachers and therapists who have worked with him over the years; if anything, at times theirs were higher than hers. This may be a result of Phil’s disability being the consequence of a traumatic accident rather than something he was born with, or the amount of time that has passed since Phil’s injury. Regardless, Karen spoke in an “it is what it is” manner that might be interpreted as having accepted Phil’s physical and intellectual state and integrated that reality into her conscience in a way Kathleen has not, and might never be able to do. Kathleen’s anger and frustration with the system are justified (although they certainly do not need to be) but I wonder also if her feelings are intensified and commingled with some sadness, or maybe some guilt about bringing a child into a world that is ill-equipped to accept her unconditionally for who she is and what she can do?

Placement Issues

Given the concerns the participants in this study expressed about the discrepancies between their expectations for their children and those of the professionals in the schools their children attend, the next logical place for both practical and philosophical disagreements between the two is in the area of placement and service provision. “Where does my child belong?” is a question most of the participants in the study brought up at some point during the interview process, but only a few of them reported having been able to obtain acceptable answers from their local school districts. Although they may share some common characteristics, no two children in special education are actually the same, and the argument that all should be treated in a similar manner does not hold water with parents or other individuals who are familiar with the system. Many children who require special education services also stand to benefit from some level of inclusion, but depending on the child’s level of need, all schools are not equipped to facilitate that effectively. This section regarding problematic issues involved in the placement of children in appropriate special education programs is divided into three parts. They include the decision parents and professionals struggle with between inclusive and self-contained classrooms, how placement decisions need to be highly individualized, and some of the different difficulties that emerge when children present with disabilities that are less visible.

Inclusion or self-contained? A difficult decision.

Leslee talked more about this issue than any of the other participants and expressed a great deal of frustration with regard to the fact that Jeff’s experiences have not been positive in self-contained special education classes or in inclusion rooms for the most part. Assessing what the best placement for him is has been difficult, but the

difficulty has been made even worse by the school district's inability to provide Jeff with a placement that even comes close to meeting his needs. Over time it started to feel to Leslee as if he was not welcome anywhere. As she explained,

We can see that he isn't with regular ed, but in special ed they are either really low, or like in his cross-cat classroom, they are still trying to fit him in to things three and four year olds do. Or the solar system. He knows his name and address but will not always give it when asked, so we've been working on that forever. But if he can't tell you his name, working on the solar system doesn't make sense. Even when he was four, they did some ABA in the classroom and it seemed like maybe it could have worked, maybe of the other kids weren't so severe. He came in with a really severe group, they were tantrumming, screaming, throwing, biting, I mean you probably see it all, but they were trying to have like little tea parties and I am like he can't even sit. And that is the drawback of being in a totally self-contained classroom is that they kind of, well, if there are behaviors and if some kid is throwing a chair then they aren't so worried about your kid doing addition. And he couldn't do letters and read and I kept trying to push them and they would tell me that it wasn't age-appropriate. Or that it (reading and writing) was a communication skill and he doesn't talk much but anyway, it was a little frustrating, and um, you know, I feel like they want to teach toward the lowest common denominator. Some of the songs and things they would do in circle time, I mean I know, I get it, but I just wasn't sure if that was what he should be working on at the time.

Leslee also described her conflicted feelings about how far to push the issue with the administration at Jeff's school. While some years were better than others, the inconsistency did not help Jeff meet the academic or social goals that were written on his IEP. Her dissatisfaction with the school's efforts toward inclusion were actually about on a par with her dissatisfaction with the program in the self-contained classrooms, and it was especially frustrating to her when there was little effort to provide Jeff with a combination program where he could reap the benefits of both settings. For several years Jeff bounced back and forth between a variety of placements, and Leslee had this to say about the experience:

Well, when he was in the regular ed classrooms he had an AlphaSmart and a laptop and his aide helped him make power points about storms, but at a certain point it was clear to me that the curriculum, that things were over his head. He can read at a first or second grade level, but he doesn't always understand what he reads, but he is getting better with fluency and understanding. It is a slow road, but he is still improving. This last year he learned regrouping in math, it took forever but he is doing it. So he would have his aide with him but sometimes he didn't need her, like the kids were great and he could just go and eat lunch with them. Cleaning up is a problem, the other kids were doing it for him because the table had to be clean for them to go out to recess, sometimes he isn't as independent as we would like him to be so we are working on that. But we loved the regular ed kids, that they would bend over backwards to get him involved in softball or whatever. And that made a huge difference because he wants to interact. Maybe he doesn't do it all the time, but he wants to be with them, you know? And for making friends, like, these kids will be friends with him at school, but we tried to have kids over and they end up being in his space, playing more with his brother so it was hard. I am glad he was with them and I think we changed their views on his abilities, but I also think we have taken it as far as we can. The academics are more important as they get older, and...it wouldn't take much to include him but with all the teaching for the tests and quarterly assessments, you know, it's not their job to include him {sarcastic} and if nobody [meaning special education staff] is teaching them how to do it then it's not going to happen. Even with field trips, I asked what I could do to prepare him and they said "Nothing." So I made some visuals to help him and they just, just couldn't wrap their heads around what he needed at all. Sometimes the teachers just don't get it. He might be in there, but it's not a lot of inclusion. I went in to observe one time and she [the teacher] did not even acknowledge him walking in to the classroom or leaving the classroom. She would pass stuff out and pass his desk up, like while I was there observing, you think she would have at least said hello to him. And it was the same when he was in self-contained and had a homeroom, they were supposed to bring him for the things he could do and they wouldn't, she like wouldn't get him for a birthday party or for these special art presentations.

Leslee acknowledged that over the years she may have been over-zealous at times. As she put it,

It's awkward and uncomfortable, but I don't mind being Jeff's advocate. If I didn't do it, nobody else would stand up for him.

Some of the other participants in the study spoke about similar feelings. What they want, in their hearts, for their children is not always an option. Even though it is sometimes painful to go along with the recommendations made by the school team regarding placement, several of the parents came to regard it as the first of many experiments in the process of figuring out what would be best for their child in the long term. Grace, for example, recognizes that George's need for assistance is much too great for him to manage a general education classroom successfully, but when asked if her preference for George would be an inclusive or self-contained setting she replied,

Mixed. So he would know and learn from regular children but he would also know that there are children who need more care, there are children like him. I think it's pretty...there was a girl in his class with Down syndrome and the parents wanted her to be in the class with regular children but also with children with Down syndrome so she would know that there are other people like she is. So I want the same and it is also on his IEP that he will get along with other children in his age so you should include him if at all possible sometimes. But not all the time, right now he is in class and I think they are sensitive because they have time to be. He is in a classroom with seven kids and five adults and they have the time to think about modifications and what to do for children with disabilities, what they can do to help them understand and learn. But if he is in a class with just one teacher and more kids, she would not have the time to do that.

As much as she wants Roger to be exposed to typically developing children and challenged intellectually, Marie wants even more for Roger to be in a classroom where people are sensitive to his needs and understand him. Although Roger does well during most of the school day, he sometimes becomes nervous and anxious about noise and the lights and chaos can be overstimulating for him. General education teachers may not be trained to identify and work around, with or through these types of issues, and it can be very difficult to pursue inclusion for a child when inclusion is not a part of the school culture. As she put it,

No matter who you are, every person has their degree of what they can tolerate in terms of stimulation. And even things we don't think about,

there's a lot involved in getting him to do the things the other kids are doing. Every person has their varying degrees of what they can take, their quirky things, and I don't know if the regular ed teachers are taught about that.

Best placement depends on the child.

Determination of placement does not necessarily have to be problematic. Several of the participants in this study reported being pleased with the decision-making process as well as with the placement outcome for their children. Although inclusion is not best for all children, it is ideal for some. Elizabeth talked about how James was in a self-contained classroom for his early childhood program but then moved into mainstream classes with the support of a teacher assistant. She has been happy, but acknowledged her concerns for his safety and emotional well-being:

For us, I can't ask for anything more. He's so happy and he's included in everything. My biggest worry was that he was going to sit in the corner and nobody would talk to him and they are basically going to ignore him, but that hasn't happened, not at all.

For James, full inclusion has been beneficial. According to Elizabeth,

He's got a lot of friends and you know, he is, I think just because of the way he's put together, I think he's just, I don't think he really sees himself as having anything wrong with him and that's why other people migrate toward him and they enjoy his company. He really wants to do everything on his own, and he goes to recess on his own now. They had a family fun night at school the other night and, it was something where they ask parents to volunteer to work at different booths and I never volunteer for that because I always need to help Brendan who is younger and James, who I always think is going to need my help and so we are at this thing and we are there for like ten minutes and James says, "Mom, I'm gonna go find my friends!" Bye, see-yah [laughing]. I was like wow. He's on his own, and I want him to be as independent as he can be because I'm not going to be here forever.

For Jeff, the most ideal situation is a self-contained classroom with regularly scheduled, predictable forays into the community of his mainstream peers. Although Leslee was not pleased with how the children in Jeff's school were tracked, one of the

best years for him, inclusion-wise, was the year that he was in a self-contained cross categorical class for a majority of his academic classes but in a mainstream homeroom class and for lunch, as well as on occasion for special activities. Leslee got tears in her eye when she talked about the arrangement:

The best homeroom for him was with the gifted kids. Maybe it was because some of them had social issues, too. They were wonderful with him...I nominated one of them for student of the month because he went, he is not in cub scouts anymore, but he put his uniform on and went out with his brother, I am going to get all misty here, he went out with his brother to collect money for autism research because of Jeff. Those kids, always so nice to him, once when I went in to observe it was interesting how they asked him things about what he was doing, like "Jeff, what color are you using?" and they tried, they asked him questions he could answer!

Karen was much less enthusiastic about inclusion for Phil. His ability to participate in the academic and social activities that occur in the classrooms where his typically developing peers spend their time is so limited that aside from being in the room with them and sharing an occasional brief interaction, there is not much there for him. Karen understands how bringing Phil into those classrooms serves a purpose for the other children and she supports that effort to a certain degree. But she does not believe that his presence in those situations should encroach on learning opportunities for other children. I asked her when she knew that Phil might never move forward enough intellectually to join his peers, and she explained,

I knew, really, in early childhood. We kept him in early childhood through the year he turned six. I was thinking he was little and doesn't belong with those kids [the other children in the self-contained class were larger and older that year]. They always wanted to include him for something and every year I say the same thing. They want him to go to art. He doesn't get art. It's fine. They like it and he has fun being with the kids but the first time he takes someone's paper and crumples it up or breaks something, in my opinion, he's done with art. Because it's not fair to everyone else. But he is sweet and very happy and I'm not saying that because he's mine, that's just his disposition. People say hi to him and he just loves it.

Kathleen conveyed an interesting perspective about inclusion. It is not likely that it will be an option for Anna, and she disagrees with the argument that touts inclusion as being best for all children. In her mind, it is not, and

...the fact of the matter is that a lot of things that special ed advocates or special needs advocates right now are after I don't agree with. Like I don't think every kid should be mainstreamed. No, I don't. My daughter should definitely not be mainstreamed. The main issue for all children with special needs is that not that they be included, because it doesn't make sense. Some kids just don't, aren't going to benefit.

But Kathleen also reflected on the ideal of inclusion beyond Anna's classroom placement. It troubles her that Anna has to attend a school outside of their neighborhood because of the intensity of her needs. In many large urban school districts, designated cluster sites are specified for children with needs as severe as Anna's, and in their particular situation this means Anna is excluded not only from contact with typically developing peers but also from her neighborhood school. Kathleen continued, on a more philosophical note:

I find it interesting as a historian because there are so many debates about segregation and integration and what the costs are to children. What does it mean to be bussed? I mean all of these things have to come up for me in the context of Anna, right? And what does it mean to not have a neighborhood school that you can go to? What does it mean that we are in the car for half an hour there and half an hour back everyday and an hour of her life is in transportation to school? For two and a half hours at school? Is that equal? No. It is not. It is separate. And I think, so for me, what drives me crazy is that there is this notion that because you're mainstreaming kids you're treating them equally, when my feeling is no, you are segregating them even further through your whole placement of children in the schools system and then you say you are so enlightened because you are pulling them in for lunchtime? Whatever! For me, it's politics and not practical reality and I find it frustrating, you know? Why can't my kid go to a school that we can walk to? Why? And I know not every place is going to be able to give her the stuff she needs.

Getting to know other children in the neighborhood was also a concern Marie had for Roger. Early on she decided to make sure that he was exposed to children and activities outside of school. This worked well for Roger, and Marie spoke with a great deal of appreciation for their community:

We've been very fortunate. We have a strong church community and a lot of people who have been involved with us who have been exceptional. We were concerned when Roger was bussed to the school because he never got to know the guys in the neighborhood, and that's why he joined Scouts. We wanted him to have other regular experiences because he was in self-contained, and Scouts was that thing. And you know, I get choked up when I talk about it, but he has a friend named Thomas who, his mom is a special ed teacher in a different district and we didn't know this when he started Scouts, but Thomas, who excels academically and is a well-rounded kid, is his best friend. And as a parent you watch how other kids interact with your kid, especially if you have a kid with special needs, and I've seen other Scouts interact with him but they are not quite sure and they are not quite comfortable, and they, he certainly doesn't get invited to a lot of birthday parties and those kinds of events. He does with Thomas, and he will come here and hang out or go to the movies. Thomas treats him, when you watch, Thomas knows that he has some disability, but treats him, talks to him as a friend who just might need some extra help. It's very heart-warming to see. So we have just been blessed with a lot of good people around us.

Invisible disabilities lead to additional placement concerns.

Several participants in the study talked about their child's disability being invisible, and some of the complications that can arise at school when a child looks "normal" but is unable to function independently in the classroom. Schools that support "full inclusion" for children with disabilities are often sought after placements by parents who believe being among their peers is what is best for their child. But parents experienced in attempting to obtain assistance and services in these settings to help their children function as independently as possible were less enamored with the situation than one might expect. Rachel talked about how painful it has been for her to know that Albert is in a room all day with children and teachers who do not understand him. She expressed concern for how his behaviors can be confusing to people around him and for the isolation he experiences because he is different:

He is a really sweet kid, but he does get frustrated and overwhelmed and he'll just start shrieking sometimes. Sometimes he will bang his head on the floor or on the wall. And people want to get mad at him because you've got to think he's doing that on purpose, but then he'll turn around and say something and you just know he's not doing this on purpose. I have no idea how, but I would like them to do something about the bullying and teasing. It's obvious that he isn't doing all the same work as everyone, he's got an AlphaSmart on his desk, but like, they pass papers back and forth and the kids grade each other's papers...well, he circles his answers instead of writing them on the blank so then when another kid looks at it they mark it all wrong. The other kids shouldn't be seeing that he only does half the problems, you can guarantee that when the other boys find out they call him names and make fun of him. I know sometimes they like him, but they pick on him on the playground or in the lunchroom.

Ivy described how frustrated she feels when teachers who are less experienced or knowledgeable about how to engage students with disabilities in the classroom activities may resort to behaviors that mask, rather than alleviate the problem. For her daughter, who struggles socially to fit in, group projects are problematic. Her attempts to communicate with the teacher about alternative approaches failed, and he

...kept doing this group thing. If I saw there were kids with social needs in the classroom, I would be very careful about the way I presented this type of activity. Well, every time he [would let the students] pick who they wanted in their groups and he would say, "Well, I'll work with you" [to Gabriella]. And I don't think that is making her a part of the classroom. That's not giving her the opportunity to facilitate friendships that she doesn't have. And I think sometimes without them even realizing it, they get their label. You need, help, so people always have to help. And I just feel like, what a loser on his part as a teacher. It's so easy to take care of that so everyone feels included, they could pick numbers out of a hat or count off in groups of, anyway, he just wasn't doing that and it's just disgusting. The thoughtful things that are so easy that you could do to be effective, it's just disappointing.

Several participants in the study discussed teachers who do not make effective accommodations for a child's needs, even when those accommodations are documented in the child's IEP. Rachel's son Albert is intelligent enough to do the work required of him, but he is not able to engage in the social aspects of the classroom environment

without a high level of support. In addition, he has sensory needs that are not being met, and Rachel thinks that is because teachers would prefer to ignore the complexities of his presentation. As she explained,

No. I do not think they're teaching him what he needs to learn. Because he is very good academically, they're just pushing ahead with the academic stuff. They are like here is what he is good at, so we are going to make him the best we can at that, instead of pushing him forward on the line {Rachel alluded here to the gap that is developing between Albert and his peers because of his behavior}. And as the line goes up he goes with it under here and, but the things he needs to work on are not moving as fast and he is getting further behind.

Summary and analysis.

Asa Hilliard (2002) defined culture as "...nothing, more nor less, than the shared ways that groups of people have created to use and define their environment" (p. 89). Nothing defines a school culture more clearly to parents who have children with disabilities than the recommendations that are made for classroom placement and the level of support available to maintain the integrity of those placements. The complexities of these placement issues are apparent in the wide range of responses obtained from participants on this topic. Tensions that arise are not simply a matter of where a child is placed, but are often reflective of what that placement means for the child as well as for his or her family. For parents who might be holding on to hope that their child will one day graduate from special education and join the ranks of the "normal," recommendations from school staff for a self-contained placement that is isolated from typically-developing peers might be met with resistance. Parents who know their child could benefit from some very simple accommodations in the general education setting are often angered by recommendations for restrictive placements as well. And for parents who know their child will never function independently in mainstream society as we know it now, placement concerns may be less about classrooms and more about the

opportunity to send their child to a local school where, by nature of proximity, they can be a part of the school and neighborhood community.

School placement has tremendous implication for exposure to typically-developing peers, and regardless of a child's level of disability, most parents harbor the hope their child will have the opportunity to form friendships with other children. Living within a reasonable distance from the school can facilitate this, as can attending a school where inclusive practices are a part of the culture of the school. All of the children discussed in this study are, for a variety of reasons, challenged in the area of connecting with their peers. Their parents were realistic about it, and voiced an understanding of how exposure to typical peers either in school or in the community might open the door for the formation of friendships, but for many children those friendships are more superficial, lacking the depth and quality of friendships other children experience. For this reason, it seemed, many of the participants expressed concern for how their children might be included in a safe and dignified manner during the school day. It is not acceptable, for example, for a student to be brought in to a general education classroom by an assistant and then not be included, in a meaningful way, in the activity his or her general education peers are engaged in. By the same token, inclusion should also be curricularly sound; activities students with disabilities are engaged in during time spent in the general education setting should be a derivation of what the other students are doing. It should not be acceptable, really, for a fourth grader to be working on a power point presentation about the weather in isolation while his peers are in literature circles focused on a novel they have just read. And it is not acceptable for a student with emotional and behavioral issues to be appeased with activities of choice or books of interest during the school day in order to avoid outbursts. He needs to be challenged in order to develop the skills required to cope with being challenged.

One of the participants in the study talked about how the school her children attend takes pride in calling itself a “full-inclusion” school. Children with disabilities are rarely pulled out of their classrooms for special education services. She described several of the children who are in her son’s class as having Down syndrome, severe attention deficit disorder and “...what I assume is cerebral palsy because he is in a wheelchair and his head is back and he drools...” She also mentioned that the children in her son’s class think these children are “just like everyone else.” While being regarded as a part of the class is certainly desirable, I also think it is important to acknowledge that students with disabilities, especially those that are severe, are essentially not “like everyone else,” and it is, perhaps, not in anyone’s best interest to pretend that they are. Inclusion for social purposes has great potential for benefit when conducted in structured settings where children with disabilities are likely, with the right support, to be successful. This is not the same thing as inclusion for academic purposes or during academic instruction, especially for children who are unable to engage in the content at a level that is within range of their typically-developing peers.

There is another layer of tension surrounding the issue of placement that was brought up by participants in this study. It is rarely discussed in the literature, but often a topic of discussion and argument between administration, teachers and therapists in schools. It is a complicated issue, and one that could easily offend, but given the nature of the comments offered by the participants in this study, I would be remiss to avoid addressing it. Please consider my perspective as a school-based professional and my bias based on experience in this aspect of analysis.

In most school districts, once the need for a special education services has been determined, parents have the opportunity to visit different classrooms before they agree to placement. This can be awkward, especially for families of young children who are in

the process of coming to terms with their child's level of disability. Although student composition in any classroom fluctuates from year to year and parents are informed of this, it is traumatic for them to walk into a recommended classroom and see children who are more physically or intellectually involved than their own child. This visit often leads to discussion of, and occasionally the demand for, a less restrictive placement. Like many of the participants in the study, I believe children can rise to the level of expectation, but I also believe that as educators, we are charged with the responsibility of very carefully calibrating the level of challenge a child is exposed to, and this can be, according to several of the participants in this study, a source of contention between educators and families.

Given this, and based on comments from participants in the study, I think it is important to consider what appears to be a common placement problem in special education. In most school districts, there are six general levels of service available to children. To paint a picture of these levels, I will use the structure that exists in the district where I work as an example. The levels of available service are as follows:

1. placement in general education,
2. placement in general education with support from a resource teacher,
3. placement in an Instructional classroom, where students receive academic instruction in areas where they are challenged but also spend up to 50% their day in a general education classroom with the support of an assistant,
4. placement in one of several self-contained classrooms located in general education buildings where children with both cognitive and physical impairments remain with one teacher all day,

5. placement in a self-contained classroom which may be located in a separate building for children with severe emotional and behavioral disorders, and finally,
6. placement in what we call the Life Skills program. These classrooms may also be located in a separate building. They maintain very low student to teacher ratio and focus on a functional skills rather than an academic curriculum. Some of the students are mobile and verbal, while others are severely and profoundly impaired.

Unlike what occurs in some large, urban districts and within many rural communities where services are less accessible, families in many suburban districts like the one described above and those described by some of the participants in this study generally have a fairly comprehensive array of services available to them. There may be plenty of skilled teachers and enough speech, occupational and physical therapy to go around. There are likely reading, behavior, augmentative communication and literacy specialists. There might even be music therapists and a traveling art teacher. What is often missing, according to many of the participants in this study, is a team of knowledgeable individuals who can complete accurate assessments or a group of experienced administrators who can communicate effectively with families to ensure appropriate placements. Acquiescing to parental wishes is much less expensive for a school district than going to due process, but because of these areas of weakness, the integrity of the program at each level (as described above, although variation exists from district to district) may be compromised. Essentially, there are classrooms stocked with supplies and curriculums appropriate for students with all sorts of learning and care needs. But the children who could benefit the most from being in those classrooms are often not in them. Instead, they are in the classrooms that are one level above what might

most effectively meet their needs. Some children who could benefit from Life Skills are in self-contained classrooms, children who require the level of support available in a self-contained classroom are in Instructional placements, children who would probably be best served in an Instructional placement are receiving resource services, and then, of course, children with the “mildest” disabilities, also those most likely to benefit from a low level of intervention and support, get the least amount of attention. This is a systemic problem in many schools, but it is deeply rooted in a culture where we prefer to minimize the presence of any sort of disability (Davis, 1995; Erevelles, 2005; Gere, 2005). Because of this, children all along the spectrum of what we define as “disabled” may suffer, both socially and academically.

After reviewing more of the disability studies literature, I find it disconcerting that almost all of the options for special education services participants in this study described involved removing their children with disabilities from the classrooms where typically-developing children are educated. Clearly, this is a more common practice than educators would like to acknowledge. This body of literature has also helped me come to recognize how deeply my opinions about this issue are informed by my upbringing, education and work in a system that legitimizes separate as equal for students with disabilities. Arguments from parents, who are ultimately the most passionate advocates for their children, certainly give me pause to examine my feelings and second guess my perspective. One such argument, cited in Murray & Penman (1996) is from a parent in England:

For us the concept of segregation is completely unjustifiable-it is morally offensive-it contradicts any notion of civil liberties and human rights. Whoever it is done to, wherever it appears, the discrimination is damaging for our children, for our families, and for our communities. We do not want our children to be sent to segregated schools or any other form of segregated provision. We do not want our children and our

families to be damaged in this way. Our communities should not be impoverished by the loss of our children.

As a researcher, it is difficult for me to reconcile statements such as the one above with my own aversion to some of the poorly-implemented inclusion practices I have witnessed over the years, as well as with the stories participants in this study shared about their experiences. For some, perhaps, inclusion at all costs is necessary, but in my experience, efforts to avoid “impoverishing communities” of children with disabilities too often leads to impoverishing the educational experience for those very children. Both Leslee and Rachel provided first-hand accounts of how placing their children in classrooms with their peers but without adequate support did not work, as access alone does not ensure or maintain meaningful inclusion. I believe we all have quite a bit of work to do, but it was reassuring to me to encounter parents who shared my concern and support the practice of inclusion in a manner that allows for exposure to both academic and social aspects of the general education setting while also preserving dignity for children with disabilities.

Communication

Epstein (2002) defined communicating as one of the most important components of partnership practice between schools and families. Although it is extremely important in the general education setting, communicating, and issues associated with effective communication, take on even greater significance in special education. Children in special education often have a large number of professionals (including administrators, teachers, therapists, paraprofessionals and other ancillary staff members) on their educational teams, and communication between all parties and parents is necessary for successful service delivery.

The special education literature supports a positive correlation between partnership with parents and school success for children with disabilities, but habits and practices that live in textbook chapters and journal articles do not always thrive as functional classroom practices. One reason this might be the case is that the IEP meeting is sometimes the only time school-based professionals meet face to face with families. During these meetings, when tensions are running high and there is pressure to be efficient, communication often suffers and puts relationships at risk. Sometimes we do communicate well; we are clear and articulate about our concerns, parents are receptive (although not necessarily in agreement), and conversations are reciprocal, civilized and focused on what is best for the child. At other times, when we are not as successful, the quality of our interactions with parents disintegrates, and as a result, relationships are damaged. Participants in this study spoke of the challenges they have faced in communicating to cultivate and maintain relationships with the professionals on their child's educational team and their frustrations with some of the systemic (and occasionally human) barriers they feel work against meaningful communication. But their experiences were not all bad, and many spoke highly of the individuals who helped them through some of the more difficult passages for parents of children in special education. This section on communication is divided into four parts. The first is about early communication with service providers, the second is about the often difficult transition between Early Intervention and school-based services, the third is focused on the need for reciprocity in communication and the fourth offers some perspective from participants on what ideal communication can accomplish.

Early communication with service providers.

Almost all of the participants in this study spoke about their early experiences with doctors and therapists regarding the diagnosis of their child's disability. Although each of them knew something might be amiss, they found the hesitancy with which professionals addressed the problem to be somewhat disconcerting. Elizabeth described the staff in the developmental follow-up clinic at the hospital where her twins were born as particularly vague. They went to the clinic for regular check-ups and knew James was not developing at the same rate as his twin, but

...that was our first strong indication that something wasn't right because they [the doctors] were recommending therapy. They didn't say anything about cerebral palsy at the time but I have a funny feeling maybe they strongly suspected it because he wasn't doing certain things like rolling over or picking his head up or whatever. And it's kind of interesting, because his physical therapist that evaluated him and saw him for the first two or three years of his life is now his therapist again. I don't know how much she really shared with me in terms of what she was thinking about James, but I'd ask her questions all the time about what she really thought, like "What are you telling me? That he's not going to walk?" And I didn't have a label for him at that point and she said, "Some of these kids don't walk."

Kathleen also talked about how early on the doctors conveniently left a lot of information out of conversations with her and her husband. As she described,

...the first time I heard anything about seizures was when we were in her newborn checkup and the doctor asked if we had seen a neurologist. And I'm like, "No." So we went to see a neurologist and the first thing the neurologist asked us was, "Is she having seizures?" And I just thought, "What do you mean, is she having seizures?!" I thought she might be developmentally delayed, nobody told me that was a possibility, and it is a very real possibility for girl children with ACC. I myself was disappointed that nobody told me, though at that point I was not actively reading anything about it because I couldn't do it, couldn't go there. And my sister actually joined a support group on Yahoo on my behalf and sort of was, would filter out information and send me things she thought I could handle. You know, which was probably a great thing to do, she really helped ease me into it and I was probably, Anna was probably four or five months old when I was able to venture into that world myself.

Leslee talked about Jeff's early delays and their struggles with differential diagnosis. She went to great lengths to have Jeff seen by a well-known expert on autism. He told them very little and sent someone on his team out to get pamphlets for them to read. He never said Jeff had autism and he provided no direction for Leslee and her husband. They eventually went to a different hospital where a neurologist was extraordinarily blunt. He said, "It is nothing else. It is autism." Leslee described the experience as painful, but acknowledged how helpful it was to finally hear the truth.

Marie and her husband also struggled with the amount of information they were given early on. As she described,

I know a little bit about the laws and my rights and that helped me feel a little more comfortable. Even though you walk in there and everyone else is the expert and you're just the mom. Not that I'm demeaning that, I think that's the most important spot, position to have, but that's not the way all people look at it. And so you're [professionals] telling me all this stuff about my kid, what do I do? Sometimes it's just too much all at once and you haven't even had time to process.

Transition from Early Intervention to school-based services.

Almost all of the participants in the study were involved with the Early Intervention system prior to entering school. In Early Intervention, many of the children were seen individually in their homes, or for center-based services in small groups. Entering school, most were placed in Early Childhood Special Education classrooms, where services are focused on educational, rather than clinical goals. The difference between the two systems can be startling to parents, especially those who benefited early on from the family-centered approach to care. As Kathleen noted,

I think what's hard about the transition into school is that everything had been family-centered suddenly becomes adversarial. I mean, the therapists we ended up working with in Early Intervention were amazing and were hugely important to me. I would have gone mad if those women hadn't been in my house every two days. They were a huge support for me. And school is just very different.

Elizabeth talked about how within the Early Intervention system she felt like a part of the team for James, and was recognized and respected for knowing her child better than anyone else could. Although she did not have complaints about communication with teachers once James entered school, she credited the Early Intervention therapists with

...really trying to work with us to figure out what would be best. Because they knew we knew him better than they did and had a big picture idea of what would work for him.

Grace spoke about how important it was for her to have a connection with the therapists who worked with George. It helped her to feel less alone and she learned from them, about George and about the system. She works as a translator for other families in Early Intervention now, and said this about sharing information with other families in the system:

And when I work with my Early Intervention families I share my experiences because I know it is very important for them to know that there is someone with same worries, same fears, same problems or similar problems not only now but in the future. I always share with them my experiences with George so they will know what to ask or what to say and what the transition will be like, where the children might be placed, what kind of problems they have, stuff like that, just educate them. It's called interpreter job but it's more than that, it's more like I wear many hats.

Good communication requires reciprocity.

Communication between parents and school staff should be reciprocal in nature. Unfortunately for both parties, families may present with very different needs at various times and schools do not always have their most capable communicators on the front lines. At the IEP table sometimes it seems like everyone is talking and nobody is listening; by no stretch of the imagination could this be considered reciprocity in communication. Kathleen described the problem clearly when she said,

I think there is a problem with the assumption that when people are talking to each other you are having the same conversation. And you're not. And people need to be trained to understand when that isn't happening. And I'm not sure that happens. Because usually I think what happens is this notion that something is wrong with the parent, that they're not getting it. Which is ironic considering that the people involved are in special ed (laughing). But the other problem is that I think Anna is seen as a diagnosis and that's not all it is. And communication is a problem because there is a sort of attitude among school personnel about parents in general which is that they are largely a source of irritation. And I think this is in schools in general but it is heightened with special ed for two reasons. One, there's this sort of adversarial relationship that can develop and two, there's judgment made by teachers and other professionals in the school that is about how well the child's being cared for at home.

Feeling judged was something that also bothered Leslee and had a significant impact on her ability to communicate comfortably with Jeff's teachers and therapists. She talked about how teachers wouldn't listen to her and how she felt like she could not approach an administrator about the lack of communication without branding herself as a "complainer." As an advocate for Jeff she described herself as "vocal" and "firm," and in spite of her discomfort with the quality of the communication that occurred between herself and the school staff, she said,

I always tried to leave the meeting on a positive note. Some teachers won't even look at you when you are leaving, and I'm like, "...that's not me all the time, that's Jeff's advocate, that's his mother!" My friends tell me not to worry about it because they don't even know the other side of me. But I have to be factual, I have to call them on everything and it is so awkward!

While the IEP meeting often sets the stage for problematic communication between parents and teachers, for Leslee, many of the communication difficulties stemmed from the IEP document. By law, parents should receive quarterly updates, but according to Leslee, those updates often do not actually say very much. She learned not to assume that things were getting done for this reason:

...we ask for a meeting every year by November, and we ask for the goal sheets and the charting. We want to know, is he doing it four out of five

times? With how many prompts? We need to know. Because for so many years we would go to the IEP and it took us a long time to realize he wasn't doing things. Why didn't we know? Because they always told us he was making good progress. That's what we got. Right up until the end of every year when he didn't meet his goals and then they would want to just continue them on for the next year or maybe write all different goals and start all over again.

But Leslee was also quick to point out the following:

We have had a lot of really good experiences and I know there are people who sit back when they are frustrated and don't do anything but I feel like if we didn't we would [be letting Jeff down]. Sometimes when we would meet with them I would feel like we were being heard, and one of the principals had an open door thing and said "Come by for a cup of coffee" so I didn't feel weird about stepping in to talk for a few minutes. I didn't do it much, but it was nice to know I could. He was nice, even if we disagreed, he was still nice.

According to several of the participants, communication can get easier over time and you learn not to take what people say to you personally. As Leslee noted,

I know parents who don't go to meetings now and that doesn't make sense. I can't see that. You have to just get over it and keep showing your face and you have to let them know you are not going away!

Karen decided early on that she was going to be Phil's advocate, regardless of how the school staff might see her. As she put it,

Most people mean well and you do find some that help you out. And the PT that works with him I know personally, and she thinks I am out of my mind. She has a very low tolerance, she rolls her eyes, whatever. But she's good with Phil, she's good with his private therapists, sometimes I have to explain things a little more to her, but whatever, she wants to know why for certain things, but you know what, she's got a right to know why, she's been with him for six years, longer than a lot of other therapists. But really, everybody at school has been great. I was a little disappointed when they reduced some of his OT time last year or two years ago. I didn't really agree with it at first but I realized that it's the aides who are with him and follow through on things with him all day, she's just the coordinator of it, not that just, and I like her a lot, I don't mean it like that. But she's the one who figures out what kind of scissors he can pound on or the grip he should attempt to use on the crayon even though he won't hold it himself, and it's the aides who do everything. We are in that sense really fortunate. The aides are the most underappreciated people ever.

Kathleen is also committed to being an advocate for Anna and will stand up for her and her needs and her well-being whenever it is necessary. She understands the risks associated with being vocal though, and sometimes has to take a deep breath or a little

extra time to decide if the issue she is upset about is worthy of a fight. Even when she knows it is, sometimes she wonders,

Yeah...but oh, it's like, do I really want to make a scene?

Grace has had some frustration, but she feels it is more with the system than with the staff at George's school. Right now she is concerned about his placement for next year and wishes that she were not being sent all over the city to look at classrooms that really would not be appropriate for George, but up until this point for the most part,

...they were very good to me. I could share my experience, they would listen to me, I gave them a lot of advice because George makes certain sounds for things, and they don't know what is "g-g-g-g-g" so I would tell them what it means. And like "brrr" means he wants to go, or he wants to leave, so, um, they were always listening to me. It was pretty good communication between us.

Marie was thoughtful about this communication question and talked about how beneficial it has been for her and for Roger. Over time, Marie and her husband have come to think of some of Roger's teachers as family. As she described it,

You know, as we're talking, my thoughts go to what might have been different about our experience is the amount of communication I was able to have with the different people on Roger's team. Not only were they open to me coming in, inviting me, but the notes back and forth, the times when there were special concerns. There was a time when Roger cried every morning going to school. We had no idea what that was about. Eventually we figured out that it has become his routine and he cried because that's what he did every morning. We never knew what the original thing was. We tried a few things, had him see the social worker to try to work some of the anxiety out over whatever it was. But just constantly having the opportunities to have that communication, whether they are in person, over the phone or in writing. As I think about it and talk to you, that was a big part of why I felt these people were a part of our extended family. You know, they knew everything about us. Um. And because of that I think served Roger very well. If it wasn't for that I don't think Roger would be at the point where he is now.

What ideal communication might look like.

All of the participants in the study offered commentary and suggestions that might be used to improve communication between schools and families. A few were complicated, “in an ideal world” sort of wishes, but most were things that could be accomplished with simple efforts. Four of them stood out to me as especially relevant to this research project because all are related to the way parents and school professionals approach one another.

First, opportunities for unofficial communication need to be increased. When parents send their children to school on a bus and otherwise visit the school only once or twice a year for meetings, it is impossible for them to feel like anything other than a visitor. Increasing the frequency of conversation between parents and schools can increase the comfort level between individuals and improve the quality of the interactions. As Kathleen said,

I do wish there was a way to have communication that wasn't legal and binding. Like a sit down, let's talk for a few minutes in a way that doesn't have the stilted nature of the IEP meeting, which is more like, OK, this is what we have to do.

Second, Karen talked about honesty and how important it is for teachers and parents to be able to talk to each other without reservation. She described a teacher of Phil's who was “less warm and fuzzy” than some of his other teachers, but seemed to have a closeness with and understanding of her students that was comforting to Karen. Because they live a few blocks from school, Karen often drives Phil there, and when it is raining, she will carry him from the van to the door of the school to avoid getting his shoes and braces wet. Karen described how this teacher initially observed her habit for a few months and then confronted her in a friendly and gentle way:

So, well, when I brought him to school and it was raining and I took him out of the car and carried him up to the door because I didn't want his

shoes to get wet because then his braces get wet. And she was standing at the door and she said to me, “You know, he can walk.” And I got the point. And she also brought me a stool so I don’t have to lift him in and out of the van, I can just hold on to him and help him...

If this teacher had not felt comfortable enough to bring the subject up, Karen might still be carrying Phil from the van to the school when it rains. He is a twelve year old boy, and although he is small, it is more appropriate for him and much better for Karen if he walks.

Third, Kathleen talked about how some people are able to talk with her in a way that is simply open and caring. They do not have to do anything other than listen and refrain from being judgmental. She understands why this is such a difficult thing for people to do and does not expect it from everyone, but it is certainly something educators might strive for in their attempts to communicate with families. Kathleen described one person in her life who does this well:

My dear friend Alison McCarthy. Um, she teaches with me. She gets it, she just does, I don’t know why. I don’t know why she does, she just does. She took care of Anna when I first went back to work. I had to scramble, because I was about to go back to work when Anna got sick [started having seizures]. So I had to scramble to not teach during that semester right after she started having seizures. And then I needed to go back to work and Alison would come for that two and a half hours or whatever that I went to teach and take care of her. You know, they bonded really well and I remember, she was just the best friend to me. I remember her saying to me once, and this is going to make me cry, she said, I was so upset, it had been such a terrible day with Anna and I went to meet her at the coffee shop and I was just crying, I was like, “This is so horrible, and I can’t believe she’s going through this.” And she said, “You’ve just been dealt a shitty hand. And I’m just so sorry.” And I thought that this is just the best thing to say, because that’s all it is, you know, it’s not like, I mean there’s nothing to make me feel better about it and she knew there was nothing. All she could say was “This sucks. I’m really sorry that it sucks.” And that’s sort of just how she’s been, just sort of incredibly open, open to it, not afraid of it, not afraid of the pain and the discomfort and um, the fear, or anything. She was just very open. And I think that’s the key piece of it.

Finally, Karen brought up flexibility as one other factor with the potential to make a difference in how school staff and families communicate. Phil receives therapy services outside of school and often has other related medical appointments. Although she tries, there are times when it is difficult to schedule these appointments after school hours and she needs to take Phil out of school for them. When this happens, she makes the effort to take him out at a time and in a manner that is minimally disruptive to the classroom routine, but it does not always work out that way. Most of Phil's teachers have understood, and that has been very helpful for Karen. Karen also talked about her appreciation for the flexibility many of Phil's therapists both at school and in the clinic have demonstrated. Although she understands their perspectives may differ and their goals might not be quite the same, she appreciates when they make the effort to work together for Phil's benefit. Consistency has also been helpful; at the clinic therapists come and go often, but Phil has had the same speech therapist, physical therapist and occupational therapist at school for the last six years. As Karen explained,

At school, he's had the same therapists the entire time. They talk to the people at the clinic and they have all been there to see what he works on there. They might not all go every year, but every time there's been a change, knee immobilizers or new hand splints, then they get together. Some of the therapists from the clinic have come to school to meet also, they, all of them have been great about it.

Summary and analysis.

According to Patrikakou, Weissberg, Redding & Walberg (2005), positive, on-going, two-way communication is a necessity for the formation and maintenance of meaningful and productive partnerships between schools and families. Participants in this study described a variety of challenges to and benefits of communicating effectively with the staff in the schools their children attend, but I think it is interesting to consider the fact that a "meaningful and productive" partnership might look very different to each of

the involved parties. Some of the participants spoke about wanting information while others talked about how they managed to protect themselves from obtaining too much at any given time. They talked about the timing and the tone and the underlying messages they received from teachers, therapists and doctors and they talked about how they did not always feel heard or that their situations were understood.

Having been in more IEP meetings and conversations with parents than I can count, I find it almost funny how simple the literature makes it sound and how layered and complex the actual interactions are. Parents and teachers and therapists and administrators are constantly checking each other out and experimenting with how to best to get their messages across the great divide that exists between them. We (both sides, if I am correctly interpreting what the participants said) generally mean well, but we also regard conflict as a negative thing, rather than as a conduit for problem solving. When used effectively, some types of conflict, much like constructive criticism, can actually foster growth and facilitate change. Raising your voice, name calling, pounding your fist on the table, or turning a school issues into personal issues are not generally helpful behaviors. Listening, responding calmly, and taking the time to talk through possible options for solving the problem at hand are much more effective.

Kleinman (1988) used the term *explanatory model* to describe notions patients, families and practitioners develop about their illness or disability. They are informal descriptions and function, more specifically, as

...representations of the cultural flow of life experience; consequently, they congeal and unravel as they flow and our understanding of it firms up in one situation only to dissolve in another. Furthermore, these models...are anchored in strong emotions, feelings that are difficult to express openly...(p. 122).

According to Kleinman, taking these explanatory models into consideration and negotiating conflicts that arise within them can both remove barriers and contribute to more empathic and ethical care. He goes on to note that

...inattention to the explanatory models of patients and their families...may signal disrespect...and failure to regard psychosocial dimensions of care as relevant. Such blatant disregard impedes the therapeutic relationship and undermines the communicative foundations of care (p. 122).

If Kleinman's work were applied to the educational setting, it might be said that the most important aspect of communication between parents and professionals in special education has nothing to do with talking, and everything to do with what he calls "intense listening." This, he stated, is a "moral act, not a technical procedure" (p. 154). And according to the participants in this study, it is this act of listening that creates reciprocity and space for open and constructive communication between parents and professionals.

Another communication issue the participants in this study presented had to do with people being honest with each other. Why is it that no one told Kathleen and her husband about the strong possibility of Anna developing a severe seizure disorder? Why have doctors been consistently vague when Rachel brings Albert in for testing? How is it that people are still suggesting to Leslee that Jeff might go to college? Participants in this study were not describing isolated or minor deceptions. They were talking about being lied to. Based on the data collected from participants in this study, this goes on all the time. Administrators tell parents the main goal in special education is for a child to return to the general education curriculum. Teachers tell parents their children are reading or telling time or playing with other children when they are not or that they completed an art project independently when it is obvious they had a lot of help. I wonder if individuals are trying to be kind, if they intend to mislead (Bok, 1989) or if they simply find their own professional identity intertwined so tightly with the accomplishments of their

students that being honest about inevitable failures is not even an option? Perhaps severe physical and cognitive disabilities are so disruptive to our aesthetic (Todd, 2003) that we simply cannot talk about them honestly. Or it may be that out of self-preservation, we elect to paint a prettier picture of reality for ourselves than truly exists.

I have very mixed feelings about this issue. I understand why teachers may exaggerate the positive when presenting progress to parents and why a doctor might gloss over some of the most brutal details of a child's prognosis as they offer a grim diagnosis. I believe hope is a powerful and necessary sentiment, but my experience in special education has led me to find false hope, and sometimes those who nurture it in others, to be either opportunistic, or cowardly and cruel. As an example, I worked for many years with a child who suffered a severe head injury when she was in second grade. Her optic nerve was severed on one side and severely damaged on the other. She was, at the age of eighteen, intellectually much like the child she had been at the time of the accident. If she could see anything at all, her ability to process that information was severely impaired. But her family was convinced by a woman who called herself a "tutor" that she could see. And they paid this "tutor" thousands and thousands of dollars over the years to come over to their house and work with their daughter on "using her vision." Other examples include therapists who keep children on their caseloads for fifteen or more years, doctors who spout technical jargon without explanation and, of course, much of the very expensive quackery that claims to "cure" various ailments. Especially autism. Participants in this study offered many of their own examples; Kathleen of evasive doctors, Leslee of opportunistic therapists and Rachel of a psychologist who claimed to know what was "wrong" with her son without ever having spent any time with him.

So why is it when we talk about disability we are so inclined to lie? According to Nyberg (1993), we

...use deception of self and others as a means of coping with fear...to tolerate stress, to gain a sense of control over the uncertain aspects of our lives and futures, to enhance our own well-being, to gain and protect privacy, and to help others...(p. 1)

Because it is in our nature to want to be liked, we also, according to Nyberg, might

...lie to satisfy selfish motivations for manipulation...to attract attention, even love, or to impress others with exaggerated abilities or accomplishments; and commonly we lie like crazy to avoid harm, punishment and blame (p.48).

Fundamentally, certain types of lies are justifiable. As he stated,

Deception is not merely to be tolerated as an occasionally prudent aberration in a world of truth telling: it is rather an essential component of our ability to organize and shape the world, to resolve problems of coordination among individuals who differ, to cope with uncertainty and pain, to be civil and to achieve privacy as needed, to survive as a species, and to flourish as persons (p. 5).

Others find a purpose in deception as well. Smith (2004) observed that “human society is a network of lies and deceptions that would collapse under the weight of too much honesty” (p. 2). He went on to note that

...self-deception is the handmaiden of deceit: in hiding the truth from ourselves, we are able to hide it more fully from others. Therefore, self-deception lies at the core of our humanity...and is probably vital for psychological equilibrium (p. 3).

I am certainly not free of guilt in this arena. I have, absolutely, told some lies to protect myself. When I was a teenager I lied to my mom about where I went with my friends, and as an adult I have lied to my dad about that dent in my car (I sideswiped a parking meter) and to my husband about where all the potato chips might have gone (I ate them in the car on the way home from the grocery store). In each case I meant to deceive, but I believe the potential for damage was minimal. When it comes to more substantive matters of both personal and professional ilk, I want to give and receive the truth. As an example, I find no joy in news from my mother’s oncologist, but I trust that he is being honest so that my mother and father can make informed decisions about treatment and care. For him to withhold information because, hypothetically, he wishes her cancer had

not spread would, in my mind, be inexcusable. By the same token, I derive no pleasure from sharing concerns with the parents of my students about their skills and progress when they are less than ideal, but it is my responsibility to be honest so they will have as much information as possible about their child. For me to omit significant concerns from our conversation or my written reports would be negligent. There are certainly parents who would prefer not to know the extent of what I might figure out from evaluating or working with their child. When this is the case, I attempt as much discretion as possible without shirking the responsibility I have to be truthful. Sometimes my efforts are helpful and at other times they fail. I have to accept this as the nature of my work.

I cannot speculate about why people lie any more than I can speculate about why people, myself included, will, at times, believe things we know not to be true. Nyberg offered this possible justification:

Generally speaking, we have a tendency to think that if something makes us feel very good, if something brings about a highly desirable and satisfying feeling of harmony and well-being, then perhaps that something, because it is so highly valued, is what we mean by the goodness of truth....The fact is we all need to be taken care of; otherwise we are liable to become utterly distracted by the anxiety of living a meaningless life until our brief moment beneath the sun is terminated by the chilly isolation of death. What makes us feel taken care of, feels like the truth. When I think of the nurturing role that belief in truth plays in our lives, I have an image of truth as being at home, with the smell of bread baking in the oven (p. 31).

Nyberg's rationalization, along with those offered by Smith and Bok do make sense. But I am uncomfortable with their application to the problem the participants in this study discussed. The parents with whom I spoke with during this research do not appreciate being lied to, or having information softened, glossed over or withheld. There is no question in my mind that Leslee needed a medical doctor to look at her in the eye and tell her that her son had autism. It would have saved her several years of wondering and thousands of dollars in pointless visits to various specialists. Kathleen should have been

informed that a significant percentage of female children with ACC develop severe and debilitating seizure disorders. That information would have helped her prepare more effectively for Anna's care as an infant. Some people seem to believe there is a very fine line between truth and fiction when it comes to information about sensitive issues. Along with the participants in this study, I do not agree, and I think if there is a lesson here for us as school professionals about how we might improve our communication and relationships with the parents of our students, we can find it in words from *The Last Lecture* written recently by Pausch (2008). He wrote:

If I could only give three words of advice, they would be, "Tell the truth." If I got three more words, I'd add: "All the time" (p. 163).

Interactions Between Parents and Professionals at School

It is one thing to talk in a general sense about communication issues between people who are doing their best but may not understand each other well, to talk about textbook-style examples and to theorize about what makes communication such a challenge for so many people. But a very different picture of those communication issues emerges when actual examples of the things people say and the way in which they behave toward one another are examined. In this section I will share stories participants in this study told me about some of the situations and conversations they have had with individual teachers, administrators and other service providers in the schools their children attend. I contemplated calling this section "The Good, the Bad, and the Ugly," but to describe some of the interactions as "ugly" would be inaccurate, as they were so much worse than that. Instead, there are good stories, there are stories about people in schools who really tried to work with the participants to solve problems, stories about

people who, according to one participant, “just don’t get it,” and, unfortunately, some stories that are really and truly horrible.

The good.

As a school administrator, Ivy holds very high standards for herself and for the teachers who are educating her own children. She knows how much time and effort and kindness goes into being the kind of teacher she was when she was in the classroom, and reported feeling fortunate that in the suburb where she lives there are many people who share her views. Ivy talked about not wanting to be “that parent” who comes in and makes special requests for certain teachers, but is thankful that up until this point

Gabriella

has always ended up with spectacular teachers. And it helps being in this area, because they do whatever it takes. They help her at lunch or after school, they will e-mail me constantly, they are really responsive and parent-friendly and I think that is why we have been able to be successful. Just that the teachers were so responsive and so helpful.

Karen talked about how Phil has changed teachers less frequently than another child might because he has been in self-contained classrooms that often keep multiple grade levels together. Transitions between rooms and teachers have been smooth and easy because of the consistency at the school. Teaching assistants often move with children from room to room because that allows for continuity of care that is more difficult to guarantee when all of the adults in a particular classroom are trying to get to know a student. Unlike many of the other participants who cited transitions as very traumatic for their children, Karen talked about how at school for the most part, everything has “turned out OK.” She appreciates the effort made at school to keep someone who knows Phil with him and is looking forward to next year when one of the assistants he had when he was in the primary grades will be moving over to the junior high to continue working with him. As Karen stated,

his teachers and all of the aides have been marvelous. And they are all consistent, they try very hard to do that. Three years in one classroom is wonderful for a lot of the kids, but especially for someone like Phil who comes in and looks happy. But there is a big difference between a sixth grader and an eighth grader and a sixth grader who is like an eighteen month old, it takes time for people to get to know him. And at the same time they also get to know me and it feels like they have accepted and I am not so easy to accept because I am very opinionated and my life is what my life is and they accept me for what I am and what I do. Like when I take him out to go apple picking in the middle of the week because it is too crazy on the weekend and I can't deal with the crowds with Phil. And they think I am crazy sometimes (laughing) but they accept.

Rachel talked about being especially pleased with Albert's teacher this year:

This year's teacher has been great. She is one of those really good ones. She was pretty young, but when I would help out in the classroom I would see her doing all the things you're supposed to do, you know, the big hand things for learning writing, every technique, she was using it. She was constantly reminding Albert to get back on task. Even before we had the IEP she figured out what worked for him...that if you give him too much he doesn't do anything, so she would go to him and she would tell him "I just want you to do this one problem and then I will be back to check on you in five minutes." And if you say that calmly to him, he will do that one thing, and then she would come back and encourage him to continue. Sometimes she would even get him to get all of the work done. Once she figured him out she also managed to teach his social studies teacher how to do that. She also tried with the math teacher, but she wasn't really on board. But his teacher this year, she really has gone beyond the IEP. She stays calm, comes back to check on him, she was really willing to compromise and she took the time to get to know him.

Two of Roger's teachers stood out in Marie's mind. The first was

his developmental kindergarten teacher. She was very good but she was not touchy feely warm and fuzzy. And I was a little concerned about that, but I knew he'd be well cared for. She was caring and I just knew she had Roger's best interest in her mind and that was the most important thing. I knew she felt the same about the other students, too. And we had a lot of contact, maybe more so than other parents, because I was there a lot, I didn't work so I could go and help out in the classroom.

And then there was Miss Gretchen. She was Roger's second grade teacher. According to Marie,

She was really exceptional. She treated each kid as if they were her own, what she would want for them. I am sure she put in so much extra time for her kids in her class to make sure they had everything. I had volunteered a lot in his class to get ideas about what to do for him at home and as I watched Miss Gretchen and her aides, they had worked together for years and the way they would devise creative ways for each child to do things, it just amazed me. And then to stay organized and coordinate everything? I am not sure how much this has to do with it, but when I think about it, here's what I come up with...Miss Gretchen was married but she didn't have any children yet. And I think that, I certainly don't think that teachers should not have children, but I think her time was a bit more free and she had a lot of energy. Because when you have a family, that's first priority. And that is understandable. But with Miss Gretchen, I got to know this woman who had all that caring I talked about, the knowledge to do it and the ability to organize and make it all happen for all those students. I think she liked the fact that I could come in and I would come in for the purpose of learning how they dealt with Roger so I could try to continue it at home. Support that, so he would get the consistency. So being in the classroom helped because she got to know me a little bit more, too. And the interesting thing about Miss Gretchen is that during the time she was with us, and I say "us" because I was in her class and learning from her, too, she had twins. She picked out her sub very carefully, someone she trusted and knew would do well by her students. And when she came back she would occasionally need to take a day off to go to the doctor or do those normal motherly things, but the quality of her program never wavered. And I always wondered how she did that. And some of things she would do were simple but they really meant a lot, like Roger would have a notebook to write back and forth and that was instrumental in my communicating with her. I could tell them when things were happening at home, you know, things that might impact Roger that were different, just so they would know. I think I could just feel her depth of caring and really wanting to do right by these kids and then being in the classroom and seeing the extent they went to to make it happen helped me have that respect and caring back towards them, to see what they do.

Kathleen talked about a number of people she has met at Anna's school who have been able to communicate well with her both personally and about Anna in a matter that conveys more care and concern than irritation and judgment. She said,

And, um, it's very important when people you know, when you can tell that someone doesn't really care. Or is able to cross that barrier. It is a barrier for us. We do, for whatever reason, human beings respond to certain physical forms in one another. It's just the way we're hard-wired. But she's [Anna] lucky that way. But I also find, what I know about her teacher is the way she asks me questions about Anna, she will say something about something she notices that is different and ask me what I think, it's the way she, um, just talks about her like she is a person. The therapists I have a lot less chance to talk to because unless they are in the room when I come to pick her up or leave Anna there, then I don't usually have a chance to talk to them. But with Lisa [her occupational therapist], I felt that Lisa in the IEP this last spring was really great because she said, well, she told a story about working with Anna. She said, "I was having Anna do pegs, you know, the pegboard? And she was just really growling and I kept trying to do it and she kept not wanting to do it and finally I was like, you know, maybe she thinks this is boring? Why am I making her do this thing that is clearly the wrong choice for us and so I decided to use some other activities because this [Anna] is a girl who tells you what she wants." And I was so relieved. I thought, "You know my kid! You know my kid!"

Working together to solve problems.

Several years ago I had a meeting with the mother of one of my students. He was a fifth grader at the time, and had recently grown a foot taller and gained about twenty pounds. He was bright and funny and interested in a lot of things, but he also had autism and was experiencing some seriously angst-producing social isolation. The growth spurt did not help matters any; almost overnight he had gone from being the student who could sort of fade into the background to being the biggest, most gangly kid in the class. And on top of that, puberty set in with a vengeance that included mood swings, acne, body odor, perseverative poking at private parts, and an attitude. His teachers seemed to me to think these were issues that needed to be handled at home, but other kids were making fun of him and I was worried about the situation escalating. So without much of a plan in my head I called his mother and asked her if she would come in to talk to me. She was there the next morning and we talked for a long time about how to help him at school and

at home. We put together some checklists for him to use getting ready for school and to post in his gym locker for hygiene and we talked about books he could read at home with her and his dad about what he was going through. And then I had to bring up what I had come to think of as “the sweatpants issue.” It was awkward and uncomfortable to say, “Umm, Mrs. Brown, I need to let you know that your son is also starting to touch himself in class.” She looked horrified and said, “No.” So I said, “I’m sorry, I know this is difficult, but yes. He is. I’ve seen it. And I think maybe wearing jeans instead of sweatpants might reduce the ease of access, but I also think it might be an appropriate time to have a very private conversation with him about masturbation.” She still looked horrified, but she said, “OK. I’ll talk to his dad and we will talk to him.” And they did and everything eventually worked out. At the time, it was maybe a little bit weird, but looking back, it really was not such a big deal.

Unfortunately, most of the time, problem solving in special education isn’t quite so simple. There are so many problems, and parents often report that as soon as one problem is taken care of, another one pops up. And solutions are rarely as quick as a simple (although mildly uncomfortable) conversation.

Many of the participants in the study talked about how willing people at school were, on many occasions, to work through problems and difficult situations together. Marie was pleased with Roger’s school, but when problems did come up she said it was helpful to have one key person to call. As she stated,

We've been very fortunate. We've run into other parents who have felt like they had to fight and I don't know, I'm not there when they walk in, all I know is if I walk into a meeting with my boxing gloves on, you get a whole different atmosphere. And I have always gone into things in a very cooperative manner and for me its paid off. Because when there have been discrepancies or disagreements, like the one year when our district had a different special ed superintendent and I could tell by the way people spoke that they were unhappy. And that year when I went in to register Roger, it was different and he was going to be placed in a different class. So I talked to Miss Gretchen about it and we had developed a really good working relationship, but when we talked you could tell she didn't want to say anything adverse. So I finally had to say, "If Roger were your child, where would his best placement be?" And she told me. So I left the school and went to the admin office and the woman met with me. And I didn't put on my boxing gloves, I just went in to inquire about why this was different from what we had agreed up on at the end of the year at his IEP meeting. And we talked about it, and I expressed where I thought his best placement would be and she totally accepted it then. So it was very much a working relationship and it worked out well.

Elizabeth also talked about her appreciation for those individuals who were able to understand her perspective on what James might need in school and then work with her to find a viable solution. She also noted that it is helpful to have more than one person who knows your child and can problem solve with you, should the need arise. As she said,

There are so many good people out there and if one doesn't pick up on something maybe someone else will. I guess we, overall, have been happy and I want to save it, you know, I don't want to be that squeaky wheel all the time, that "Oh, it's her again..." I think you have to save it for when you really need it. It's kind of like when I had an issue with the one aide, they did meet me half way on it. We've been lucky, but there was one situation I wasn't happy about. They did accommodate us. It was a situation where one of the aides, her job was eliminated so because they do things based on seniority in the district, she bumped the aide that was with James at the time. We did go to the principal because the replacement had health issues. She was, um, a very large woman and she had back problems and my bottom line was if there's a fire, can she lift James and get him out of the building? And the answer was no, so what they did was work out a job-share. So she would be with him in academic classes where he spent half the day and someone else, actually his old aide, was with him for music and gym, anything where he would be moving around the building and not necessarily where anyone would know where he was at any given time. And that's how they solved the problem for us.

According to Ivy, it is very important to have a child's needs clearly written in the IEP because that is what helps teachers know what to do and encourages collaboration with families. Initially Gabriella was getting some accommodations from some teachers who would help her at lunch or after school or give her extra time to complete her work. But that support was more consistent after an IEP was written for her. As she reported,

Ever since she got the IEP, things have improved for the better. And all they did was put in a "check-in" and "check-out" for her each day. They designated a system and asked me to buy the materials for it, so she would have binders and folders set up in a certain way and we did that. And that's pretty much it. It was just that it needed to be in writing so the teachers would provide accommodations. She [Gabriella] didn't change, you know she's still the same child.

Leslee described a social worker who was in frequent contact with her so as to make the daily routine at school easier for Jeff. Because she had known him for several years and spent time with him both inside and outside of the classroom, she was a keen

observer of Jeff's behavior and could read his warning signs, anticipate and deal with problems or behavior issues before they got out of control, and coach his teachers on how to respond to him in similar situations. Transitions and changes are very hard for children like Jeff, and she did her best to prepare him for them in a calm and reassuring manner.

According to Leslee, it made all the difference for

...her to stay with Jeff [through several school years] because she knew him and she knew what to do. If a big change was coming or if there was a problem with behavior, she wrote the social stories, you know. A little social story or a schedule and she would problem solve.

Problem solving with the school team has taken many forms for Karen over the years. Meeting Phil's physical needs is sometimes a challenge because there are only so many hours in the day. Children who use wheelchairs often benefit from being positioned in a stander at regular intervals during the day, and this is especially important for Phil because although he needs to be out of his chair, it is not safe for him to walk freely in the classroom or hallway without close supervision. Karen talked about shared responsibility in this situation. She told me she

asked the school to get a stander, so he could not wander, but stand during their activities. So they did, but after awhile, you know, it was a pain in the ass and we also didn't have time at home. So they were going to put him in the stander twice a day, then it turned into once, then even less and but you know, it's fine. So I went in and explained it to them and told them why and it was better. Sometimes they would tell me that he was only in it for ten minutes and I'd tell them it was fine because, you know, maybe I didn't put him in it at all over the weekend.

Making sure Phil is comfortable and his behavior is appropriate for the classroom is also something Karen has worked with the school staff to assure. She told me that last year at the IEP meeting there was some discussion about Phil beginning to "put his hands in his pants," and how they might work together to alleviate the situation. Karen did not seem perturbed as she described the meeting, but did sound maybe just a little weary. Although this is a common concern for parents of both boys and girls in special education, it is

often one that goes unheeded because sometimes there is little that can be done. Karen said they talked about

keeping his hands busy. But he can't wear pants with a zipper because they don't fit and his stomach is distended because of the tube and after he is fed it's a little more, so to zip and button, it's really hard. We always make sure there is an undershirt tucked into the pants and typically a long shirt on the outside so it's a little less accessible, but, well, if you want to get to it, you're going to get to it.

While privacy and dignity for Phil are important to Karen, she also expressed concern for how his behavior can impact other children. Given Phil's cognitive limitations, there are certain behaviors she cannot take ownership of, and school staff needs to step up. For example:

Last year he got out of the classroom and pulled the fire alarm. Not because he even knew what he was doing but because when he is walking, he goes like this [demonstrated moving both hands along the wall while walking] and the fire alarm is right at eye level and it didn't have a cage on it. So in the middle of January the entire school had to go stand outside. Um, yeah, although I did have to ask, "Where was his aide?" So we talked about it and he cannot be out of the classroom on his own, he doesn't know stairs. He would step right off the edge. They are going to have to keep the door closed.

Marie talked about problem solving with people at school being a learning process. She feels like she had an advantage because of her knowledge of the system, but that it can be complicated by where a parent might be emotionally, what the child's needs are and what issue is at hand at any given time. She was very thoughtful as she said,

For a lot of parents, I've run into a lot of families, just from personal experience, I think, a lot of times, there is such a process that you need to go through, when your child or your children are not doing what everybody expects that they should be doing. And um, and everybody has their own way of dealing with it. And if there's anything that's lacking in...when parents start maneuvering the special ed realm, there's nobody else next to them, telling them what to expect, or letting them know what the school district's responsibilities are. I mean, I've walked into every single meeting knowing a few things. Knowing about my child and what the jobs are of the people in the meeting, but also knowing everyone there wants to do the best they can, I know that. But I also know that so many people are overworked; there are so many children in every school district and there are just a handful of special people there to manage all of that. So sometimes they have to move a meeting around or something, I mean sometimes there's just not enough time.

"They just do not get it!"

The fact that there may not be enough hours in the day or staff at the school to get everything done in a manner that will make all parents happy is no excuse for insensitivity or incompetence. Although I sought out parents who had positive experiences in their child's school, I also expected to hear some stories about interactions that were less than stellar. I wish I could claim to be surprised by some of the things they told me, but truthfully, I am not.

Like Ivy, I have heard teachers, therapists and administrators defend themselves (or their methods or behaviors) to parents when there is no question about their error. For Ivy, this brought up a lot of discomfort, for a variety of reasons. As she said,

I would think, one thing about Gabriella is that I had her when I was sixteen. I would say that I didn't always know what to say or what to ask for and I had some really bad experiences. I remember when she was in kindergarten and they decided to call me in for a meeting, a pre-referral sort of thing. And I was a student, I was in school and it was very frustrating and it became very heated because what I heard them suggesting was that something was cognitively wrong with her, and um, it was very frustrating. The teacher she had was new and she responds better to teachers with experience, you know it's just not going to work if you are a new teacher and just trying to figure things out. And I would go to the principal and he would tell me to stick it out but I knew it wasn't working for her. And she ended up going to summer school, and she always got recommended for summer school until after third grade. And you know, we didn't always live here. We lived in [another state] and it was a less affluent area and her school wasn't always that good.

In the grand scheme of things, Gabriella's needs, according to Ivy, are not as severe as those of many other children in special education, but on several occasions, seemingly minor issues that could have been handled with relative ease got much more complicated than they needed to because of miscommunication and misunderstandings. Ivy told me she has asked, repeatedly, to be kept informed of Gabriella's needs so that she can intervene or assist as much as possible at home. Ivy acknowledged that Gabriella's disorganization can be frustrating, but at times, she feels the way her teachers responded just did not make sense. Ivy described one situation as follows:

So, for her, it's not only the academic things, but also the physical space, trying to negotiate and navigate and go to all these places and understand where you are supposed to be...at this level [sixth grade] there are different sets of expectations in different places. Apparently she failed to return some library books, just kept forgetting them at home, so instead of communicating with me, they took all of her library privileges away at one point. So, now she can't, like all of the other students, print her assignments out that she has done on the computer to turn them in. So it's all these little, simple things that I would think would just be in your heart as an adult to help her with. They do not understand her or how to help her, and that does not make sense. Clearly, they just do not get it.

Leslee reported being frustrated over and over again by a similar lack of understanding on the part of the school staff about Jeff. When he was young, there were

only a few children with autism in the district, and there were very few teachers who were knowledgeable about teaching children with autism. Various administrators promised at one time or another to secure a consultant to help set up a program for Jeff (and other students with autism) and train the teachers in instructional technique and methods for inclusion. But nothing ever happened. As she said,

We were supposed to get a facilitator, an autism specialist, but I don't know! They would say that every year and I request it every year, someone to train the staff. I think the biggest thing is to educate the teachers, you know, Jeff might do this or that but if they don't understand autism they get offended or angry at him or take it personally. And that doesn't help. It would make me feel like it was me against them. In other years I felt like it just took them a while to understand what I wanted for Jeff, and he always had to prove himself in the first couple of months. Then they would be like, "Wow. He can add!" And I would be like "Yes! He can. And he is learning to read. He doesn't have to just sit and match colors!" Like he is so beyond that.

Grace's take on how the school staff misses out on what George is capable of doing was similar, and she expressed very little tolerance for what she perceives to be a type of laziness on the part of the school staff. It was the only time during the interview that Grace sounded really angry. She said,

Yes. Because I don't know if I told you? But they do not read the IEP. They read the first page with the labels and then they assume they know [him]. So the placement, all the placements we have looked at have been inaccurate and it is frustrating! Because those people [case managers in the public schools] get paid and they should be more accurate.

Another source of frustration for the participants in this study has been professionals who refuse to acknowledge their input with regard to what their children can and should be working on in school. Granted, there are always going to be some inconsistencies in a child's performance between home and school, but these are parents who know their children. Why wouldn't teachers and therapists want to partner with them?

Leslee talked about a teacher and a social worker who refused to compromise:

It's the same thing every year, we tell them he can already do the things they want to work on. And then when there is something he needs to work on, they don't do it. This year was pretty bad though. He had clocks [and telling time] on his IEP and the teacher told me in September, "Well, we don't do clocks until January." I was like, "Well his IEP expires in February so that will not give you much time to address those goals." But you couldn't tell her anything. She was very old school and so there was an entire page of goals that was never worked on. And then the social worker only wanted to do this dog [therapy] program and I said, "We have a dog! He needs to learn to socialize with people! With other children his age!" So you know, that's how that went.

In a similar vein, Kathleen talked about her frustration with the over-reliance on standardized testing to determine goals. Anna, according to Kathleen, doesn't need more tests. She has been tested enough. She needs teachers and therapists who can look at her to qualitatively assess her skill level and then figure out what to do to move her forward, to push her to the next level. This has not been the case with her speech therapist at school.

And her speech therapist I am very uncomfortable with because she insists Anna doesn't know cause and effect. Because she won't consistently indicate it 10/10 trials when she is tested. And I'm like, you know what? If you were a person who were forced through such an insulting and boring task, what would you do? When she wants something, she knows cause and effect! But she is not going to be testing well on something like that, she's not a robot! She's a human being. So there is something so inherently dehumanizing about the whole testing structure anyway in education, period. It does not work.

Even worse than those professionals who refuse to see children as anything other than their test scores are those who insist on making their unofficial and often inaccurate diagnosis of a student based on one brief classroom observation or according to some checked boxes on a rating scale of some sort. Rachel was open about her frustration with the assessment team that "just didn't get it" and the low quality of efforts by the school

staff to figure out how to help Albert. According to Rachel, they seem to be overly focused on his high test scores while ignoring his social and functional skill deficits and she is uncomfortable with the labels that have been assigned to him. As she said,

Sure it is possible that Asperger Syndrome could be the umbrella [reason for all of his other difficulties] but he really doesn't have all the parts. When I filled out the forms during the school evaluation, they checked off Oppositional Defiant Disorder because, well, if you ask Albert to do something, he does not always do it. So is he oppositional? Yes. But I object to that label for a kid who also has OCD [Obsessive Compulsive Disorder] and attention problems and probably sensory issues. I don't think he's doing it to be oppositional. Although certainly sometimes, but he's also a fifth grade boy. And he may get stuck on something else, he's overwhelmed, he's screaming, and you know, his music teacher described him as "passive aggressive." He doesn't refuse to do anything, he doesn't say "No." He just doesn't do it.

On the surface, Rachel's frustrations appear to be with ineffectual people and the poor quality of her interactions with them, but in listening to her stories, it becomes clear that the source of her frustrations are also deeply rooted in a system that simply is not working very well for her child. After an evaluation at school and an elaborate and expensive private evaluation to clarify his issues, Albert still is not getting the help he needs at school. During the interview, Rachel questioned how she might better be able to determine the difference between indifference and ineptitude as well as what she could do differently to help him. It hurts her to see him hating school because of the stress he experiences there and she also alluded to how hard it is sometimes to live with an intensely unhappy child. If she had not gone outside of the school system for an evaluation it is unlikely that he would be getting the minimal amount of assistance he is currently receiving. Even that, as she explained, is inadequate:

So the school psychologist didn't even really evaluate for Asperger or not, the whole thing was really just to see if he qualified for services or not. And they said he didn't at first. But then they agreed with me that he has dysgraphia and scheduled him for an adaptive [assistive] technology evaluation. So then they gave him an AlphaSmart and an IEP that says he should get extra time and a reduced homework load...but even when he finally got that AlphaSmart in his hands then he had to learn how to use it, because he didn't know how to type. But that didn't really help with his social things, or his organization. His teacher worked hard with him but she did not get the right support, and she would start with him at 3:00 and it would be like 4:00 until he would get his book bag packed. And his coat on and get out the door.

Kathleen also used the phrase "they just don't get it!" during the interview, and her perception of the interactions she has had with some professionals at Anna's school has led her to question their competence. The interactions with the speech therapist have been the most difficult for her. As she explained,

Well, we know most of Anna's seizures originated in her occipital lobe and her occipital lobe is deeply malformed. So although her eyes are normal, um, there are definitely visual processing problems and auditory processing things that are not right for her. And I think that's a huge obstacle and I notice for us that how much we communicate to her with touch. You know, we have accommodated a lot of that [visual and auditory processing deficits] physically. I cue her all the time with physical touch. I say, "Anna, look at me," and I touch her face, just constantly touching her and she's trying, so we have a really good rhythm for how to communicate. But what I notice is that her IEP the speech therapist said she gets bored with what they do and I said, "Really?" And she said, "Yeah, I show her toys and she looks away all the time." And I said, "Well, you know don't you that she's got visual processing delays so you know that means she needs you to wait." She said, "Oh, really?" And I was like, "Yeah. If she doesn't want to do something, she will tell you. She will tell you by moving away, her whole body, she'll roll away from you with her whole body and she'll try to get away. But if you just get a turn of the head, give her five or ten seconds and she will look back." It's overwhelming for her to try to process it. And I am like oh my fucking god, you crazy woman! You are sitting here telling me Anna doesn't get cause and effect and you don't even know the most basic thing you should know about a child who can't process visual information very well! Eech! How many people know this? It's basic. I learned it in the first three weeks of working with the Early Intervention therapists. So you know, that's a moment when I was like "hhmmmmph." So I took some videos of her and I took them to school and I told her I wanted her to see what she does in therapy [outside of school] and I wanted her to see what she does at home.

And the really horrible.

It is a well-known fact among parents that the first IEP meeting for most families is rough. As Karen said,

You know that first IEP meeting? It's horrible.

Most of the participants in this study reported that they do get easier over time, but that every once in a while someone who should know better will say something awful that will never be forgiven or forgotten. Karen was advised before that meeting by a kindly social worker to

...take someone with. Or maybe take two people with, not necessarily a lawyer unless that would make you feel more comfortable. Besides

parents, there should be a friend, a family member, somebody else with another set of ears to listen.

Karen attended that first IEP meeting with her husband, her sister-in-law and a friend, and she described it as

probably the worst three hours, even worse than when we were at the hospital because at the hospital everybody is focused on the same thing. Here you are sitting around the room with a bunch of people, you know because you've done them. And they ask about what my hopes are, what my dreams are, what are his strengths, what are his weaknesses? And at that particular time they want to go through the whole thing. And there was this social worker, she was so horrible. I can't even remember her name. She went through the whole thing. This meeting was supposed to be to determine if he was eligible to go [to special education] or not and she wanted to go through the whole thing, how the accident happened and the police report and she actually asked if I wanted to tell them how it happened. Do I want to go over it? And I remember at the time my husband is crying, my girlfriend is crying, my sister-in-law is crying and I said to her, "You know, it really doesn't matter. I didn't throw him out a window. I didn't shake him. He is what he is. It was a tragedy." And when I came out of that meeting there was the nurse there, she was wonderful. She was a little older and she came up to me and said, "I am so sorry." And I told her, "You don't have to apologize, but just keep her [that social worker] away from me." I don't know that was necessary. I'd like to think I'm pretty stable, fairly well educated, I can read, I know a lot of people. How dare she subject me to that? Can you imagine what some people, what do people who don't have a big mouth like me do, and what about people who don't speak the language?

On the morning of her evaluation for placement in an Early Childhood Special Education classroom, Kathleen described how Anna

had one of her worst types of seizures and had to be given Diastat. Which you may be familiar with? So she was absolutely wiped out. Like asleep from this drug. So we got there and nobody could evaluate her, and so I had to testify as to what she could do. We brought with a psychologist who knew us and knew Anna well, her name is Eileen, and she said that at one point during the meeting the school psychologist had pulled her aside and went into another room and said to her, "Do you know that child has Rhett Syndrome?" And our psychologist was like, "What are you talking about?" and this person said, "Those parents don't know. That child has Rhett's!" And so Eileen said to her, "First of all, do not say that to them, ever. And second, that is not true. She has doctors who know what she has! Nobody's confused here! Everybody knows what she's got!" So, do you believe that? Who in the hell does she think she is? Here come these people with this child who has been through

every medical establishment in the city, and this psychologist thinks she knows something? From looking at a child passed out from Diastat that she's got Rhett Syndrome?! These moments are very disheartening.

Ever the positive one, Marie reiterated her feeling that people who go into special education because they care and want to help or make a difference. But even she was unable to find a kind words for the psychologist and the teacher who obviously had very little faith in Roger. As she described,

The psychologist who did the testing, because of her personality, she didn't seem very hopeful. It was if she has his life sort of scripted and there wasn't a whole lot of change that could happen. But because there were many people who never talked like that, I just dismissed it and it didn't impact me a lot other than she wasn't somebody that I talked to. And there was this one teacher who in sixth grade said, "You know, this might be it for him, this might be where he tops out." And I said to her, "You know, it may not be," [laughing]. And the more we raised the bar, the more he attained. If we kept it low, his attainment would have been lower.

Rachel's first contact with the school psychologist about Albert's evaluation was almost unbelievable. She already knew it was possible that Albert had Asperger Syndrome, but she was told that if he did it was mild and that his main problem in school was with attention. A full educational evaluation was warranted at that time, but Rachel had to contact the principal multiple times to get it started. Finally, a psychologist from the evaluation team called her. Rachel briefly explained Albert's issues in school and the testing that had already been completed. Her response was:

You know, I can evaluate autism in about five minutes.

So Rachel called that woman's boss and requested someone else do the evaluation. But Rachel and the new psychologist did not start off on the best note, either. According to Rachel, she

had me fill out that Connor's form [a rating scale for attention issues in young children] and that was it. That's it. She looked at it, but I don't think she ever observed him in class. She never met him. She just had us fill out the form and then we went to the meeting. She said he had ADD and we should put him on Ritalin. And when I told her we weren't in favor of putting him on medication, she just started yelling at us. "I don't understand these parents and why they won't try this medicine that can help their kids!" And so I just told her I would talk to our pediatrician. And that was how that ended.

In spite of the warnings from the therapists in Early Intervention, Kathleen's first attempt to enroll Anna in the Early Childhood program was even worse than she expected. In many large, urban school districts, prior to placement in a special education program, parents who have children with special needs are required to register them as non-attending students at their local school. So Kathleen went to the school in her neighborhood to sign up. She said,

It was horrible! They were so rude to me. They were just hostile. They would not give me a date. And I had been told by the therapists in Early Intervention that I didn't want a summer evaluation. So I kept trying to get her scheduled and they kept delaying and delaying and that forced her into a summer evaluation. Because she was so complex. And the fact of the matter is, everybody knew she would go to [her current school] but nobody would say it. And I am like, you know what? This is a waste of my time! And I even called the cluster special ed person. And I said, "I would like a list of all the schools in our special ed cluster that have programs and what their strengths are." And she said that there was no such list. And I said, "What do you mean?" And this is what she said. She said, "Well, you don't know what your child needs. We know what your child needs and we'll tell you what the best place is for your child."

Another problem in large, urban school districts is that special programs for children with severe disabilities are not available in every neighborhood. Although transportation is provided, sometimes the ride is long and the staff on the bus is not allowed to administer medication in an emergency situation. This means the bus is not an option for Anna. As Kathleen stated,

Yeah. If she was on the bus, she would have to be picked up early and be on the bus for forty-five minutes to an hour each way. And so I have the luxury to drive her or I can pay someone to drive her. But if I didn't have that option? Then she would be on the bus. And on top of that, the reason she'll never be on the bus, ever, in [this city] is that they have decreed that no one on the bus can administer Diastat, which is the seizure-stopping medication. That if a child has a seizure that won't stop, they're to call 911 and even if there were a CNA or an RN, they could not administer it so they have to wait for 911 once they figure out the seizure's not stopping, which is five minutes and then they can't give the drug even though it's in her backpack? Right? To me that is discriminatory. Like, so, what if she has an allergic reaction on the bus? You wouldn't give her an epi-pen on the bus? She gets that, she could have that, too. She could have an anaphylactic reaction and they wouldn't administer, they would let her die because they'd rather call 911? That doesn't make any sense, but that was the decision that was made for, I'm sure, some crazy legalistic reason.

Seizures are scary and several participants indicated how important it is to them to be confident that their children are in the care of people who are competent to provide the necessary care, should a seizure occur. Karen was not happy with the arrangements one year in Phil's classroom because

...there were eight boys in there. Phil. Another boy who was a shaken baby. Two with Fragile X and the others were severely autistic. One was bouncing off the walls, one flushed shoes down the toilet, it was too much. In all that commotion, Phil was, I would say it was benign neglect. But then the nurse would call and say that he had had a seizure and his lip was bleeding. And I asked, "How did it happen?" And she said, "I don't know. They found him in a corner." What?

Certainly not every situation participants in this study described were life threatening, but many of them were still stupid. Ivy talked about how the system is set up so that a child has to fail before they can get help:

There is so much question about if her disability, if ADHD is really a disability. But it is. And they do not understand. If I had to show you some of the e-mail that I had to send, just losing it with them, I'm saying my daughter is drowning. If one more person wants to describe the water to me I am going to lose it. Because that's what they were doing. They would call me and be like "I am just letting you know that Gabriella is failing my class." It was like I am just letting you know to cover my ass. And when you get to the point where, well, I got to the point where I exploded. And then everyone comes running to the rescue like they want to help. But at that point, like you know, it is too late. My baby has failed. Her esteem is on the floor. She doesn't understand why she is struggling so much and she is feeling like a failure.

Making sure that does not happen again is difficult, but it is a job Ivy has no problem taking on. What happened was unacceptable, and she knows that she has to advocate for Gabriella, regardless of how others might perceive her. She is more aggressive now because, as she said,

I have to be. And I will. Because I feel like my approach in the past has been, OK, I am an assistant principal and I do not want to come off as intimidating, like I am going to get people in trouble. So I was more laid back in my communication with them, until things got really bad. But now I will. Because I am not going to let her have another year like the one she had last year. For a kid her age, if school is bad, everything is bad, you know? And she really struggled and had a rough time and I am not letting her go through that again.

Kathleen also reached a point where she thought she was going to explode.

Although she was angry about how the evaluation and registration process unfolded for Anna, she was even more upset about how the school district might be treating others, especially those with fewer resources. As she described it,

...and that 's when I got really angry and I never, never do this but I said, "Look. I hold a doctorate and I am no fool. So do not talk to me like I am an idiot." And I never pull rank or do anything like that but I was so offended and so angry and I thought about how it might be if I was a mother that did not speak English. Or if I was a mother who was getting beat up at home and had no sense of ability to assert anything. You know what I mean? And this raving bureaucrat at the school is telling me she knows what's best for my child?!

Summary and analysis.

There is a significant range in the quality and functionality of the interactions the participants in this study reported as taking place between them and the individuals who work with and care for their children in school. Although it would be nice to assume that everyone means well and that the “really horrible” stories the participants recounted were the result of a few ornery, burned out or incompetent individuals, I think that might be an oversimplification of the issue. As educators, we are both products and perpetrators of the values of the culture in which we live. Our histories and experiences influence our habits and our ways of interacting and being with one another. Living in a culture that regards disability as a weakness, a defect, or a deformity (Davis, 1995) we consistently treat individuals (children with disabilities as well as their families) as “types” or “cases” in our schools (Noddings, 2003) instead of as “whole, fully-developed people whose impairments place them within a continuum of ability of which everyone is part” (Davis, 1995, p. 165).

In earlier sections of this paper, several of the participants were quoted as they spoke about “people who get it” or “can cross the divide” and seem to understand that their lives are different and sometimes difficult, but certainly not deviant or dysfunctional. These people participants described are the teachers, administrators and therapists who interact in a manner that communicates care and compassion because they are able to acknowledge the inherent randomness and unfairness of the situation without being threatened by it. They are the ones who are aware of their deficiencies and allow themselves to learn from them and the people around them. They do not have to know everything and they do not try to fix things that are impossible to fix. In her book called *Expecting Adam*, Martha Beck (1999) wrote about her pregnancy and the birth of her son who has Down syndrome. She described how she witnessed “native kindness spike

upward” from people where and when she least expected it but needed it most. She wrote about how it helped her to think of these moments as proof that angels were at work. In her words:

...it’s enough for me to think that angels, or for that matter any forms of goodness, function like water; they run into any opening they are given. There may be some people who are born open, who soak up goodness like sponges and leave traces of it on everything they touch. But even when an ordinary person (like me), or a bad person (like, say, Hitler), has a moment of openness, a moment of compassion, goodness rushes in to fill that space, to make us capable of receiving grace and transmitting it. Mother Teresa called this being “a pencil in the hand of God” (p. 268).

Not being a very religious person, I never gave much thought to the concept of grace, but in my first job as an occupational therapist I met a woman named Julie who had been working in the field for many years. At the time I was consumed with the technicalities of therapy, worried more about things like assessing muscle tone and measuring range of motion accurately than about any of what I now know to be the much more important aspects of a therapeutic relationship. She was a mentor to me as a new therapist, and after we would talk about a child and the activities or exercises she thought might be helpful, she would always take the time to ask me what I thought about how they were doing emotionally as well as physically and how their families were coping with whatever was going on. I remember feeling overwhelmed and sad about the children I was working with one afternoon, and I asked her if she ever felt that way and how she dealt with those feelings of being inadequate or unable to help enough to make a difference. She assured me that she did. She also told me that her husband was a minister, and that over the years she had come to see being an occupational therapist as her ministry, her way of bringing a little bit of love and grace into the lives of the children she worked with. I have thought long, hard and often about what she said, and it always makes me feel sort of peaceful, although never completely at ease, which is probably a

good thing. Arthur Kleinman (1988) wrote about a professional grace between doctors and patients who have chronic or terminal illnesses. He said he learned

a grand lesson in patient care: that it is possible to talk with patients, even those who are most distressed, about the actual experience of illness, and that witnessing and helping to order that experience can be of therapeutic value (p. xii).

Although we are educators and not doctors, Kleinman's words can easily be applied to the role we take on when we are among the parents of children who are experiencing severe illness or disability. He described how practitioners have to make a choice between making things better and making them worse:

We can envision in chronic illness and its therapy a symbolic bridge that connects body, self, and society. The network interconnects physiological processes, meanings and relationships so that our social world is linked recursively to our inner experience. Here we are privileged to discover powers within and between us that can either amplify suffering or dampen symptoms and therefore contribute to care (p.xiii).

Participants in this study talked about a few of the ways educators interact with them that are guaranteed to make meetings worse. Being rude or acting like a know-it-all when you have no clue what you are talking about rank at the top of the list. Making generalizations about children and families that you do not know well, arrogantly claiming to "understand," rigid adherence to rules and talking more than you listen are close seconds. Although none of the participants spoke directly about personal anguish, their pain was very apparent in the stories they told about their children. Obviously, there is nothing we can do in the school setting to alleviate this pain, but almost all of the participants talked about the one or two people who really listened to their stories and in doing so, made things bearable, or maybe even a little better. If we substitute "parents" for "patients," Kleinman's lesson makes perfect sense in education:

We live in a time of great concern for the practitioner's response to the [parent's] request...But the primary ground of care is not that response; it is rather the [parent's] discourse on illness [or disability]...[for this reason,] practitioners must ...audit the speech of their [parents] with great intensity, with something approaching awe in respect for hearing the [parent's] story in his or her own words and with deep sympathy for the human condition of suffering. That, it seems to me, is the best way to come to understand the illness experience and take it into account in practice.

Systemic Barriers to Relationships

Unfortunately, even when individual teachers, administrators and therapists are able to interact and communicate effectively with parents, they are still working within a system that maintains some significant barriers to successful relationships. There are the obvious constraints which include limited time, inadequate resources and professionals with negligible experience and a history of questionable training. But there are also a number of subtle barriers that participants in this study have had to recognize and work around in order to connect with the professionals in the schools their children attend. Some of these barriers include the challenge of obtaining individualized care in a system that is extremely large, being excluded from a school community, and having to deal with what feels like an unequal distribution of resources.

Obtaining individualized care in a system focused on the masses.

All of the participants in this study talked about how difficult it has been at one time or another to obtain services for their child. For some, entering the system involved considerable time spent on evaluations and other diagnostics to determine need, but even for those with unquestionable need, the system was not at all welcoming. Truly individualized instruction cannot be based solely on one assessment, and Kathleen found

the entire assessment procedure to be completely ridiculous for Anna, because she is not a child who will demonstrate the abilities and strengths she has on a standardized test. As Kathleen noted,

And what's so incredible, the incredible irony of it is that the very nature of our children puts them out of any sort of standardized world. And all we are trying to do in special ed is force them into another standardized world. And while it's wrong in and of itself, as a philosophy, in my view, to standardize everybody, it's utterly backwards to try and do it with this set of children. And everybody knows this.

Large systems are fraught with inadequacies, and from the perspective of a person who works in the schools, there are a few understandable reasons for the fact that information about some special education programs in a very large school system are not readily available. From the parent perspective, however, this lack of information can feel evasive and dishonest. It may also be perceived as a power issue where those in charge of distributing resources do so in a less than impartial manner. Kathleen questioned the ethics of the system:

And it's like so why can I go on the website for [the school district] and find out all the details for every magnet school in the city and every charter school, but I can't find a single thing about special ed programs? What are the great programs for kids with autism? What are the great programs for the kids who need a lot of medical support? How do I know this? I know this because I talk to parents. I don't know this because anyone, anyone in the school system has ever shared that information with me. And I am sorry, but that is flat out discriminatory. Period. So we have all these structures, the IEP, everything in the world that is supposed to make it open and transparent...but it basically allows them to hide the stuff that's most important, which has to do with choice. You know, because if we could choose, we might, I don't know, raise some hell? You know, it just drove me crazy. Then this woman, who knows what's best for my child {see above section about really horrible interactions} and then she got, you know, she said, "Well what does your child need?" and threw off some edu-speak at me. And I said, "I'll tell you what she needs. She needs a place with a full-time nurse." And she said, "Oh. Then there's only two schools you can go to in the cluster." And then later I find out that I can ask for a nurse in the IEP and she can actually go anywhere in the city. But nobody told me that. Right? Right. What was her responsibility? Her responsibility at that moment was to

tell me that if my child needs to be in a building with a nurse than I am allowed to ask for that in the IEP meeting. She did not say that.

Fighting the system was infuriating to many of the participants in this study, but Grace talked about being even more frustrated by the amount of time wasted because of how disorganized and confusing the system is and how that has been getting in the way of finding an appropriate placement for her son. According to her,

We should have someone at [the school], this is a person who is in charge of not really the placement, of working together between the parents and the school system, something like that. When we went to one school we were told it was a big mistake that she [their case manager] was not there because she had some meetings so we decided we would just go ourselves. And thanks God we went there and saw the program because I know it wasn't for him. On the other hand, if case manager had been there, she would be more supportive and probably they would show us different programs. Because the case manager from [the school they were visiting] would not know the IEP for George and I think it would be a big mistake. When I went to the school to look, I did not question. But when I went home I questioned the program and what they were doing. And I told my husband what I didn't really like and how I was trying to prove to the case manager that this program is not for George. It is too easy to say that, you have to prove why. So this is the reason I am taking a lot of notes when I visit the school. There are things at some that I like but others that would not be OK. And it's a hard choice. For me, like I speak English, I know what to ask for, but other parents, I think they are in a lost position because they are placed last minute and they don't have time, especially if someone works, they have no time to see the program, thinks about it, call someone if they have questions because they don't speak English or know the terms. It's hard.

Parents who do not speak English well are at a distinct disadvantage when attempting to negotiate the system to obtain special education services for their child, but there are other circumstances that disadvantage parents as well. Being poor and living in a neighborhood with scant resources or in a rural or remote community with limited access to services can be problematic, but there are also barriers between parents and schools that are related to culture and the level of educational attainment parents possess. Kathleen described her reaction to what one of her colleagues who has a child with autism told her:

He said when he goes to his child's school, he is always Dr. Williams. And I said, "Really?" And he's like, "Oh yeah. Because that's what they recognize and then they are perfectly happy to respect my authority." And I'm like "Oh, I can't do that." But it makes me really mad. Because it suggests that the class system within the schools is so profound that that if you're poor or uneducated or working class or an immigrant or whatever, you're going to have a much harder time getting what your kid needs because nobody is going to listen to you.

Creating an educated community of parents.

When parents are not educated about their rights and how the system works it is even harder for them to communicate with the professionals in their child's school to obtain necessary information and services. It also, according to some of the participants in this study, makes it easy for the system to take advantage of or ignore them. Kathleen talked about how getting more parents actively involved in the special education community might lead to improvements in this area. In conversation she highlighted many reasons for the importance of family-centered care, especially at the primary level:

Family centered care needs to be operational in the public schools. It is so interesting, what's so fascinating is that they [the schools] are so clueless about this. When the schools encounter these families, many have been through three years of Early Intervention, which is very family-centered and most of them have been dealing with advanced medical care at excellent hospitals, so they know what its like to be treated badly and they know what its like not to be. And they've learned to have some cultural expectations about honoring the parents in this child's life as being integral to the child's future. You know, it seems to me that the school system is not, has no imagination about who these people are before they come to the door of the school. It is a major shift when you come into the school system. For the parent, it ceases to be family oriented, and it becomes far more institutionally oriented. And it's stupid to do it that way. First of all, you are more likely to make parents mad and cause them to become pains in your rears. Secondly, there's no benefit to the child to creating a bifurcated world for them. There's no benefit. When a normal child, quote unquote, comes home, mom and dad ask what happened at school. They talk to their children and they talk to other parents. We don't have that. I don't have that. I don't know any of the mothers at the school where my kid goes. Well, I know one. Why? Because we're all bussed in. We don't live in the neighborhood. All these other moms have a neighborhood experience with each other and they find out what their kids are doing through that communication. They have all these sorts of unofficial ways about learning how their child is in school. And there is not an attempt by the schools to fill that gap for the parents of special needs kids. I think if my kid was riding the bus to school, I would not know a thing. The only reason I know anything is because I am there to pick her up. I go in and I talk to them to find out what is going on. So I know that what I am getting is because I am out there getting it and that doesn't make sense.

Kathleen also talked about how important it is for people in school to be aware of the stress families with children who have disabilities are under and how closely intertwined their needs as adults are with the needs of their children. As she said,

I do not see my needs as a parent separable from what I need to do as an advocate for Anna. I see them as being pretty tightly intertwined. Because the degree to which we are under extra stress or difficulty is, affects her life. And for me, the problem with having to drive her is that she spends over an hour every day in the car and many people don't care about that, but being constantly in the car is not how we want to live. We live in the city and we don't want to do that. If we didn't mind, we wouldn't be where we are. So in a way, it's like a lot of choices people make about how they chose to parent may have a lot to do with where they live and how they want to organize their day and where they want their time and emphasis to be. What's interesting is that Anna's disability is forcing us to go in directions that we would otherwise not go in the way of making those choices.

Kathleen was open about the fact that she is lucky to have the resources to fight for what she believes in right for Anna as well as to move elsewhere if things do not work out to her liking. But that does not change things for the scores of others who are in a similar situations but do not have the same resources. Ivy expressed the same concern and talked about her efforts to make sure parents in the district where she works are treated well:

It's like a catch-22 because I am on one hand from the school district but on the other hand I am a parent and I want to be an advocate to the parent and let them know when something is not right but in my position, I'd be paying for that. And I find that even though it should not, the socioeconomic status of individuals impacts the quality of services delivered, the type of knowledge people have. One of the things I have done since I have been here is to make sure people get a copy of their rights. Not just the abbreviated packet, but the whole thing. And I have seen people joke around and downplay that in meetings and I just feel like it is important, you know, to let them know that this is a lot of information but at some point they should read it so they can be a proper advocate for their child.

Although many schools are constantly seeking to improve upon the services they provide, it is often parents who are passionate about a specific issue who instigate major changes in individual schools and within districts. Unfortunately, changes and improvements can take a long time to come to fruition, and many parents who have

children with disabilities do not have the time to wait. Like Kathleen, many of those who are able prepare for flight from the city to the suburbs where the schools are more apt to provided needed services closer to home. This is a difficult choice for many families, and one that is not making Kathleen happy. As she stated,

It may just be the way life is, you know? This is what happened and these are the choices that will be restricted and changed for us, um, but unlike other things that limit us which are unchangeable, this is not. Schools are not unchangeable. This [local organization of school programs for students with special needs] is a policy choice made by certain people who have chosen to not make this population of children a priority. And the thing that's frustrating is that Anna's school is amazing, she is in an amazing program [at a school that has only preschool and kindergarten classes]. It is a gift. And we are messed up in this city that we are not actively seeking to reproduce what they are doing there at the higher grade levels and in all parts of the city. And so people are leaving. People who could, parents who could make these schools better places, who could be the greatest advocates from kids and a huge asset to the system are leaving the city because of that. It's really not right. We can't afford to go to a lot of those places, but we will probably go to [name of suburb] and it will be fine. But why is it not possible to have what [Anna's current school] does elsewhere is absurd. And I know they've closed down special ed programs in the city to make magnet schools for people who want their children to be in achieving schools. And while I think that's very important, we have an entire segment of the population that's being systematically disenfranchised by, in fact, it's a lawsuit waiting to happen. And if I had the energy and wasn't taking care of this child, I'd sue 'em!

Priorities and resource distribution.

Aside from Kathleen who spoke directly to the issue, many of the other participants in this study alluded to the notion that the problems they face in special education might be reflective of some much larger problems in our society. Most of the difficulties are essentially only minimally about what happens within the walls of a particular school, and more about what happens to people in this society when they have disabilities that render them dependent on others for care. In spite of the legal mandates, children with disabilities are very much regarded in a separate light from their typically

developing peers in our schools, and because of this they are not a part of the typical school culture, even when they are placed in classrooms alongside of their peers. The inclusion of children with disabilities, when instituted poorly, provides a frightening example of how different the priorities are among parents than those of the staff at many schools.

During the interview, Leslee shared numerous stories about how hard she tried to encourage various teachers to include Jeff in classroom activities over the years. Last year, she heard that there was going to be a dance. On the surface it sounded like an enjoyable way to spend the last afternoon before Christmas vacation, but because it was being held during instructional time, Leslee was wary of its purpose:

So I had to ask what they were going to be working on, what the kids were going to be learning from participating in this dance. I always try to approach it this way and hope for the best. Really? It was just a big photo opportunity. People from the office and the library came to gawk at the disabled. And yeah, they were all dressed up and the aides were all dressed up, some in long dresses, but they didn't, you know. Somebody was serving the pizza, the kids did not ask each other to dance. In preparation I had sent a dance DVD in with Jeff to school, I thought maybe they would practice. Well, I went because parents were invited. They had Christmas music on and I danced a little with Jeff, but that was it. I felt like they could have involved the kids more, danced in a little train or maybe someone could have helped him, teach him to hold the door open for someone or, something?

Being from Poland, Grace had a slightly different take on the situation. In spite of her frustrations and fatigue from fighting the system, she said,

I feel like American society is more, will tolerate disability, more than in Poland. Like nobody really stares at you if there is something or with Down syndrome or I am happy here because George will get more help. In Poland you have to get the child to school, they are just starting to do bus service, but the children have, you have to find the special schools for those children, they are not a part of the schools like they are here. The teachers are not understanding of their needs but it is not because of them, it is because of the system. I think it's a level of society development. The more a society develops, the more people are included, the more they understand. Um, so I am happy that we leave. Here we have rights, there we wouldn't have so many rights.

It is impossible to talk about priorities and available resources without taking into consideration how much money is involved in providing special education services.

Kathleen believes it all comes down to the bottom line:

Taking nurses out of our schools is a perfect example. Somewhere, somebody saw that as an expense and a bottom line issue. And they thought not every kid with a disability needs a nurse so parents should not be asking willy-nilly for nurses and they certainly don't need to be on the busses and this is costing us X amount or it's costing us X amount to have them just do the feedings and somebody decided that is something they don't want to spend money on. WHAT IS GOING ON HERE? I mean, that's crazy! That is discrimination! And it is a hard conversation to have without it seeming like you are being unreasonable, it seems to me that they start off in a place of thinking that it's absurd to cry discrimination when the school is bending over backwards just to let your kid, who probably doesn't really need to be in school anyhow, be in school. I mean that's still there. It's like all the bunch of sort of retarded kids who can't talk and can't walk and you know, just go to school for day care anyway and so quit your belly aching. That's what I think is at the bottom of it, this oh well, we kind of have to get these kids, and right, there's very few people, very, very few people higher up in any school district who have spent any amount of time with children with disabilities, who know anything about what they can do, what their daily life is like. So it seems like I am so demanding? No, I think it is all about competition. Instead of seeing society as sort of having many people with many different talents and all of those talents are valued, we don't as a culture, we don't say that we value all people the same, especially people who fall outside this sort of very rigid notion of success. It's like you're, no, the law says you have to include these people but the impetus and the goals of the school are to shun anyone who can't compete. So to submerge that they try to make everyone look better according to some pointless rubric that looks only at things that can be measured. Which is just, oh, fundamentally flawed.

Summary and analysis.

Participants in this study spoke very directly with regard to some of the obvious barriers that exist and have had an impact on their ability to connect with and relate to the professionals in the schools their children attend. While these issues are troublesome, participants in this study seemed to consider them more of a nuisance than as major concerns when compared to the larger social and cultural barriers that they have

confronted both in school and in the community. Among the participants, Kathleen, Leslee, Marie and Grace spoke most openly about how it feels to be treated differently and excluded from mainstream school culture right along with their children, and in their voices I heard an equal mixture of pain, confusion and thinly-disguised rage.

These social and cultural barriers are more difficult to explain and uncomfortable to explore than structural or institutional barriers to relationships in the context of schooling. Education, according to Horace Mann, is supposed to be “the great equalizer,” but after listening to the participants tell their stories, it is clear that adage is not a reality for everyone. Because the “dominant paradigm conceives of disability s a physiological condition rather than as a political and social identity,” (Erevelles, p. 422) the assumption in the superstructure of our culture is that disability is socially problematic and pathological. It has become a common sense expectation in our culture and in our schools that treatment and cure are the only normative options (Oliver, 1996). Unfortunately, as the participants in this study pointed out, treatment and cure are not always viable options for some children. This, I think, is where it would be nice for the conversation to turn to issues of care, compassion and meaningful inclusion.

Instead, as both Kathleen and Leslee pointed out, the conversation more often turns to the bottom line. Spending per pupil per year is much greater in special education than it is in general education, and there is, in my opinion as well as theirs, a usually unspoken reservation about investing so much in a population of students who are unlikely to provide much return on that investment. Bérubé (1996) noted that “special ed *should* cost more than regular ed, particularly when severe physical disabilities are at issue: More vulnerable children need a greater degree of care” (p. 217). Sadly, some people have argued against the “diversion of funds” to support programs for children with disabilities in the public schools. Percy (1989) cited a 1980 editorial in the *New York*

Times which stated "...it is perverse for Congress and the courts to define an 'appropriate' education only for the handicapped and to write rules that result in the deprivation of other children" (p. 167). While this argument is both dated and infuriating, it would be pointless to deny that similar sentiments still exist. The fact that there might be some futility in the provision of a high level of service for some students is something I have rarely heard parents and professionals speak of openly, but it is an undeniable undercurrent parents have to work against in their quest for services. Among all the barriers that impede the formation of healthy and productive relationships between parents and professionals in special education, this is the one that strikes me as the most hurtful and the most likely to result in irreparable damage.

As discussed earlier and in the Literature Review, it is unfortunate that many medical, educational and rehabilitation professionals continue to use the medical model as a framework for understanding and making educational decisions for children with disabilities. This model impacts school policy and practices and, according to many parents, perpetuates the notion that children with disabilities need to be isolated in order to be cared for appropriately. Bérubé (1996) argued for his young son to be included with his typically developing peers in the early elementary school years, and wrote about how it is really

...not a good idea to socialize our children into the belief that "special" children – and the "special" adults they will become – are so abnormal that they can only be administered by being cast elsewhere, out of sight and out of mind (p. 206).

I am not sure that the politicians who make the federal, state and local rules or the administrators, teachers and therapists who execute them in our schools are aware of how the way they examine the educational needs and educational performance of children with disabilities is influenced by their conceptual lens of choice. I am even less sure that

these individuals are conscious of how the decisions they make define the future of our society for children and adults with disabilities. As Bérubé (1996) also pointed out,

...schools are as important for what they teach socially as for what they teach academically. To wit, if we're going to learn how to incorporate the disabled – those *other* people – into our “regular” lives, schools are a very good place to start. Conversely, if we can't imagine inclusion in school, it's not likely that we're going to manage it anywhere else; thus, if you want to argue against inclusion in school, then you are also necessarily arguing against inclusion in any other number of social settings, many of which *depend* on the socialization provided in school. The anti-inclusion advocates see themselves as proponents of realism; I see them as proponents of the politics of denial. For the fact is that many millions of us humans *are* disabled, and it's just wishful thinking to expect that they can all go live someplace where we normal people don't have to deal with them. But if we *can* manage to integrate special and regular kids whenever possible in the early grades of elementary school, we'll not only be teaching them spelling and math, we'll be teaching them how the disabled and nondisabled might integrate themselves after they're through with school (p. 213).

Acceptance? Resignation? Finding Peace?

In the schools where I work, I often hear my co-workers say things like, “That mother is in denial,” or “Those parents need to accept who their child is.” There are times when those statements make me intensely uncomfortable because they are arrogant and unjustified, but there are also times when I find myself in agreement with them, even though I do not like to admit it. All of the participants in this study talked about how much they love their children and how they have accepted them, without regard for the complexity of their needs. I believe them, almost completely, even though some of their narratives did not indicate the same level of acceptance their words implied. As a researcher, I have to take into consideration the fact that sometimes, especially in an interview situation, a person might respond to a personal or difficult question with what they perceive to be the most correct, rather than the most honest answer. It is important, for this reason, to be alert to the possibility that some of the participants may have left some of their true feelings out of their narratives.

There is, of course, nothing wrong with thinking about how your life might have turned out differently under altered circumstances. Most of us do it all the time and there seems to me to be little difference between contemplating what might have happened if you had won the lottery or taken a different fork in the proverbial road at any juncture in your life and wishing an accident never happened, cursing a genetic mutation, or wondering if it was toxins in the soil or drinking Diet Pepsi when you were pregnant that caused your child's autism. Accepting how your life is, in actuality, is an altogether different endeavor. Living with, caring for and loving a child with severe disabilities is something most people never experience, and while there are some joys and pains associated with it that seemed easy for the participants in this study to talk about, I want to be respectful of other aspects of the experience they may simply have preferred to keep private.

Although I did not ask any direct questions about how the participants eventually came to terms with, resigned themselves to or accepted their child's disability, almost all of them brought it up in one of three specific ways while in the process of answering other questions. First, they talked about appreciating when people try to do or say what they think might be the right thing, second, they talked about a philosophical sense of resignation and finally, several of them shared their hopes for the future.

People are trying.

When Jeff was younger and included more often in general education classrooms, Leslee often worried about how he would connect with the other children in his class and if he would be able to develop friendships with children his own age. Although she invited children over to play, Jeff's response to them being in his personal

space was unpredictable, and they often ended up playing with his brother. She said she was touched when

...a regular ed teacher called me. He told me how Jeff would talk about his train table at home all the time, and he was wondering if they could load up the kids on a bus and bring them over to see it. I thought it was very sweet, but at the time I didn't know how Jeff would react so I had to say, "Thanks but no thanks." Instead I brought some pictures of it in to show the kids.

Kathleen also talked about how she has come across people who are trying, and she appreciates that they mean well, although it is still hard for her to deal with the people who comment on how Anna looks. Seizures are inherently disorienting and the medications she takes are all very strong; they blunt her affect, reduce her arousal and often leave her lethargic and unable to remain awake. As Kathleen shared,

Yeah. And she's having forty seizures a day, so you would be like that, too. It makes me want to say, "What do you know about her?!" But it's the sort of thing that's going to happen forever now, which is that outsiders will always look at her with different eyes than we do and we sort of joke about Anna-world, and how in Anna-world everything makes sense and she's smart and amazing and awesome and in the outside world she's retarded and disabled and out of it and unconnected and all this other stuff. Right? There's these totally parallel worlds and the amazing people are the ones who can travel across the divide. And there just are not that many people who can. And it's not people's fault that they can't, it's just hard. I'm not sure I could have.

Sometimes the people who are "trying" do so in a manner that is a little hard to take, but Karen said she understands why they say what they say. When Transition Services are brought up at an IEP meeting when a child is nine or ten years old, many parents are not quite ready to discuss their options for the future. Unfortunately, planning for care after high school is something that needs to begin very early, especially in this area where services and supports for developmentally disabled adults are lacking. Karen described her first encounter with the Transition Coordinator in her school district:

They are trying to help me prepare for that. They sent me over to talk to someone from Transition. I went there thinking it was going to be about the transition to middle school, but it was for when he turns twenty-one. I kind of got overwhelmed. I want to think past this year, but, you know. I would love for him to live at Lamb's Farm and be able to feed the dogs. And she said, "Good luck. They have taken about six people in the last ten years." And I was thinking that was kind of brutal, sort of wondering if we really have to talk about this right now. And she called me the next day and sort of apologized. She said her point was that even though he is young, it is going to take a lot of advocacy to improve things here and what she said was, in all fairness to her, that we need people like me to be a mouth, to go to bat. I see the point and I am OK with that, but she still didn't answer my questions about the transition to middle school.

In a manner much less pragmatic than I expected, Karen briefly embraced her resistance to reality:

I'm not ready for that. It takes someone telling me to put him on a list for Miseracordia, I don't need someone calling me to tell me to do that, because he's not going anywhere. But if something happens to me tonight, it would be nice if he could get in tomorrow. I guess that's the flip side.

Resignation.

Many of the participants in the study talked about how, over time, they simply got used to being the parent of a child with disabilities. They described it as an evolution more than as an adjustment. Kathleen said:

One of the things about Anna's situation, about our situation, is that there's no pretending. It's pretty obvious. I think sometimes it's almost harder for people who have kids who are closer to normal than it is for people who have really severely disabled children. Because there's like one, you have to struggle to get people to recognize what's wrong, and two, you yourself may struggle to recognize what's wrong, Right? So those things may make it a very different world experience than what I'm familiar with.

Leslee described it as a process, some of which happens at school:

It's a process for everyone; it's a process for the parents. When he first got diagnosed, we didn't know where he was going but we thought maybe he'd be quirky, maybe he'd do something with computers, and then we realized. And you know, when he was in Early Childhood I was wanting to know when he was going to be with the other kids and they didn't know how to answer that. I think they knew then, and by first grade we knew. Now we totally accept he's not going to college. But I think you need time to get there. And you grieve.

Another part of the process happens at home. Leslee continued:

Even now, our friend's kids are going out or they can leave them alone and do things spontaneously, but for us, everything has to be written down and planned and it's like I am envious, so it still kind of makes me sad. Every couple of years you realize how yeah, we are kind of different, but that is why it's so good to have friends who also have kids with disabilities, if it is the same thing or something similar. But I have Andy's friends who come over, and we have a lot that other families might not have if they have an only child. And once in a while, still, someone will say, "Hey, maybe he'll go to college." And I'm like, "You know what? No." I want to be realistic. And sure, there could be a cure, but I think it's kind of permanent at this point.

And part of the process has to happen in your heart. Sometimes, as Leslee noted, it just takes a while to convince your brain that that way things are is the way they are going to be:

If you had told me five years ago that I am going to send Jeff to a school with all disabled kids, I would have said, "No way." But now we are seeing that he is going to be isolated anyway and is it worth all the awkward arm-twisting to get him to fit in for a half an hour a day when eventually, no. We've accepted it.

For Kathleen, the process has some additional complications. As a mom, she has certain feelings, but as a university professor, she has had others to grapple with. In her words:

Well, it's weird. Because I am somebody who has achieved about as high a degree of success on that arc as people do, right? And it was definitely my natural inclination to do that. But my child will never live in this world that I occupy. And it's interesting because before we had Anna I remember having this conversation with my husband about you know, if we had a child, what would he or she do? And I said, "You know, it's OK. I don't really care if my child goes to college or whatever." I feel like if they want to be a motorcycle repair person and that makes them happy, then cool. Like I really do feel like that and I think that comes from my background. And my husband was definitely not so sure about that. And it's interesting to me, now since having Anna, that I thought that way.

But I thought Kathleen sounded sad as she continued:

It's like that's a good thing. I do feel at peace with it and what I found is so interesting is that what I wish I had with her, what I know I am going to miss, is a sort of adult relationship with her that probably won't develop. Although again, I keep being surprised about the relationship that develops with her anyways so I am learning more and more. And I am not imagining the future. Because I can't.

Hope for the future.

All of the participants in this study spoke cautiously about their hopes for the future. Predictably, Ivy was the most hopeful that as Gabriella grows and matures, she will gain insight into her disability and be able to manage her needs independently. Given the nature of her difficulties, Ivy has no reason to believe these things will not happen. As she said,

She'll be fine. I hope so and I think so. And we talked about it, finally, so she knows what the problem is. And this time, when she was getting off the medicine, we just weaned off of it for the summer, she told me that she needs it. That when she takes it, it helps her to focus. I think it is very mature of her to realize that and know that it is helping her.

Marie is hopeful that Roger will find meaningful work:

He doesn't volunteer to do physical labor, but if you teach him, he will do things. Like he and his dad built this garden, he taught him how to use the shovel and put your foot on to shove it down and get the dirt going and stuff like that. Once he knows, once you get him on a task, he will get it done, pretty well. He gets opportunities through Scouts, again, if we didn't tell him he had to do it I am sure he wouldn't do it, but then when he does something he does it and he owns it and it's his thing. He's helped with Eagle projects, putting together benches for the park district, so in high school and his young adult life I can see him working for Wal-Mart or some retail or possibly a restaurant, the teenager type jobs. I know there will be a lot packed in to the next four years and a lot of new experiences. He talks about driving, and I don't know if that's going to happen, but we'll cross that bridge when we come to it. I want to encourage him, but I don't know. He talks about having a car and having a girlfriend, stuff like that. When he does the normal things we delight in them, but when his brother does them [laughing], oh! No!

Leslee thinks Jeff will do well in a group home eventually, but is hopeful that family will long be a part of his life. She said she thinks the transition to that type of living situation might be better for him sooner rather than later:

Like maybe when he is in his twenties. I went to see a residential center and I thought oh, this might be the kind of place for him. There were a lot of different kids and they ate together, went on trips together. And I know there's a lot of group homes and options, so, I want him to be able to continue on with his hobbies, find people who share his interests. And also just to be as independent as possible, to have a job and go somewhere every day. If left to his own devices he will watch TV and play video or computer games all day, but he likes swimming and school, so as long as he goes to some structured place every day. Even if the job is something monotonous. And he is on medication, we tried to take him off, but he was less focused, had more meltdowns and more behavior so we had to put him back on but really, I see him being happy. He is happy in general. And I see him being close to his cousins, aunts and uncles still.

Kathleen also talked about the possibility of Anna eventually living in a group home, but as an historian, had some concerns:

...if they don't do away with all the group homes and institutions. You know, Misericordia apparently is under a bunch of, some people are going crazy about how they want to undo that. This movement to like stop state subsidies for large institutions. Which in general is not a bad idea. But that institution [Misericordia] is an awesome one and there are others that are also good. It's sort of like public housing, everything, it shouldn't be a one size fits all solution. Like know everyone should be in a small home in the community. That won't work for everybody and it's OK if people do different things.

Kathleen would like Anna to be in place where she can have friends:

Oh, I hope that in the future she will be happy and have friends, that's what I want most of all. Is for her to have, I like really treasure this hope that when she is older, like in her twenties, that she will be able to go live in a nice home with other people her age and have community and be independent. Like, I would love that if that happens. Because I don't want her to have to always only have us. I want her to have a broader little world than she does right now. And I kind of think it's going to happen. I do. Yeah. I think that, um, I do. I don't know why. You know? [laughing]

Grace has similar hopes for George:

I mean, what I would like him to be is a regular child. But it is probably a dream. A dream even more than a hope. And I would like for him to be prepared to exist in society and do as much as he can by himself, as he is able to do. Just able to exist in society and do certain things. I know that he might not be able to do very complex things, but the easy ones, you know, he, just to be independent.

Nothing about her life with Anna has been quite like Kathleen expected it might be. But ultimately, as she concluded,

...you have to find your peace with it somehow. It has not at all been easy.

Summary and analysis.

An acceptance of, a resignation to or the act of making peace with your child's disability is a very personal endeavor and it is one about which all of the participants in this study spoke cautiously. Some described how once they were able to come to terms

with and accept (for lack of a better word to describe the sentiment, as a few noted) their child fully it became easier, in general, to cope. It was also easier to acknowledge an appreciation for the efforts of those individuals around them who meant well and were trying, in their own way, to be helpful. Being the parent of a child with disabilities is something several of the participants in the study described as an identity that takes some getting used to. It requires a certain degree of resignation to adapt to a situation you are powerless to change, and several of the participants talked about the conscious decisions they made to make the best of their situation and to not let feelings of frustration or anger take over their lives and influence their interactions with everyone they come in contact with. Three of the participants spoke directly of their experience of “making peace” with their children and their disabilities. All expressed a profound sadness that their children will never be independent, but acknowledged that they will be content as long as their children are safe, healthy, happy, and cared for.

I have mentioned my friend Joanne several times in this research study. She has been an occupational therapist for over twenty years, and she has two children. Kelly is in high school, and Michael is twelve and has Down syndrome. Joanne was kind enough to participate in my pilot study for this research project two years ago, and her words have remained with me and become the title of this dissertation. As an insider in the field of special education, Joanne has been able to predict, with reasonable accuracy, Michael’s expected trajectory of achievement, and one of the things she talked about in great detail was maintaining hope while keeping things in perspective. The process of coming to honest terms with Michael’s strengths and limitations and adjusting her vision of what the future might hold for him was a painful progression for Joanne. Looking back over her reflections, it is impossible for me to miss the ache lurking beneath the most surface interpretation of what she said. She wants what is best for both of her children, but what

is “best” for Michael has become something very different from what she thinks of as “best” for Kelly. In spite of her prayers, Joanne knows Michael is not going to grow out of his disabilities. So in her heart, she has replaced the vision of a successful future for him with one that is safe, the hope for a fulfilling life with one that is happy and the dream of him being independent with arrangements for compassionate care when she is no longer able to provide it. The toll that type of adjustment takes on the soul of a parent is one that I cannot begin to comprehend. Joanne told me there have been very few things professionals have said to her over the years that ever made much of an impression. Some people have been kind, others indifferent, and still others obnoxious. The most helpful to her have been the ones who were respectful, thoughtful, and considerate of the fact that even though she might describe her life as “normal,” it is really anything but that most of the time.

In 1989, the author Michael Dorris published a book called *The Broken Cord*. In it, he told the story of the son he adopted who had Fetal Alcohol Syndrome. Adam had difficulties in school, and Dorris described himself as behaving like “a lion defending his cub from a pack of hyenas” (p. 71) in early meetings with his son’s teachers. He wrote about the years of resistance to the slow descent into acceptance of his son’s condition:

During those middle years of the 1970’s I continually struggled to understand my little boy as he grew older. My recognition that Adam had a problem more serious than a “slow start” came in bits and pieces over the course of many years. In retrospect, the signs were all there, but at the time I stored in a file of nagging worry the poor hearing, the convulsions, the hundreds of repetitions of even the most basic instructions, the abbreviated attention span, the many minor, dismissible incidents, mistakes and shortfalls. Finally the accumulation became so numerous, so insistent, that anxiety spilled into my every thought. Yet even then, my capacity for rationalization proved almost limitless (p. 65).

Dorris also described his early interactions with school personnel as extraordinarily negative. He found his best line of defense to be knowledge:

In those years of Adam's early childhood, I trusted no diagnosis that wasn't encouraging, no road that didn't lead to a normal adult life for him. I rejected as impossible the judgments of the "experts" I had so far encountered, so the only choice was to become an expert myself. Equipped with enough data, I could overwhelm the naysayers and broker my son into success. If Adam's impairments were more than random bad luck, more than transitional stages, one obvious, personally nonthreatening source for their understanding was in the history of his biological parents. As I grudgingly began to concede that he might have *some* handicaps, some of them potentially beyond the ability of my love, my energy, to affect or cure, I turned once again to the familiar reassurance of intensive study. I was trained to believe that the answers to almost everything resided in the library, ready for discovery if one looked in the right card catalogue and with enough persistence. Research meant authority, and authority, I once believed spelled power (p. 76).

In the end though, Dorris acknowledged the futility of his early efforts to deny his son's disabilities in the face of growing evidence. As he wrote,

In my defense of him, his liabilities were nothing more than pointers to the fact that, as an [American] Indian, he conceived the world in different, preferable terms. To read the sheaf of my letters during those years one would gather I believed Adam was lucky not to be able to tell time, to tell a nickel from a quarter from a penny, or to consistently discriminate between large and small. The world, American culture, individual assessors had the problems- Adam was just as he should be.

I must have been a formidable force for Adam's teachers to deal with as I tried to intellectually or culturally coerce them into sharing my views. I talked more than I listened, demanded reports of "progress," and vigorously protested any opinions that seemed to limit Adam's chances. To judge him lacking in innate ability, I darkly hinted, implied poor teaching, racism, or a defeatist attitude. My justification for pressure was rooted in my wish that Adam will be all right, but it stemmed also from pride, from my arrogance, from terror.

I look back now on Adam's Cornish [School] report cards, at all those *Satisfactory*'s and *C*'s in math and science and history that I had insisted appear, all those passing marks, when in truth he didn't grasp for more than a minute any of the material. To what extent was Adam's steady progress from one grade to another due to my bluster? How far did Ms. Alexion [his teacher] lead him by the hand? To what degree did his teachers, for liberal or self-image reasons of their own, need to believe that he should be granted the benefit of the doubt? Yet the further on paper Adam got ahead, the further he fell behind (p. 113).

Peace with Adam's condition proved to be elusive for Dorris, as it is, probably, for many parents who have children with disabilities. The ability to reconcile who you would like your child to be with the child he or she actually is is not, as Kathleen noted during her

interview, an easy thing to do. It is a process, as many of the participants in this study indicated, and one that is often without a definitive beginning or end. The ambiguity inherent in situations like that Dorris described and that of many of the participants in this study is, I believe, what Boss (1999) wrote about in her work on ambiguous loss cited in the methodology section of this paper. It is a very painful loss for many parents, and to acknowledge it as a loss, to concede to the opinions of professionals or to accept it, simply for what it is, may be too much for some parents. Educators need to know this, and to allow this knowledge and understanding to inform their interactions with parents in special education.

The participants in this study were open about their troubles, their struggles, and some of the very personal pain associated with accepting or finding peace with the knowledge that their children will always be dependent. For some of them, interactions with people and opportunities available through their child's school have been or continue to be helpful or at least of small comfort. For others though, the experience has been less than ideal for reasons that have nothing to do with their child's disability and everything to do with the quality of the interactions they have had with the staff in their child's school. This is, perhaps, unnecessary. As Ayers and Quinn (1999) pointed out,

For every human being life is, in part, an experience of suffering and loss and pain. But our living experience also embraces other inescapable facts: that we are all in this together, and that much (but not all) of what we suffer in life is the evil we visit upon one another, that is, unjustified suffering, unnatural loss, unnecessary pain- the kinds of things that ought to be avoidable, that we might even imagine eliminating altogether (p. xiv).

Eliminating some of the suffering and this "evil we visit upon one another" via incompetence and insincerity might not be such a difficult thing to do in special education, if we, as educators, could consistently take the time and make good faith

efforts to be thoughtful and improve the quality of our interactions with the parents of our students. It sounds simple but it is not, because, as Ayres and Quinn continued,

...education is, of course, an area of struggle as well as hope-- struggle because it stirs in us the need to reconsider everything we have wrought, to look at the world anew, to question what we have created, to wonder what is worthwhile for human beings to know and experience, to justify or criticize or bombard or maintain or build up or overthrow everything before us-and hope because we gesture toward the future, toward the impending, toward the coming of the new. Education is where we gather to question whether and how we might engage and enlarge and change our lives, and it is, then, where we confront our dreams and fight out notions of the good life, where we try to comprehend, apprehend, or possibly even change the world. Education is a contested space, a natural site of conflict – sometimes restrained, other times in full eruption – over questions of justice (p. xv).

Participants in this study indicated how, in spite of occasional “eruptions,” they felt that effort could make a significant difference in their perceptions of sensitivity on the part of school staff members toward their experiences. Leslee, Grace, and Kathleen, for example, all described themselves as having learned how to pick their battles and to focus on the conflicts that will have long-lasting value in their own lives and in those of their children. In the next section I will discuss some of the additional recommendations participants offered for improving the relationships between parents and educators in special education.

Recommendations from Parents for Improved Relationships

Participants in this study were not without hope for continued improvements in the relationships that exist between parents and professionals in special education. Given consideration to the concerns noted in previous sections about all of the things that impede positive relationships, participants also indicated a variety of things professionals can do to improve the quality of their interactions and subsequently improve their relationships with parents. They suggested professionals refrain from passing judgment,

regard the family as a partner, strive for better communication, and work to provide advocacy and support during transitions.

First, do not judge.

During the interviews, all of the participants talked at one time or another about feeling as if school staff members were passing judgment and labeling them along with their children. This made them uncomfortable, and as Grace pointed out,

...to be a better special education teacher, it is important to, like, not label kids. Because labels are just labels and sometimes people forget there is a person behind the label.

As a school administrator, Ivy agreed. Regardless of where a child is from or what the circumstances are, the focus should always remain on the child. As she explained,

I would just say that it is important to remain true to what is in the best interest of the child. Sometimes people try to put other interests first but to me, I always try to go by what I believe in my heart is best for the child. And if that means I have to fight, then I keep that as my guiding question. What is best for the child? Another thing I do, and I would recommend that others do, would be to just keep in mind what you would expect for your own child. What would I want in this situation? You know, if the people at the table can't advocate for themselves, I am not going to give them any less than what I would want for my own child. What would I suggest? What would I recommend? What level of service would I want them to provide? A lot of people in the field of education are willing to do a lot of things for other people's children that they would never put up with for their own child. They take advantage, and I don't think they should.

As a parent, Ivy also agreed with Grace about the negative influence of both judgments and labels. As she continued,

I also don't think we should judge, you know. Even though I am what I am and I know who I am professionally, a lot of times in those meetings for my daughter I can feel myself shrink down and become that sixteen year old girl again. Again, you know. And you can be quiet in places where you can't speak up and I think it's just like when you go to the doctor's office, you need to write down the things you have to say and if need be, bring somebody with you, somebody who is going to be tough

and help you get it out. You can't get pushed over, you know, for some things you need to stand up and say what you know is right and what you want for your child. And they can look at you like you are the crazy parent, that's what they call parent's who stick up for their children, "Oh, she's crazy." But it's all right to do that.

Karen also expressed the feeling that people in school have been quick to judge and often seem to be intolerant of the sometimes controlled chaos that is her family life. As someone who tries not to become perturbed by minor annoyances, Karen indicated that she often tries to understand issues that come up from the school's perspective. She also acknowledged her own advantage as compared to many other parents in similar circumstances. Multiple trains of thought seemed to be arriving at the station simultaneously when I asked her about recommendations for what we, in schools, might do differently:

The first thing is do not be so quick to judge. I see it in the teachers, they have a low tolerance for parents. Some are deserving. And a lot of times a miserable kid comes from a miserable family and so even if they were fine, they would all still be miserable. Fine, that happens. But I also think teachers need to look at the whole big picture. Maybe some parents never come into the classroom or they [the teachers] don't want to see my face every day. But it used to be that the opening and closing of the bus doors used to cause Phil to have a seizure and so we are not on the bus and we are only a block away so I bring him and pick him up and so they see me a lot. So I think having tolerance and not being judgmental are important, but also the flip side of that is to not be afraid to stick up for what you think is right. And it helps if I don't need to defend him in an IEP meeting, if there is something we need to talk about, let me know and we will talk. I have never had to come in for a conference. Why would I? I am there every single day. If they have something to tell me, they tell me at the end of the day. I have a babysitter who is intolerant of them at school. She will come home from picking him up and say, "I asked what time he ate and nobody could tell me. That it was sometime between 1:00 and 1:30." So to me, what's the difference? It's not that important. Now did he drink his water? That I kind of need to know. Another problem is the language barrier. Huge problem. It's hard, we are not all the same. We are fortunate. We have insurance, a nice network. We have a lot less money than a lot of people, but we sort it out. But I know how to read and can figure out how to get places and do things. Not everyone can do that.

Second, regard family as a partner.

All of the participants strongly recommended the school staff regard parents and families as partners in the education of their children. Within this type of partnership, both parents and professionals would have an increased level of understanding about how children function when they are with the “other” partner. Rachel suggested the following:

You [school staff] need to be aware that the kid with special needs, that doesn't stop when they leave school and go home. Whatever they do at school, they do more of at home. And the things they don't do at school, like the work that gets sent home, it's harder for a parent to get it done than for a teacher. Ideally, it might be better if Albert didn't bring anything home. I would rather take him to do other things, like a martial arts class or something else than spend three hours a night on homework. And to be considerate of the fact that a lot of times we have appointments. Like when he goes to see the psychiatrist. And by the time we get home it is time to eat dinner and at that point the kids are overwhelmed from the day. By the time he has been at school all day and had a long session with the psychiatrist and, well, the likelihood of getting anything out of the homework is, it's overwhelming.

Kathleen also recommended teachers and other school staff members educate themselves about the non-school portion of their student's daily lives. As she pointed out,

I think in general, they [teachers and school staff] should know a lot more about the non-school day. Why doesn't the special ed teacher get to see what happens at the hospital or at therapy or at home? I'm thinking that would be of immeasurable value. What does it take for this mom to get her kid to school? Um, why is it that, or like what happens if a child has three seizures in the morning before school? How hard is it to get her ready and get her dressed and get her fed when she is sleeping and half out of it? It might just be a little memory, a little thing that puts it all in context for the people at school. Yeah, I think that would be awesome.

Although it is something none of us have much control over, Leslee suggested that it would be helpful if the school staff could keep in mind how the high turnover rate among teachers, therapists and aides can impact trusting relationships between parents and school staff. It takes time for new staff members to get to know students, and all new staff members come in with their own ideas and philosophies about what should happen in the classroom. As Leslee stated,

The high turnover rate is a problem, too. If they get trained and then they leave, well, that doesn't do us any good. I really want Jeff to become more independent, when I look at him, I think he could be doing more. There is an aide who is filling in and she follows him on to the bus to buckle his seatbelt. He can do his own seatbelt, he has been for years! But she doesn't know that. And like at home we are working on him fixing his own food, simple things, but he needs to work on at school, too. Like at school the kids could be making their own things, passing out plates, whatever, but if that's not encouraged, then, you know. And then you get these people [teachers] going into administration, that's the sad part. You [educators] cannot know how hard it is until you live it. We have one [teacher or administrator] now who is very narrow minded, has tunnel vision. And does not want to give services.

Leslee also talked about how, given that new teachers and different staff members from year to year do not really know Jeff, it would be nice if she could be more a part of the school team and in the classroom on occasion. Then she could explain what Jeff needs to new staff members and there would be more opportunity for everyone to get to know each other. She described an ideal situation as follows:

For the team, if the parents could be more a part of things, it would be good. I know for regular ed teachers, Jeff is pretty severe to be in a regular ed room and I know they want to be like, "Tell me exactly what I need to do!" If his teacher can't figure that out, then the aide has to tell her how to include him, tell her what questions to ask, but regular ed teachers may have no idea sometimes. Sometimes the teacher can spend time with Jeff while the aide can do things with the regular ed kids, it is like the aide doesn't have to be attached to him. And having the speech therapist and the occupational therapist go into the room instead of pulling him out is good, they notice little things about his posture or his attention or other things and then they can talk to the classroom teachers and that really helps.

Kathleen agreed with Leslee and talked about how it would be ideal to have someone to be a liaison between the family and school. That might be a step toward changing the fact that right now,

...the family is seen as an obstacle instead of as a partner in the child's education and I think that's a really difficult thing for parents to cope with and I think it's not good for the kid. In the end, you would do better in education if you come to see parents as partners.

Third, communicate!

Better, more frequent and more open communication was something all of the participants in the study recommended. Parents and members of the school staff need to talk to each other, and they need to do it on a regular basis so they can become comfortable and learn to trust one another.

According to Marie,

This communication needs to be opened up between parents and anyone else who is involved.

This is a challenge, because, as Kathleen noted,

Thinking about the relationship between parents and teachers and therapists at school, I feel there can be communication that's not really great. Because unless I run into them when I come to school, I don't really find out what's going on until we get the progress report and that's a little late. There should be a monthly goal, and we should know what you are working on so I can reinforce it at home.

Based on participant responses, this issue of communication between parents and teachers and therapists is especially important to parents who have children who are unable to communicate verbally. Grace wished George's teachers could be "in good touch with" her because although he cannot speak clearly, he has an evolving repertoire of sounds and gestures he uses to communicate his thoughts and needs. As Grace comes to understand what he means, she would like to be able to share that information with his teachers and therapists. As she explained,

The good communication is important. Because for George, I can tell the teacher what he wants or what he likes the best. He can try to talk, but I can tell the teacher what the sounds he is making are meaning and then she can build on that, she can be aware.

Both Leslee and Elizabeth talked about how important it is for the regular and special education teachers to be in communication and for parents to be linked in as well

so they can provide support in challenging areas and reinforce developing skills at home.

Elizabeth provided an example:

Keeping the lines of communication open is so important. I feel like with his special ed teacher and with math, because of his processing delay, some things are harder than others and for example, adding and subtracting are more difficult than multiplication. He multiplies easily. And there are other things, even though he understands the information, he has a visual perceptual thing, so too much, too many things on a page is hard for him. So they need to adapt materials for him. And then the other thing is that sometimes if he was having trouble with something I didn't always know about it and if he was having trouble with his math or if we weren't warned about a test or some of those things, well, one year he had a special ed teacher who was really, really good. She worked with him and she made sure he really knew exactly what he was doing. Another teacher he had would just leave him on his own for tests and if he didn't know something she would tell him he should just skip it. I'm like, "Skip it? How about finish the test and then go back and try again." Or something like that. It's when the teachers and the special ed teacher and the aide are all hooked in to each other, into what's going on, things run smoother.

In terms of communication between home and school about assignments or behavior or other daily concerns, most of the participants in this study appreciated a notebook or a folder that travels between home and school with the child. Some enjoyed monthly newsletters about what was going on in the classroom, but Kathleen was critical of that scripted and formulaic process and told me it felt to her like an ineffective substitute for actual face-to-face communication. As she explained,

...a little newsletter with the different projects and things going on, that's great. Fine. But you also have got to think about how you can get parents in that school. Like physically there. Maybe to shadow their child for a day and also, there really should be specific, I would love it if there could be a parent night for the parents of the kids in her classroom, right? And if parents can't leave a child, then there should be childcare available. So you pay some of the aides to stay one evening and the kids play with them and the parents hang out together. Then they could communicate, because they would know each other.

Fourth, provide advocacy and support during transitions.

The fourth thing several participants recommended was better advocacy and support during transitions. Follow up on this recommendation would require assistance from district level administrators to provide information. As Kathleen stated,

More information! I want a clearinghouse of information about programs in the school system. I want information about the teachers. I want information about the principals. I want to be able to get that quickly without having to beg anybody. I want it to be public. I want the way we [the school system] treat our kids to be public and I want someone to be accountable. That's what I want. And that's not that much to ask for. And if you don't have anything you are ashamed of then you don't have any reason not to share it. And so not sharing it, as in what is going on right now, suggests that they [the school] don't feel confident about what they are doing and actually know that what they are doing [failing to make information about special education programs readily available] is kind of, shitty.

She went on to further explain,

And this is the thing. Why isn't there a system of advocacy? Wouldn't it be awesome if there was a service where someone was an advocate for you, maybe did an observation or two and came to the meeting? Epilepsy Center did that a little bit for us, when we went for our first IEP, two social workers and the dietician just did it. They volunteered to do it. And that was so huge for us because they were there simply as her advocates. And as our advocates. And there could be so many ways that would help because parents don't have any point of reference. We only know what we know.

Lelsee talked about how principals and other people who are likely to be at meetings need to be trained to provide the right level of support and to be advocates for both parents and children in preparation for transitions between buildings and programs. It is all well and good to talk about your hopes and dreams and visions for the future, but it is a lot harder to talk about the steps required to get there. As she explained,

...if special ed would take ownership, look at these kids as whole people and what they can do, how they can be a part of the school community, if that were encouraged, it would really help out. You know how we start talking about transition when kids turn fourteen? We talk about jobs and the future and it's OK but it's not really realistic. We, maybe we need to talk about them wiping their butts independently. Sure there is stuff that

won't get done, but we need to talk about what motivates kids and be putting things in the IEP that are going to be steps in the right direction. And that people will be held accountable for.

Marie also mentioned that it would be nice to have a better system in place for helping families with the transition process. As she said,

And then there is the transitioning from one school to another. It would be helpful for the teacher at the first school to be aware of what they offer at the next school and vice versa. If there was a way to make that a formal process, I think that would be really helpful. Roger's teacher did what she could to make sure we would understand, that was one of her concerns, and time was an issue. For her to go visit the sixth grade, she would have to take time off of work and the district wasn't too supportive of that. She did actually consider calling in sick and doing it on her own. But there should be a way, you would think, to facilitate that so a teacher doesn't have to do that.

Summary and analysis.

The recommendations made and suggestions offered by parents and discussed in this section are very reasonable. They involve withholding judgment, regarding families as active participants in the education of their children, communicating effectively and providing advocacy and support during times of transition. Essentially, it sounds as if the participants in this study are recommending a partnership. What appears to emerge as problematic in the narratives of the participants is that this type of partnership is sometimes a strange and difficult one. Partnership implies a common interest, which in this case is the child, but unlike a business partnership or a partnership between significant others, it is most often not one entered into by choice. This, as discussed briefly in the literature review, can have a detrimental impact on the relationship. As Murray (2000) noted in her work on partnership between parents and special educators in the UK,

Neither the parent nor the teacher necessarily chooses the partnership—we certainly do not choose it on an individual basis as both parents and teachers are ‘given’ each other. We cannot end the relationship when and if we might want to, neither can we extend it if we think it is working well; within the relationship it is assumed that our common goal is one of in ‘the best interest of the child’—as this is an entirely subjective matter, it is a goal that cannot be assumed. A complicating factor for a partnership between a parent and a professional is that of the different nature of their long-term responsibilities within the partnership. A parent is a parent for life and has to assume responsibility for many aspects of their child’s life. A teacher is in a relationship with a child for a matter of years at the most with the main professional responsibility lying within the school. In addition, a teacher holds only educational responsibility. Such differences of the very nature of the relationship with the child are bound to have an effect on the relationship between parent and professional (p. 689).

This issue of parents and professionals looking at children through different lenses is a recurrent one in this study, and it appears to have come full circle at this point. Although it feels like a problem, I think it would be a mistake to regard it only as such because children, especially children with disabilities, need more than one adult to be looking at them and it is often helpful if those eyes are attached to different brains. Children need their parents to love them unconditionally, nurture them, advocate for them and on occasion, ferociously defend them against enemies. But children in our society also need to go to school, and as all of the participants in this study pointed out, their children need most of the people they encounter there as well. They need administrators to organize, teachers to educate, counselors to facilitate, therapists to push them and peers to befriend them. Although there are some who scoff at educational institutions and elect to home-school their children, most people consider school to be a necessary and (hopefully) enlightening experience for those who attend. In order for schools to fulfill their intended purpose, it is necessary for them to contain a variety of people with varied perspectives.

The suggestions and recommendations in this section were made by the participants almost in passing; I asked for any thoughts and ideas that might be of benefit

to the special education community toward the end of the interviews. Looking closely at the details contained in the suggestions and recommendations bothers me for one reason that warrants mention here. Not judging, being a team player, communicating well and providing necessary support and advocacy are all common sense components of our jobs as educators. Even if working effectively with parents and families is not yet considered to be an important aspect of the curriculum in most teacher preparation programs (Lightfoot, 2003), enough information about these four things can be found in the beginning of most basic introductory texts in general as well as in special education (see, for example, Friend & Cook, 2003; Jordan, 2007; Marzano, Pickering & Pollock, 2001; Stronge, 2002; Turnbull & Turnbull, 1997; and Wehmeyer & Agran (Eds.), 2005). In light of the availability of information, why is it that parents still feel judged, that school staff members still have difficulty working as a team, that parents report communication as inconsistent or ineffective, and that the parents who participated in this study repeatedly described situations where educators failed to advocate for their children or support them as families when they needed it most? As difficult as it is to acknowledge, answers to these questions will never be readily accessible unless we are able, as a culture of educators, to come to open and honest terms with the fundamental issue that encapsulates how we feel about and negotiate issues associated with disability and difference among children in the school setting.

Conclusion

Keeping in mind that writing is an interpretive act, it was my goal to let the data obtained from participants in this study speak for itself as much and as clearly as possible. According to Denzin and Lincoln (1998),

A thin description simply reports facts, independent of intentions or circumstances. A thick description, in contrast, gives the context of an experience, states the intentions and meanings that organized the experience, and reveals the experience as a process. Out of this process arises a text's claims for truth, its verisimilitude (p. 324).

To ensure readers the words here are authentic, I included longer sections of narrative in the results, and it is my hope that this will allow my readers to "...live their way into [the] experience" (Denzin & Lincoln, p. 325) through my account of what was said in each of the interviews.

It was a challenge to select the material that was included in this chapter from the vast amount of information participants in this study shared. Their experiences with their children and with special education professionals may have varied widely, but their stories, when woven together, speak collectively to some of the most concerning issues in special education at this time. These issues include the seven thematic categories by which this chapter was organized and it makes sense to me to view them as "lessons" for school-based professionals. Clearly, we need to pay attention to how having a child with moderate to severe disabilities impacts a family. We need to be clear about our expectations and sensitive to the fact that we, as professionals, often have very different expectations for children than their parents do. It is wise for us to consider all perspectives when making decisions about special education placement and services. We need to keep in mind that our communication skills and habits impact relationships between families and schools, and it is our responsibility to communicate our knowledge and concerns in an honest, thoughtful, and compassionate manner. Parents and educators alike need to acknowledge the many systemic barriers that have the potential to deter the formation of healthy and productive relationships between them. And finally, we need to be considerate of the fact that having a child with disabilities is a life-altering experience. Some parents believe it has altered their lives for the better, while others do not, and the

only way for educators to really be helpful is to remain mindful of the circumstance and respectful of each child and his or her family.

In the following chapter I will discuss the results of this study, attempt to answer the research questions, and revisit the theoretical framework. I will also discuss some of the concerns that emerged from the research process and end with some discussion of why I think this study matters and where this type of research may lead us in the future.

CHAPTER FIVE: DISCUSSION

Introduction

Like many qualitative research studies, this one developed slowly over a long period of time. In the beginning, it was just a term paper. It was a required component of one of the first classes I took in curriculum studies in the doctoral program at DePaul University. It was about twenty pages long and was mostly about inclusion issues in special education. I was happy with it, and encouraged by the suggestions my professor offered in the margins. He listed some authors and books for me to look at, and then wrote one word at the bottom of the last page. It said, "Onward!" I took it literally.

In the middle, this research project took over my life. I thought about it all the time. I kept articles in binders and folders at first, and then piled them up on the dining room table, the bedroom floor and on my desk at work. I bought books, racked up overdue fines at the library, scribbled outlines and notes everywhere and tried, as I progressed through my studies, to connect just about every project and paper to this interest. Gradually, with the help of a wise and tolerant committee, it began to take form. There was a problem, a pilot study and a proposal. There was the actual data collection, which was a great pleasure, thanks to the honesty and good humor of the participants, and the transcription of the data, which was tedious but informative. And then there was the year of sorting it all out. I was moved by the stories, stressed by their complexity, disheartened by what they seemed to be saying about what happens in special education and more than anything else, overwhelmed by the volume of information I had collected.

There is an anonymous quote on the wall in one of the classrooms where I work that says, "A mind, once stretched by a new idea, can never return to its original dimensions." It must be true, because I know my way of thinking about my students and

their families has evolved. I also know that my view of the administrators, teachers and therapists with whom I share inhabitation in this professional world has been altered by the experience of completing this research project. I felt torn between them and unsure if my allegiance should be to the organization of the school or to the children we are charged with serving. I floundered in it all for a long while, and now, in the end, I remain overwhelmed, but more by the possibilities and potential for shared growth and understanding that rest within the stories participants in this study shared with me than by their sheer volume. There are hundreds of little stories in each of the stories the participants told, and as I noted earlier, each one could certainly stand as a dissertation independently. There are also probably hundreds of ways in which these stories could be organized and used as data to support any number of interpretations about how things could or should be done in special education.

As it stands, I think one of the most significant results of this research is how the findings, once sorted into the thematic categories I selected, represent how thoroughly the discourse of educational practice is influenced by dominant ideological views on disability in our society. These views impact the organizational structures of our communities and our schools, and it is important to keep in mind that they are not always helpful, especially when they are administered by individuals who may lack knowledge related to childhood disability or empathy for the impact of childhood disability on families. While this realization was initially discouraging, as I looked back over the mountains of articles and books about children with disabilities covering every surface in my home, reviewed the interview transcripts and my notes and thought about the participants in this study and their children, I came to the conclusion that it is our troubled society that makes these stories even more important. We cannot expect people, even trained teachers and administrators, to understand things they have never been

exposed to, or, by the same token, to always know what they do not know. In that respect, these stories have the potential to be great teaching tools. And when this research project is completed, I hope I will be able to live up to the responsibility of putting them to good use.

This chapter is divided into three parts. Consistent with Narrative Inquiry as described by Clandinin & Connelly (2000), the literature is woven throughout this chapter as it was in Chapter Four in an “attempt to create a seamless link between the theory and the practice embodied in the inquiry” (p. 41). Although my intent was and is to have this narrative flow like a story while remaining closely linked to the literature, there are some discussion points that lend themselves to being linked to the literature with a heavier hand than others. In the first section I return to the research questions in an attempt to determine if the information obtained from this study served to answer them. I also briefly revisit the theoretical framework to clarify the link between the stories participants shared and the schools of thought that represent the foundations of my analysis. In the second section I reflect on some pertinent issues that emerged from the research process. Some of the issues are methodological or reflective in nature, while others have broader social and societal implications. I do believe all warrant some attention and discussion in the context of this study. These issues include the privileging of perspective, how difficult it is to talk about loss and disability, issues related to power and control, inclusion and the use of literature and concepts from the field of Disability Studies. The third section concludes Chapter Five with an attempt to explain why this study matters and to address the “so what?” question asked in dissertation research. It is also a forward-looking discussion of where we might go from here.

Return to the Research Questions and Theoretical Framework

I posed three general research questions for this study. The first was **“How might the experience of parenting a child with disabilities impact parental relationships with educators?”** Unfortunately, there was no simple answer from any of the participants. The experience of parenting a child with disabilities is very different for each individual, and it would not be fair to generalize the experience of one person to that of the many. As previously discussed in several areas of this study, one of the issues professionals in special education constantly encounter revolves around the level of knowledge and understanding they possess as individuals about the complex lives that exist outside of school for their students and the families who love, support and care for them. Participants in this study expressed a wide range of thoughts related to how their relationships with professionals in the schools their children attend have been impacted by their experiences.

As the parent of the youngest child discussed in the study, Kathleen expressed quite a bit of frustration with the teachers, therapists and administrative staff members who appear to have minimal understanding of the conditions Anna’s disabilities create in their home life. She described how difficult it can be to communicate effectively with medical providers and school staff members who look through the lens of the medical model and have a very different way of understanding Anna than she does. They tend to regard Anna as more of a diagnosis than a child, and they fail to recognize that her disabilities are not only something requiring medical management, but also something that Kathleen and her husband and Anna live with as a family. Her frustrations are compounded by the assumptions people make about Anna before they even know her well enough to understand what she is like, or what she would be like more frequently if

she did not need such heavy doses of strong medication to control her seizures.

Assumptions about intellectual ability based on motoric output are usually inaccurate, and according to Kathleen, have driven a wedge between her and several of the professionals in Anna's school because they have been unwilling to look beyond standardized testing measures as a gauge for her abilities.

Rachel talked about a similar feeling. Albert's disabilities are sometimes described as "invisible," and teachers and administrators have long been making assumptions about his abilities based on his typical appearance and high test scores. According to Rachel, people at school have no idea how hard it is for her to manage Albert's behavior at home. She described how she gets frustrated with him in the mornings:

In the morning before school I will follow him around for like forty-five minutes to try to get him to eat breakfast and then to try to get him to brush his teeth and then get him to get dressed for school. And if I take my eyes off of him for a minute, like to check on his brother, he goes and hides behind a chair with a book and starts reading and he doesn't answer when you call him and so I have to find him and get him back on track.

Rachel stressed to me that Albert's behavior at home is probably worse than his behavior at school, and that the teachers do not seem to appreciate her understanding of him. Instead of feeling like a part of the school team, Rachel described feeling put off and put out by the people who have been unwilling to take her requests for help for him into consideration. Her willingness to enter into relationships with school staff has been compromised over the years by this battle.

Leslee talked about what she expected when Jeff started school and how school staff have repeatedly disappointed her and let Jeff down over the years. Some of those early experiences established the foundation for how she relates to people in Jeff's school now, and she is constantly on guard, no longer hesitant to make noise about what he

needs and always ready to jump to his defense. It is stressful for her, and not at all conducive to relationships with his teachers and therapists. Leslee wishes things were different, and she thinks it is unfortunate that she has to decide between being Jeff's mom and advocate or being a part of his school team. Like Kathleen and Rachel, Leslee's stories about her experiences can be understood in many ways. On a superficial level, it is clear from all three narratives that the experiences with their children and with the professionals in the schools their children attend have had a significant impact on them. And on a deeper level, it is also clear from all three narratives that there are complex issues and dynamics operating to create and shape that impact. There are certainly families who have the financial resources required to shelter their children and themselves from some of the more practical problems, but even they are not immune to being affected by the way in which children and adults with disabilities and generalized dependence are viewed in our society.

Marie seemed to feel differently about Roger's school experience. She described several positive relationships she has had with school staff members over the years and appears to use those relationships as a framework for her expectations. Marie described several of Roger's teachers as having become like "extended family" to her, and talked about how they were supportive and sensitive to what her family was going through as they came to understand the severity of Roger's intellectual disabilities. Karen also indicated that her experiences with Phil's teachers and therapists have been, for the most part, positive. She approaches these relationships with openness and honesty and reported that she usually gets the same in return. Elizabeth was also comfortable with the services James was receiving at school. One possible explanation for this discrepancy in participant reports of general satisfaction with school experiences and special education services is that Kathleen and Leslee both expressed concerns related to school culture and

societal views on disability. They talked about inclusion in a broader and more philosophical sense, and expressed the desire for immediate changes in the system that could be of benefit to their children. Marie, Karen and Elizabeth, on the other hand, expressed greater levels of appreciation for the strengths and tolerance for the inadequacies of their local school districts. Fortunately for them, they have been more satisfied with school programs, but like Kathleen and Leslee, they have actively sought out private services and enrichment activities outside of school for their children. Although I posed the same questions to all participants during the interviews, Marie, Karen and Elizabeth remained focused on their own children and expressed fewer concerns than Kathleen and Leslee did about larger, societal issues. I do not believe this focus was due to a lack of concern for broader issues, as I know all of the participants are deeply concerned about how children with disabilities fit in to our society and what they as parents and we as educators can do to ease and facilitate inclusion. I do think, however, they interpreted my questions differently and that in turn steered our conversations in slightly different directions.

To summarize, it is clear that the experience of parenting a child with disabilities does impact parental relationships with educators, sometimes for better and sometimes for worse. How could it not? Regardless of what parents bring to the relationship, it is the responsibility of the professional to meet them in the middle, to be understanding and respectful, and to remain committed to creating a positive learning environment for the child. I also believe that conscientious special education professionals are obligated to be informed (at very least) and adequately practiced in the art of critically examining some of the larger contextual issues that impact children with disabilities both inside and outside of school. Meaningful inclusion begins in school for many children, and it is important for us, as educators, to understand how our selection of a conceptual lens (such

as a medical model perspective on disability) influences our thinking about educating children with disabilities and relating to their families.

The second research question was **“What are the pertinent issues identified by parents of children with moderate to severe disabilities that relate to successful working relationships between parents and educators?”** Unlike the first question, this one was more straightforward, and participants in the study provided ample information in their narratives to answer it.

As both a parent and a school administrator, Ivy was adamant about school staff taking the time to inform parents of their rights, maintaining frequent communication with parents about student progress and issues and providing the same level of service and care to all children and families, regardless of socioeconomic status. Ivy is a strong proponent of inclusion and spoke passionately about the role of teacher preparation and mentor programs for new teachers in facilitating meaningful classroom experiences for children with disabilities.

Karen identified compassion and communication as the most pertinent issues factoring into her relationships with staff members at Phil’s school. Circumstances surrounding Phil’s injury were traumatic for Karen’s entire family, and she found staff, with the exception of a few individuals, to be concerned and helpful. Self-contained special education classrooms in the district where Karen lives are limited to eight students, so teachers are more accessible and there are fewer turnovers than in other districts where the classes are larger and support is less readily available. Karen reported that many of the teachers and therapists who have worked with Phil since he was young have been knowledgeable and dedicated. In addition, the district has provided adequately for both human and material resources; Phil’s needs are fairly extensive, and Karen has

never felt as though they were unwilling to provide him with an assistant or any of the equipment (such as a stander or communication device) she has requested.

Marie also talked about communication being the most important factor in the most successful relationships she has had with Roger's teachers. She mentioned two teachers in particular who took a special interest in Roger, and explained that it was because she was able to speak with them frequently and visit their classrooms on a regular basis as a volunteer that the relationships developed into friendship. Both relationships were based on mutual understanding and trust, and it helped Marie feel confident that Roger's educational needs were well-attended to at school. Having those relationships with the two teachers she talked about also made it easier for Marie to seek out their informed opinions when she had to make decisions about placement or other issues during the school year.

Grace defined communication as the most important aspect of working relationships as well. Because George does not speak clearly, she finds many of the efforts his teachers make to communicate with her especially helpful. There is a notebook that gets sent home each night with a message and she in turn can respond to any questions or let the school staff know if anything out of the ordinary is going on at home. George's teacher also sends home a sheet of paper with a brief description of what the children did during the day so parents can ask their children questions about it in the evening. This type of ongoing communication initially helped Grace get to know the teachers and form friendly and productive relationships with them. These relationships are not necessarily without conflict, but because they are comfortable communicating with one another they can agree to disagree without fear of alienating each other. As Grace phrased it:

The IEP was reflecting my wishes for him. We agreed with everything. We agreed on everything. I mean, I see George in a different light and they see George in a different light, but, so, we compromise and so I really don't have a hard time. They have been helpful and open-minded and I am frustrated because the school has been so good, and he will have to go someplace next year that might not be so good. So it is like you are in heaven and suddenly you have to go to [laughing], you know.

Although I was hoping to maintain the focus on more positive aspects of relationships between parents and professionals, Leslee, Rachel and Kathleen all described multiple experiences with professionals in the schools their children attend that were less than ideal. These interactions left lasting impressions on them, and were very clearly detrimental to their interest and investment in other relationships with professionals they have dealt with since. Her narrative was somewhat disjointed at times, but Leslee was very clear about the source of her frustration with the staff at Jeff's school. Although he has had some good teachers and caring assistants, kids "like Jeff" are simply not a priority and there is an unspoken unwillingness to invest in the training or outside consultation that could improve the quality of the classroom experience for Jeff and others with comparable needs. Along similar lines, Rachel wondered why it has been so hard for her to obtain help for Albert. His needs are significant, but his potential to benefit from a minimal amount of assistance is great. Like Leslee, Rachel also spoke of the kind and creative teachers who really made a difference some years for Albert, but from her perspective, those teachers were on their own, working hard, doing what they did for Albert because they wanted to. They did not receive any support from the system, and did not have input from a team of knowledgeable professionals who could likely have offered assistance. This lack of support from the school system for children with disabilities and their families is a common concern in many large, urban school districts as well as in other underserved areas. The participants in this study were all active in seeking out what they needed for their children, but this may not be true for the general

population; I think it is likely that many families may understand certain services to be unavailable when in actuality, they may simply not have the knowledge required to access them.

Kathleen's personal narrative echoed Leslee and Rachel's words in perhaps a more organized and history professor-like manner that was no less emotional, but she put a socio-political spin on it that the others did not. The fact that she has to beg for information about school programs, bring in her own advocate, defend Anna's right to an education, worry about separate and discriminatory placement practices, pay for needed therapy services out of pocket and drive her child to school and back each day because she is not medically safe on the school bus speaks to one central and deeply disturbing issue in special education. It is as Leslee described, that students with disabilities are not a priority in our schools or in our society as a whole. I think this may be the reason many parents like Leslee, Rachel, Kathleen and Ivy report feeling that the needs of their children are relegated to a status more marginal than those of typically developing children. It is impossible to deny that this "pervasive cult of perfectionism is still evident in present-day society" (Parmenter, 2001, p. 289). Erevelles (2005) also described the same issue in this way:

After all, the disabled student embodies the "unruly" subject whose physiological excesses are seen to disrupt the disciplined control of schooling. In fact, the actual existence of special education programs that serve children with a variety of labels- learning disability, emotional and behavioral disorders, mild, moderate and multiple disabilities- are predicated on the inability of regular schooling to effectively control the disruptive interruptions of these bodies that appear impervious to the rigid demands for conformity and rationality in schools (p.72).

Leslee, in her intense desire to have Jeff included with his peers at school and Kathleen, in her anger at the school system that has repeatedly failed to provide adequate educational services for her child both indicated the sentiments they believe to be central factors at the core of this issue. They are, according to both Kathleen and Leslee,

ignorance, intolerance and fear of disability. Erevelles (2005) used even stronger language to describe the underlying roots of the issue:

...the disabled subject has historically occupied unruly spaces where (ir)rationality, (in)coherency, (in)completeness, and contingencies abound, [and] these excessive embodied experiences have done little to alleviate other experiences of extreme poverty and involuntary social and economic segregation. As a result, many disabled people are compelled to be dependent on state welfare for their daily survival and are therefore relegated to the role of consumer within the social order, while at the same time not making any observable contribution to economic production. However, unlike the wealthy bourgeois consumer whose separation from the world is, in fact, celebrated because of his/her independent access to capital, the disabled subject's singular role as a consumer is deemed parasitic and is especially despised for his/her (non)location on the social division of labor. Therefore, in the specific historical context of capitalism, where it is individualism that is valued and not interdependence, the disabled subject is seen to inhabit a "despised body" and is relegated to the zone of terror in the social sphere (p. 73).

Using milder terms and thinking about the scenarios and experiences participants in this study described, it feels to me as if schools (the schools I know and those participants in this study described) have little intention of doing anything more than what they are required by law to do. This is because we, as a society, are frightened by disability and, as a culture of educators, have decided it would be much easier for all of us if these children who do not look, think, move, interact, eat, or play like "normal" children, were simply not around. We noisily proclaim our schools to be "inclusive," but our mindsets are not. Therefore we continue to separate and marginalize children with disabilities by adhering to policies and practices that deprive them of opportunities for meaningful participation in academic and social activities in both self-contained settings as well as among their typically-developing peers. Schools are often seen as a microcosm of our society as a whole, and such vivid description of this troublesome and pervasive problem in our society is not what I was hoping to find as the answer to this research question. Sadly though, it feels like the truth.

My third research question, "**How do organizational structures and practices support or impede effective and meaningful relationships between parents of children with moderate to severe disabilities and educators?**" was also one that

without being asked directly, participants spoke plainly to. Unlike the larger issues addressed in the second research question, the information obtained from the participants pertaining to organizational structures and practices had a much more local feel, as in things we might actually be able to do something about sometime soon.

The most significant structures and practices noted by participants that impede relationships between parents and professionals are numerous. According to the participants, some of these structures include, but are certainly not limited to the following: service availability in cluster sites that are often far from a child's home; the IEP process; time-limited meetings facilitated by administrators who are unfamiliar with the child; reliance on test scores for placement determination; high turnover among professional and support staff, insufficient time for collaboration between professionals and parents; general education teachers who are ill-equipped or unwilling to have students with disabilities included in their classrooms; school policies that do not allow parents to visit classrooms; and the fact that there is usually no "escape hatch" for parents or professionals when a relationship is not working in the best interest of a child.

The most significant practices that impede relationships mentioned during the interviews by participants include: bureaucratic disorganization that creates difficulty when parents attempt to obtain information about school programs and staff; poor communication and facilitation of transitions between classrooms, schools and programs; professionals who read reports instead of talking to parents during IEP meetings; insincerity in progress reporting; parents being relegated to "outsider" status along with their children who have disabilities; administrators who send the message that special education services are a bonus rather than a right; a lack of sensitivity on the part of educators for the difficulties that may occur at home with a child with disabilities; and limited training offered to and general lack of appreciation for paraprofessionals.

In spite of the extensive list above, all of the participants in this study were quick to acknowledge the many structures and practices that have been supportive of their relationships with the professionals in the schools their children attend. Sometimes a reliance on institutional norms as a framework for practice can initially feel more institutionalized than individualized to many individuals. This may be why the stress and jargon of the IEP process can at times appear to be detrimental to relationships but it can also, when used effectively, protect and support those same relationships.

Organizational structures parents described as supportive were varied. Participants who lived within smaller suburban school districts found centralized services and teams of professionals who know each other and are accustomed to working together to be much easier to negotiate than participants who lived within larger districts and had to travel farther to obtain services. All of the participants in the study found the IEP process, when used in the spirit with which it was intended, to be a necessary support for their children as well as for their relationships with professionals. When the process is used to review progress, discuss concerns, and collaboratively make plans and set goals, participants reported feeling good about the meeting. They reported feeling even better when school staff remained mindful of their child's limitations while figuring out how best to provide the right opportunities for their intellectual and social growth. Because IEP meetings are often stressful, I think it is important to note that many of the participants indicated a preference for an IEP meeting facilitator who is not only familiar with the district programs and staff, but also familiar and knowledgeable (within reason) about their child. And they noted that it is also helpful, in smaller as well as larger school districts, for parents to have a special education coordinator or case manager who is not their child's classroom teacher who can serve as a point person for questions and concerns as well as a guide through transitions as the child ages. Although participants in

the study talked about positive experiences with both new and veteran teachers, all articulated the thought that it would be nice if teachers and administrators were offered training in how to communicate and work effectively with parents.

Participants also described a variety of practices they have found to be supportive of their relationships with school professionals. The first thing all of the participants talked about was time. Participants indicated an understanding of the fact that schools are often forced to schedule multiple meetings on the same day but also described how much more comfortable they are if they do not feel rushed. Given that IEP meetings are usually only once each year, they also indicated that it is nice when general education teachers take the time to stop in (even if it is only for a few minutes) and when paraprofessionals are included, because they are often the people who have the most direct contact with the child. IEP meetings and parent conferences are formal in nature, and participants talked about how informal opportunities to connect with school staff are sometimes more effective for building relationships. Leslee mentioned the school principal who maintained a “my door is open, please stop in for a cup of coffee” policy during his tenure. Although she only stopped in a couple of times to talk, just knowing that he was available was reassuring. Karen talked about Phil’s teacher, who was always at the door when the kids were coming in the morning and going in the afternoon and available to chat for a few minutes. Participants also mentioned teachers and therapists who provided their home or cell phone numbers so they could be reached in the evening or over the weekend if necessary. Several of the participants talked about how the tone of IEP meetings is altered by how information is communicated to them. Participants expressed an appreciation for those professionals who share their reports in a conversational rather than a lecture format and for those who take the time to provide qualitative data in the form of stories, work samples or descriptive explanations of their child’s responses to

testing or academic and functional routines. Kathleen talked about the difference between Anna's speech therapist who simply reported numbers and her occupational therapist who took the time to question her approach and talk about Anna's responses to specific activities. According to Kathleen and several of the other participants in the study, it is these shared qualitative observations that assure parents that school professionals really do know and care about their children. Participants also talked about how meaningful it is for them when their help is solicited for class projects or field trips and when they know their children are included in activities that involve the entire building.

Because of the complexity of the subject, I did not expect to be able to sum up the data obtained from participants in this study in a simple manner, but it seems clear from both the results noted in Chapter Four and the answers to the research questions above that most of the issues discussed throughout the study are centered around how individuals come to terms with and negotiate relationships around disability and difference. As educators, we need to be aware of who is advantaged or disadvantaged by how we engage with these issues, and we need to challenge ourselves not to simplify or ignore them. Studs Terkel (2001) stated it clearly when he wrote that we need to "...get our fears and our anxieties out in front of us, take a look at them, and then begin to deal with them" (p. 23).

After returning to the research questions, it makes sense to return to the theoretical framework to briefly examine its function as a guide for analysis. Background knowledge of works by Rauner (2000) on care, by Kreisberg (1992) on power issues in school and by Boss (1999) on issues associated with ambiguous loss in conjunction helped me to consider the stories participants shared about their experiences in a manner grounded in established theory. It also,

I believe, helped me to link the stories participants shared directly to each other in order to create the narrative flow of this research study. Looking at each aspect of the theoretical framework and some general examples of how the stories participants shared fit into each school of thought helped me to clarify these connections and establish a patent link between the theories I found useful and the stories I was attempting to illuminate.

Beginning with Rauner (2000) and issues of care, many of the participants spoke clearly of how their relationships with school professionals were influenced by their perceptions of how those school professionals cared for their children and about them not only as parents, but also as individuals. They described how administrators, teachers, teacher assistants and therapists let them know they cared through their efforts and actions, even when the institutions themselves did not feel particularly supportive or caring.

Moving on to the issue of power, I think it is important to consider this issue in both a positive and negative light. There were, among the participants in this study, a few who felt there was some equilibrium between their own power and the power they perceived to be held by professionals in their child's school. In many respects, this power was balanced and collaborative; it contributed to parental satisfaction and was fundamental in the creation and maintenance of positive relationships between parents and professionals. Other participants described how they felt oppressed by the power held by the professionals in their child's school and the work involved in active resistance to it. It may have been

easier at times to acquiesce, but these participants knew their rights and stood up for themselves and their children. There were also those who described being angered and frustrated by feelings of powerlessness when they attempted to obtain the supports and services they wanted for their children from the school. In these situations, there was little equilibrium in the distribution of power and unfortunately the relationships between parents and professionals were damaged.

Finally, I believe it is virtually impossible not to see the strong parallel that can be drawn between the stories contained in this study and the issue of ambiguous loss. Drawing on Boss' (1999) theory makes sense for many (but perhaps not all) of the families whose stories are in this study; children who are physically present but psychologically, emotionally or intellectually compromised (as well as medically needy) present many different challenges for their families. No two families employ the same coping strategies in the same manner, and it is important for professionals to be aware and considerate of the impact of these challenges on the integrity of the family and their connections with the professionals they encounter in schools.

Issues Emerging from the Research

It is inevitable in narrative research that the exploration of one issue or concern will open the door to many others. In this study, the stories participants shared are “filled with narrative fragments, enacted in storied moments of time and space (Clandinin & Connelly, 2000, p. 17), but within these narrative fragments are “texts about lives that could be interpreted to reveal intersections of the social, cultural, personal, and political” (Reissman, p. vi). It is these intersections, I think, that do not fit neatly into any of the

thematic categories I selected for organizing data in Chapter Four. Instead, they represent what I feel are broad areas of curiosity and concern that are central to making sense of the stories told by participants in this study. These five areas are framed as questions or concerns and are discussed below. The first issue is a methodological one and involves the privileging of perspective. The next two are more reflective and involve issues surrounding conversations about sensitive topics and issues associated with power and control. The last two concerns have broader societal implications and are about inclusion and the use of literature and concepts from the field of Disability Studies.

My first question is about perspective. This study is about parent perceptions and perspective on their relationships with the professionals in the schools their children attend. Throughout this project I have been mindful of the fact that I am a professional in a school much like the ones the children of the participants in this study attend. Although I listened carefully and made my best effort to interpret what they told me accurately, there is no way around the fact that my perspective is influenced by my professional role. The relationships in question in this study are not unilateral, and when parents talk about their children it is very personal, and very different from when professionals talk about their students. For this reason, I have questioned, and need to ask that you, as my readers, carefully consider which voices making noise in this work deserve to be privileged.

Given my perspective as a professional in the field, I found myself wondering how I might have responded to some of the situations participants described had I been wearing their shoes. Would I have angrily told off that woman in the office or stood up to the ignorant social worker or given it right back to the regular education teacher who told me my child did not belong in her class? Could I have mustered up the courage to calmly state my case to a principal or remembered all of the important questions for a doctor I had been waiting months to see? I am not at all sure. But I am sure my perspective on

everything participants in this study told me is in no way, shape or form as personal or present as theirs. There is no way for me to “walk a mile” in Karen or Kathleen or Elizabeth’s shoes. I just have to take their word for which shoes are most comfortable and which ones really hurt.

In this study it was my intent to explore relationships between parents and professionals in special education through stories parents told of their experiences. Although I did my best to make sure the results are presented in a manner that gives voice to the participants and their perspective, because of the nature of this study, I remain conscious of two problems Reissman (1993) noted. First, it is virtually impossible to “give voice” to another person; the best a narrative researcher can do is “hear voices that we record and interpret” (p. 8) as accurately as possible with consideration given to the context in which the words were shared. Second, Reissman warned narrative researchers to be aware of the “inevitable gap between the experience as lived...and any communication about it (p. 10). It is very easy to make assumptions about other people’s lives and experiences, and as I reviewed interview transcripts and notes and constructed my narrative of participant’s narratives, this issue was always on my mind. Looking back over the data, it is very clear to me which participants have younger children and which have had more time to process and temper their experiences. I have spent too much time in schools and with families who have children with disabilities to allow myself the luxury of face-value interpretations of anyone’s account of what happens between parents and professionals in schools. These interactions are loaded and there is always another side, an alternative perspective or an opposing view to be considered by all involved individuals.

A second question I have been pondering is this: Why is it so difficult for us to talk about sensitive issues in a sensitive manner with parents? As educators, the way in

which we acknowledge (or fail to acknowledge) issues related to disability, illness and loss can be very important to parents. Because these things can be uncomfortable to talk about, it is often easier to avoid talking about or attending to them at all. This avoidance tactic, I think, is a pervasive complicating factor in the relationships between parents and professionals in special education. It is, obviously, easier to focus on concrete concepts related to academic progress than it is to talk about the deeper meaning represented by a child's academic and functional performance. Some of the participants in this study briefly referenced their sense of loss and the emotional side of living with a child who has a chronic illness or severe disability, but they did it quickly and at the time, I did not think to question them further about their comments. I am disappointed in myself as a researcher for this; had I probed more effectively Kathleen might have described missing the relationship she might have with Anna in the future in more detail or Marie might have elaborated on her feelings about the fact that Roger will never be as independent as his siblings.

In spite of my disappointment with the fact that I failed to probe participants more thoroughly in relation to this particular issue, I have no shortage of stories about families of children I have worked with over the years. Some of the happier stories involve families who were able, as Moses (1987) noted, to grieve for the perfect, healthy or whole child they had lost and then re-attach themselves to this "new" child. Some of the less happy stories that stand out in my mind are the just the opposite; they are of parents who remained too sad or angry to secure supportive connections with school staff and whose relationships with almost everyone in the school system were subsequently characterized by combative, unpleasant and unproductive interactions. I do not recall any of these families being described in pleasant terms by people I worked with, and while I know there are some situations that are doomed from the start, I cannot help thinking

some of the ones in my recent memory might, with a little bit of thoughtful attention to the underlying root of all the contention, have been reparable. Attending to the root of the problem, which is usually fear, anger, sadness, unacknowledged loss or unresolved grief (Boss, 1999), can be accomplished when educators and parents talk to each other about the things that are hardest to talk about. Both parties need to have a vested interest in this conversation; educators may need to open the door, but parents need to engage, and both parents and professionals need to remain open-minded and committed to listening and responding in a respectful manner. But it is the responsibility of the educators to acknowledge and validate parental concerns. It requires time and patience, and it does not work all the time, but if it does on occasion, it is certainly worth the effort.

My third concern stems from issues participants discussed related to power and control in their relationships with educators. In Chapter Three, I wrote about power relationships in schools as a theoretical lens through which to view the quality of the interactions and relationships that exist between parents and professionals in special education. I referenced Kreisberg's (1992) theory of how relationships of domination have become widely accepted as natural in schools and wrote about how I feel there is an undercurrent of violence embedded in the coercive nature of professional conduct in relation to parents of children with disabilities in our field. Participants in this study did not speak explicitly about power, but they confirmed some of Kreisberg's notions; they talked about expecting and accepting poor or inconsiderate treatment, being at the mercy of those who appeared to care little for their well-being, and walking away from interactions with school staff members without having their needs or those of their child met. They also confirmed my speculation about there being some coercion and violence embedded in the interactions; examples included a secretary who told a mother she doesn't know what her child needs, a social worker who asked a parent to rehash the

accident that left her child severely disabled, a psychologist who screamed at a mother who did not agree with her recommendation about medication, and a principal who bullied a parent into accepting a classroom placement for her child she did not agree with.

Advocacy should not damage relationships, but participants in this study indicated that it does. Evident in the power struggles they described are elements of dismissive resistance from parents, but also of the *power over* relationship Kreisberg defined in his work. They are clear representations of circumstances where "...the ability to control and manipulate others [is derived] from privileged access to control of valued resources..." (p. 11). The power to control these valued resources can have a corruptive influence on some individuals, but for others it may be rooted in a form of misunderstanding or lack of knowledge. According to Asch (2001), many people without disabilities question the value of a life lived with disabilities (p. 311), and are therefore unable to presume that an individual with disabilities has capabilities of worth. Biklen & Burke (2006) elaborated on the danger of this issue in the educational setting and argued the need for educators to "presume competence" of their students who are individuals with disabilities. They indicated that being open to an individual's competence is "a stance, an outlook, a framework for educational engagement" (p. 168) that does not allow an educator to "project an ableist interpretation" (p. 168) on student behavior and interactions. This openness is integral to connections between individuals and necessary for building and maintaining relationships between parents and professionals in special education.

Returning to the episodes participants in this study reported, it also looks as though professionals in special education may use some degree of perceived power to create and maintain protective boundaries. Special educators tend to burn out and leave the field at a rate higher than professionals in other areas of education, and I wonder if

some of what appear to be the more inappropriate attempts to control the environment in special education are actually attempts by educators to distance themselves personally from some of the more painful and emotional aspects of the lives of students and their families? I have heard teachers, psychologists, administrators and therapists say things to parents in meetings that are incredibly insensitive and it is not my intention to defend their bad behavior. I do find it difficult not to feel a little bit defensive, as well as a little bit sad that the actions of a few individuals can reflect so poorly on such a large field. I also think it is important to note that while many report feeling powerless, not all parents are actually powerless in the school setting. Occasionally parents with knowledge and resources may want something for their own children and threaten to sue their local school district, forcing educators to make accommodations to appease them which may or may not be in the best interest of the child. But more often, many parents are increasingly influential in decision-making for policy and practice in regular and special education and are progressively involved in the day-to-day functioning of the schools their children attend. This reflects a shift in the accepted role of parents in schools; no longer passive consumers, parents are now empowered participants in educational planning for their children. It is a role that has been a long time coming and needs to be viewed in a positive light by the educational community.

The fourth area of concern that materialized from this research is about how the ideals of meaningful inclusion might best be implemented for children with moderate to severe disabilities in a dignified and inclusive manner. This is a concern that is much too large to be addressed adequately in this paper, but based on the data obtained from the participants in this study, it warrants attention. Like many of the participants in this study, I have mixed feelings about inclusion. I also hope anyone who has spent a considerable amount of time with this population of children either at home or at school

would have reason to question both hard-line proponents of full inclusion and those who accept segregated classrooms as appropriate. Some of the participants waffled when questioned about their feelings. Leslee wants Jeff to be included but she does not want that inclusion to cause him stress. Grace would like to see George included so he can see what other children do but she also wants him to be in a classroom where there are other children who have needs similar to his. Marie would like to see Roger included with his peers for some activities but she also wants him to have the benefits of academic instruction in a special education classroom. Other participants did not waffle at all; Kathleen stated very clearly that she does not want Anna mainstreamed. “No, I do not!” were her exact words, but she absolutely believes the option should be there for other children. Karen does not want or worry about inclusion for Phil; he is unable to participate in activities with his grade level peers without total assistance, and while she knows he enjoys the social stimulation, it is not a priority for her for academic purposes.

There is a great deal of pressure on schools right now to be inclusive and offer children with disabilities as much opportunity as possible to learn and play alongside their typically developing peers, but grand theories and ideas do not always translate well into reality. Based on my experience in schools where children with moderate to severe disabilities are included in the general education setting, I often question the benefit of certain types of inclusion. Does a student with cerebral palsy, sitting in his wheelchair with a teacher assistant beside him really benefit from a recess period when all of the other children are running around on the playground, engaged in a game he is unable to play? Does a child with Down syndrome benefit from attending a fourth grade social studies class three times each week if he is unable to follow the discussion, write his name on a worksheet, or participate in group activities and instead grabs things from other children or sits under a table laughing and ripping his workbook? Does the child

with autism, who is overstimulated by noise and odor, benefit from being forced to eat in a cafeteria at a table with other boys who are his age? Maybe he is “included” at lunch, but if he does not have the ability to engage in social interactions with those boys, and it creates an unpleasant lunchtime experience for him, is it meaningful? These scenarios call into question our overall goals for the inclusion of children with moderate to severe disabilities in general education settings. We need to examine our practices and clearly define the social, academic and emotional benefits and costs that may result. We also need to consider the larger picture in cases such as those described above. With whose terms do we define inclusion and on whose territory do we tread in our attempts to practice it fairly?

I am not saying inclusion is bad or that it can never work for this population of students, but we need to be very careful not to let legal mandates and administrative expectations define best practice in special education. I also think we have a responsibility as educators to constantly question and evaluate what is happening in our classrooms in order to improve practice. Meaningful inclusion can be accomplished, but it requires compassion and a substantial investment of time and resources. Joanne, my friend who participated in the pilot study for this research project, told me her son who has Down syndrome has never been fully included with his typically developing peers but that he has benefitted tremendously from a “reverse” form of inclusion, where students from general education join the students in his class for a variety of activities. For Joanne, this success highlights the need for inclusion to be implemented in a very individualized manner. While her son does not thrive in the general education setting most of the time, some children can certainly be placed there for gym or art or music or reading with support. Others simply benefit from remaining in a smaller group setting and having peers invited in to their classrooms for structured activities. Lunch and recess

can also be inclusive, but it might be more dignified for the students with disabilities if it is facilitated in a smaller space and with children from general education who wish to be a part of the experience. It is, then, “collective and voluntary, rather than coercive and bureaucratic” (Rauner, 2000, p. 123).

These are only a few examples and are, by no means, an exhaustive sample of the possibilities that exist for meaningful inclusion that is compassionate and caring. These examples also embody the “ethic of care” Rauner (2000) discussed in her work. She wrote,

...an ethic of care can be considered a disposition to approach self, group and society from a point of view that values interdependence, respects the uniqueness of others, and considers individuals from a holistic perspective...There is, in an ethic of care, an orientation toward active involvement in the maintenance and well-being of the social organizations of which one is a part – not only to one’s intimate others, but to the larger social systems that comprise one’s world. In its orientation toward attentiveness and responsiveness, as well as its value of interdependence, an ethic of care compels one toward participation in large-scale systems that value the individual, respect otherness, and celebrate the connectedness that arises from shared enterprises (p. 25).

The question of best practice in inclusive education is a complex one. We can continue to go through the motions and haphazardly place children with disabilities in classrooms with their typically developing peers and hope for the best. Or we can incorporate the ethic of care Rauner (2000) discussed, take the time to determine what manner of inclusion is of most benefit to each individual child, and then do our best to make it work. Essentially, including children with disabilities does not have to be a source of contention between families and schools. It does not always result in textbook perfection, but it can and does work when our behavior is attentive and responsive to the needs of all involved.

Finally, throughout this research I referenced literature from the field of Disability Studies to support issues brought up in discussion by participants and to shed light on various aspects of interpretation. Disability Studies is a vast field of scholarship,

and the body of literature is written with the view that disability is more of a social, cultural and political construct than a physical characteristic within an individual that begs repair or cure. According to Brueggemann, Feldmeier, Dunn, Heifferon & Cheu (2001), Disability Studies defines “impairment” as a physical difference, and “disability” as how society interprets and makes sense of that impairment (p. 372). Disability, then, takes on meaning from the social and cultural context in which it is examined. This perspective has a great deal to offer the field of special education in many respects. According to Linton (1998), the Disability Studies perspective can inform the way we think about “issues such as autonomy, competence, wholeness, independence/dependence, physical appearance, aesthetics, community, and notions of progress and perfection” (p. 118). These are certainly issues that deserve additional informed thinking in special education.

It was very easy for me to get caught up in this body of literature while thinking about the participants in this study and their children, as well as many of my own students. It is edgy, provocative and fascinating in its historical, theoretical and philosophical grounding, and it is thorough in its coverage of the experiences of individuals with a wide range of disabilities. It is not, like most of the literature I am accustomed to perusing in occupational therapy and educational research, focused on prevention, rehabilitation or curative options. It is unwavering in its critique of the dominant ideological stance on disability and unapologetically caustic in its call for change in the way society views people with disabilities. It is also, to my reading, focused on individuals with physical or sensory impairments and tends to exclude children and adults with severe or severe and profound intellectual disabilities.

Because of my reliance on Disability Studies literature, I find this tendency to exclude people with intellectual disabilities to be problematic for two reasons. The first is

that I am referencing literature with regard to a population of children for which I believe it is applicable but for whom it was not intended. The second problem is that there is one fundamental issue within the Disability Studies literature I strongly disagree with. Several of the authors cited in this dissertation have argued that mental retardation is nothing more than a social construction, and that it is the societal perception of incompetence that limits the potential of individuals with cognitive impairments. They also argue that as “helpers,” medical, educational and rehabilitation professionals have a vested interest in pathologizing difference and making sure a certain percentage of the population remains disabled, subordinated and in need of help. There is no way I can agree with this or, in an effort to see only their strengths, turn a blind eye to the intellectual, social, emotional, and motor challenges my students face. And as a human being, I will never subscribe to the notion that the children I have worked with over the years are “just like everyone else.” They have many fundamental similarities to typically developing children and the extent of their disabilities does not in any way diminish the essence of their humanity, but their social, emotional, academic and functional skill learning needs are very different. As individual educators, we can elect to reject the norms by which children are compared to one another and we can attempt to intellectualize their disabilities to the point at which they are no longer recognizable as differences. Or we can elect to look at each of our students as an individual with gifts and challenges and make our best effort at providing them with a relevant education and a dignified school experience. In my opinion, in order for schools to provide appropriate services, disability in any shape or form needs to be acknowledged in an honest, realistic and respectful manner.

While Oliver (1996) argued convincingly that disability is a social problem and society needs to change the way people with disabilities are viewed, I do not think society is going to change without education. In order to break down some of the

misunderstandings that perpetuate a division between people with disabilities and those who are “temporarily-abled,” (Davis, 1995) the public needs to develop a greater understanding of the many disabling barriers and “exploitive forces and relations” (Peters, 2005, p. 164) that exist within our schools and function to shape our society. It is going to be a long time before this is accomplished, but I believe the stories participants in this study shared about their children and their experiences with professionals in the schools their children attend can function as starting points for conversations about these issues among interested people. These conversations may take many forms and might be about individual children or the broader societal issues related to how we, as a society view and (mis)understand both practical and theoretical perspectives on disability. In spite of the misgivings noted above, I believe literature from the field of Disability Studies can inform these conversations immeasurably.

Where Do We Go from Here?

In the introduction to this research project I stated my theory for this dissertation is that a little bit of love can go a long way toward improving relationships between parents and professionals in special education. The kind of love I was talking about is the kind Todd (2003) described as “connectedness.” She wrote, “To be able to love means to be able to be free; love as an act of reaching out toward another disrupts the convention of oppression and domination through which “otherness” is constituted” (p.77). This kind of love, this reaching out toward and disrupting of oppressive and dominating relationships is what the participants in this study described as one of the most important components of successful relationships with professionals in the schools their children attend. It may be a subtle act, but it makes all the difference. Most of the time parents and school staff members know very little about each other on a personal level and little

attention is afforded to the challenge this poses for relationships. According to Todd, it is necessary for us to be attentive not only to the present, but also to the histories that shape our interactions with others and theirs with us; without this history, we are “...theoretically impoverished when it comes to considering the delicacy and complexity of human relationality across difference, and the difficulties that arise as a result” (p. 106). Educators need to be attentive to the histories of the parents of their students, but they also need to be mindful of their own. Based on the way participants described their relationships with the professionals in the schools their children attend, it seem as though this is a challenge for many people.

The word “impoverished” is one burdened by connotations, and I am not sure they are all applicable to the sentiment in Todd’s work as applied to the context of relationships between parents and professionals in special education in this research. Some of the interactions participants in this study described were certainly impoverished in the sense that they lacked sensitivity, compassion and consideration. Others, especially those Karen and Marie described, were not impoverished at all, but characterized by rich potential generated by warmth, understanding and a great deal of care. What accounts for the discrepancy between the two types of relationships is, I think, the main lesson (or if there is one), the deep truth (Opie, 1992) that can be extracted from this research study.

This truth is that schools are not benign places. Educators, even those with the best of intentions, are products of a system that maintains a long and regrettable history of sorting and segregating children with disabilities and failing to support their families. In spite of the progress that has been made, the laws that have been passed and the programs that have been implemented in special education, it is still not a place parents want to have to place their children. This has little to do with the individuals who happen to work in special education, but a great deal to do with the fact that the structures we

have in place in our schools to support families who have children with disabilities are inadequate as well as the fact that it can be extremely challenging to have a child with disabilities in a society that views disability in such a negative light. Hunter (2002) described it as, among other things, overwhelming, an “uphill battle in unfamiliar territory” (p. 77) and an “emotional rollercoaster” (p. 77). She wrote,

No amount of book learning had prepared me for the job of special needs parent...No amount of book knowledge could supply me with the patience, understanding and empathy needed to perform the role of special parent. No words could adequately describe the pain and anguish of the loss. Most parents are thrust into the special parenting role without any advance warning or training, and often get discouraged. We strive to be ordinary families in the midst of extraordinary challenges. We must provide care for our children every day – lifting and carrying, putting on braces, feeding, toileting, diapering, bathing, dressing, brushing teeth, repositioning, programming a communication device and providing programs, therapies and transportation – yet the child with [a disability] is often not the only child in the family who needs attention. There is guilt in nearly every decision we make, because it is impossible to always provide what is right for everyone (pp. 78-79).

Hunter also discussed the strength and insight gained from the experience, and how it introduced her and her family to “...a most powerful love, the depth of which we never knew existed” (p. 77). She also wrote about how difficult it is to explain that to certain professionals, and how some could understand and others could not, no matter how hard they claimed to try.

In his book about his son’s first few years of life with Down syndrome, Bérubé (1996) wrote about how he and his wife often think about the fact their son

...will always be “disabled,” that his adolescent and adult years will undoubtedly be more difficult emotionally – for him and for us – than his early childhood, that we will never *not* worry about his future, his quality of life, whether we’re doing enough for him (p. xi).

Bérubé touched on something many of the participants in this study expressed. It is, as he described their experience, the wondering if he and his wife could “bear not only the obligations but also the sense of never fulfilling them, not only the disappointments but

the probability that the future would always contain the possibility of further disappointment” (p. 141). He described the sadness he heard in her voice when his wife wished aloud that their son could always remain small. In the book he quoted what she said:

“But if he were always one year old, he’d never have his little heart broken. He’d never be turned down for a date. He’d never learn that other children might make fun of him. And he’d always have us to make him laugh” (p. 142).

All parents worry about the future for their children, feel their pain, and suffer some of the angst of growing up along with them to a certain degree. But parents who have children with disabilities have an additional worry to face. All of the participants in this study stated it very clearly. No one will ever care about their children as much as they do.

What does this mean for educators and for those who wish to facilitate improved relationships between parents and professionals in special education? Unfortunately, there is no recipe for success here, but participants in this study all described similar feelings about the school professionals with whom they have felt most comfortable and connected. They talked about these individuals being caring, compassionate, honest, competent and flexible, not at all unlike the way Rauner (2000) described the attentiveness, responsiveness and competence necessary for the practice of care. Participants also talked about being listened to and feeling accepted, respected, and understood in a manner that reminded me of Todd’s (2003) discussion of the humility that is required for teaching and learning across difference. She wrote about the difference between learning *about* another person (that would be anything we might read and form assumptions about from a student’s record) and learning *from* another person. Learning *from* another person involves “listening, attending, and being surprised” (p. 15). It does not involve wedging another person into the realm of one’s own experience in order to understand them, but instead allowing that person to affect you (p. 15). This,

according to Todd, is where “ethical possibility for nonviolent relation to the Other” (p.15) exists. It is also the key, I think, to improved relations between parents and professionals in special education. As she stated,

...learning *from* as opposed to *about* allows us an engagement with difference across space and time, it focuses on the here and now of communication while gesturing toward the future and acknowledging the past; it allows for attentiveness to singularity and specificity within the plurality that is our social life (p. 16).

As educators, it might be helpful if we could ask ourselves this yes/no question Todd posed:

Could we not (simply) get to know the other better, teach ourselves to be more empathic, learn to care for and about the other, and/or act more in accordance with principles of justice, respect, and freedom in order to make the violence of our lives disappear? (p. 7)

Along with our answer to this question, we might benefit from taking the time to think carefully about each interaction we have with parents. These could become our stories, and if we allow ourselves to learn from them, we might be able to channel them into future behaviors that could be perceived by parents as caring, thoughtful, and maybe even helpful.

Finally, why does this research matter? What is so important about the stories parents tell of their experiences with the professionals in the schools their children attend? Speaking only for myself, I would say the stories participants in this study shared are important because they brought me someplace I have never travelled. They made me think and they made me cry and they made me care about the characters depicted in them in a different sort of way. Hearing the stories during the interviews was moving, but listening to them and reading them over and over in the process of analysis was even more so; they sucked me in and it was impossible for me to look away. Marie Howe (2008) suggested that “this might be the most difficult task for us in postmodern life: to

not look away from what is actually happening” (p. 173), and I agree. It is difficult for many people to look directly at things that are painful, like autism and intractable epilepsy and cerebral palsy. The stories participants in this study shared were a reminder of how easy it is for me to look away from things I would rather not see. I might work all day in school buildings full of children, but I walk away at the end of the day. I go home to a calm house, a quiet husband and two peaceful, geriatric pets who require nothing more than a belly rub and a bowl of pellets most days. I am profoundly disconnected from the families whose children I work with in that respect, but within the stories they tell I can find alternative modes of thinking about what I do all day as well as why I do it. As educators, we talk about progress and goals at IEP meetings. It is unfortunate that leaves us with little time for the stories that could make that progress and those goals so much more meaningful.

Besides bringing us face to face with life for families who have children with disabilities, these stories (and others like them) offer a framework for understanding the histories many families bring with them into schools. They provide safe exposure to both positive and negative experiences, point out commonalities that exist between us, link us to the past, connect us to the present and provide us with wisdom by which we can shape the future. Stories like those told in this research may also provide us with an invitation to re-examine our understandings about disability and difference, and to think about how these understandings impact the relationships we enter into with those around us. Lerner (1997) wrote about the importance of keeping history alive through stories. She believes all human beings are practicing historians, and that keeping memories alive through stories is an obligation we all have to one another (p. 12). As she wrote,

All human beings are practicing historians. We live our lives; we tell our stories. The dead continue to live by way of the resurrection we give them in telling their stories. The past becomes part of our present and thereby part of our future. We

act individually and collectively in a process over time which builds the human enterprise and tries to give it meaning. Being human means thinking and feeling; it means reflecting on the past and visioning into the future. We experience; we give voice to that experience; others reflect on it and give it new form. That new form, in its turn, influences and shapes the way next generations experience their lives (p. 211).

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

Conclusion

The primary purpose of this study was twofold: to explore parental perceptions related to healthy working relationships between parents of children with disabilities and special education professionals, and to explore how the experience of parenting a child with disabilities impacts the relationship parents wish to form with those professionals. It was also an attempt to examine how parents, school systems and societal understandings of disability intersect in the realm of providing educational opportunities and care for children with disabilities, to obtain more comprehensive understanding of how raising a child with disabilities may impact parental relationships with special education professionals, and to explore and reflect on the multiple meanings healthy working relationships with special education professionals may have for families of children with disabilities through the stories they tell of their experiences. In addition, it was my hope that this collection of life story case studies (McReynolds and Koch, 1999) would not only help me answer my research questions, but that those answers might eventually be of benefit to the special education community as well as useful as teaching tools for pre-service professionals in the field.

Results revealed parental perceptions of healthy working relationships to be dependent on several contextual factors. These included professional competence in

communicating an understanding of the child and of family circumstances, expectations for the child and school programs among parents and professionals that closely parallel one another, a reasonable level of agreement between parents and professionals with regard to placement issues and parental perceptions of the quality and quantity of communication between school and home. All of the participants in the study acknowledged the fact that parents and professionals view children through different lenses, but all of them also indicated that through caring, thoughtful, considerate and compassionate behavior, professionals can reduce the tension that sometimes results from these dissimilar viewpoints.

Results also revealed that the experience of parenting a child with disabilities significantly impacts parental interest in relationships with professionals. Many of the participants in the study spoke highly of teachers and therapists who have worked with their children over the years, but they also acknowledged that this relationship can depend on the child's level of need and the parent's perceptions of the professional competence in meeting those needs. Karen, for example, expressed confidence in the abilities of the school staff to meet Phil's educational and care needs, while Leslee, Rachel and Ivy all expressed doubts that school staff members were intellectually prepared to meet the complex needs of their children. They also did not sense a significant level of investment in their children from certain staff members and were disheartened by the feeling that it was not likely they would do anything more than what was minimally required of them.

During the interviews for this study, some of the participants reflected on what it means, in the society we live in, to be disabled or to have a child with disabilities. They reported some feelings related to there being a distance between them and "normal" families, and tended to use that discrepancy as a segue into talk of how their school

system either supported or failed their efforts to obtain the services they perceived as appropriate and necessary for their child. Kathleen and Leslee spoke openly about how children with disabilities are marginalized in a capitalist society and discriminated against by a school culture that values independence, productivity and test scores. Other participants focused more on their own children and expressed concerns for how they fit (or have difficulty fitting) into their current school settings and how they might fit into a larger community when they become adults.

Given consideration to the issues noted above and others discussed in this study, results plainly suggest that the relationships between parents and professionals in special education are troubled by a variety of complicating factors associated with childhood disability and the resources, both human and material, available in our schools to meet the needs of this population of children. Participants in this study described how they learned to negotiate relationships with the staff in the schools their children attend, and as educators, it is important for us to reflect on their experiences as we continue to negotiate similar relationships with the parents of our students. Rather than focusing on all that is wrong or missing, it would make much more sense for us to attend to what is present and working as we attempt to improve on the current situation. As I noted previously, we have much to regret in the field of special education, but I also believe we have much to be proud of. We also have a great deal left to learn, and much of it can be learned from the stories of parents like the participants in this study. They are the experts.

Limitations of Study

Results of this research should be regarded only in relation to the boundaries of the study. This study is a narrative account of the stories told by eight mothers, and thoughts and opinions of participants may or may not be representative of the thoughts

and opinions of the general population of parents who have children with moderate to severe disabilities. As a narrative inquiry, this study was not designed to be generalized to other populations, but readers may see a transferability of some of the findings to situations with which they are familiar. This study was conducted in the vicinity of a large urban area where the infrastructure of special education is well developed, and therefore it is likely that the results and subsequent discussion and analysis may have turned out very differently had the study been conducted in a rural or less affluent area with fewer available resources. Participants included only women, one of whom was African-American and the rest of whom were white. Although they ranged in age from their late twenties to their early fifties, all of the participants in this study were college-educated and all appeared to have at least adequate operational support systems. Participants in this study also appeared to me to be within relatively close range in terms of socio-economic status; they owned homes, drove cars and were able to access medical and therapeutic services for their children without extensive hardship. Results may have been very different among a different population of respondents, especially if they were not native speakers of English, if they were lacking family or other social supports or if they were living in poverty.

Recommendations for Future Research

In order to enhance understanding and continue to work toward improvements in the relationships that exist between parents who have children with moderate to severe disabilities and professionals in special education, additional research is recommended to explore the qualities and intricacies of this relationship further. Several ideas are listed below.

Participants in this study all referred to numerous communication issues that emerged between them and educators in the schools their children attend. Further study of the quality of these interactions, factors precipitating dissent, and parent and educator perspective on possibilities for improving these interactions may have potential for improving practice among educators and perceptions related to the quality of service delivery among parents.

Many of the participants in the study acknowledged the challenge young and inexperienced teachers face in developing the skills necessary for partnering effectively with parents. Several of them suggested that teacher education programs might include some coursework, observations and research specifically about working with families. Although a course addressing partnership with families is a requirement in some programs, it is not yet a universal component of general or special education teacher training. Further research into the benefits of this requirement are needed, and further exploration of curriculum development and experimentation with options for practical experiences for pre-service teachers with families who have children with disabilities are also recommended.

Intertwined in the need for better teacher preparation is the need for additional resources for teachers who are already in the field related to improving understanding of how families experience childhood disability, the impact it has on siblings and other close family members and actions educators can take to alleviate (instead of exacerbate) stress. This is something that might be accomplished with a periodical or series devoted to qualitative research and to stories parents write or share through other media about their experiences.

Both new and experienced teachers could benefit from additional resources related to coping with and resolving conflict in special education. Research into

communication training for teachers, therapists and administrators in this area is warranted.

Based on opinions expressed by participants in this study, the inclusion of children with disabilities in general education classrooms is a frequent source of conflict between parents and educators. Although there are strong bodies of pro- and anti-inclusion literature, little attention has been paid to the grey area in between. Qualitative studies focused on the benefits of programs that combine inclusive and separate approaches to providing special education services could be of benefit to the special and general education communities.

This study contained narratives from parents with very young children as well as from parents who have older children who have been involved in the school system longer. A longitudinal study focused on the relationships between parents and educators might provide insight into the evolving nature of those relationships and determine how time impacts interactions and expectations among families who have children with moderate to severe disabilities.

Finally, inherent a commitment to teaching is a commitment to continued learning. There is a need for both pre-service and experienced teachers to explore resources outside of the field of education in order to more fully understand how educational and disability issues interact and manifest themselves in the policies and practices we maintain in our schools. Further investigation of the issues that arise for individuals with cognitive disabilities and their families in the context of a Disability Studies framework could also add new insight and perspective to the special education and Disability Studies literature.

APPENDICES

Appendix A: Letter to Colleagues to Locate Potential Participants

Dear Professional Colleague (name was filled in),

As many of you know, I am a doctoral student in education at DePaul University. For my dissertation, I am completing a research project designed to explore the experience of relationships between parents of children with disabilities and special education professionals. I would like to do this through the process of interviewing parents who have children currently between second and seventh grade with moderate to severe physical, intellectual or emotional disabilities. While I am sure this research will increase the depth of my understanding of the parent experience, I also hope to add to the current body of literature about relationships between parents and professionals and in that respect, improve the quality of special education services provided in public schools.

Involvement in the study will entail participation in one semi-structured interview. I am anticipating that the interview will take between 60 and 90 minutes. The interview can be conducted at a time and location convenient for participants. During the interview I will ask participants to describe themselves, their family and their experiences with the special education professionals in their child's school. I am interested in the experiences as described, and I hope participants will feel comfortable enough to be completely open and to describe experiences as they occurred. There is no right or wrong way to describe experiences and feelings, and whatever stories participants chose to share with me will be much appreciated. Participation in this research is voluntary. Every effort will be made to maintain confidentiality and anonymity. All participants will be free to withdraw from the research at any time.

I am looking specifically for families who meet the following criteria:

- Parents who have a child between second and seventh grade with moderate to severe physical, intellectual or emotional disabilities,
- Parents who maintain positive working relationships with the general and special education professionals in their child's school, and
- Parents who are willing to participate in an interview with me that is estimated to take between 60 and 90 minutes.

If you know of any families who might be willing to participate in my study, could you please ask them if it would be acceptable for me to call them and then provide me with their contact information? If the family would prefer to contact me directly, please give them a copy of this letter and let them know that I am looking forward to hearing from them.

Please feel free to contact me if you have any concerns, questions or would like additional information about this research project. I can be reached by phone at (xxx)xxx-xxxx or at the e-mail listed below.

Thank you,

Donna Smith

Appendix B: Flyer to Parents Seeking Potential Participants

Dear Parents,

I am a doctoral student in education at DePaul University. For my dissertation, I am completing a research project designed to explore the experience of relationships between parents of children with disabilities and special education professionals. I would like to do this through the process of interviewing parents who have children currently between second and seventh grade with moderate to severe physical, intellectual or emotional disabilities. It is my hope to eventually add to the body of literature about relationships between parents and professionals in the school setting as well as to improve the quality of special education services provided in public schools.

Involvement in the study will entail participation in one semi-structured interview. I am anticipating that the interview will take between 60 and 90 minutes. The interview can be conducted at a time and location convenient for you. During the interview I will ask some questions about you and ask you to describe your family and your experiences with the special education professionals in your child's school. I am interested in the experiences as described, and I hope you will feel comfortable enough to be completely open and to describe events as they occurred. There is no right or wrong way to describe experiences and feelings, and whatever stories you choose to share with me will be much appreciated. Participation in this research is voluntary. Every effort will be made to maintain complete confidentiality and anonymity. If you decide to participate in the study, you will be free to withdraw from the research at any time.

I am looking specifically for families who meet the following criteria:

- Parents who have a child between second and seventh grade with moderate to severe physical, intellectual or emotional disabilities,
- Parents who maintain positive working relationships with the general and special education professionals in their child's school, and
- Parents who are willing to participate in an interview with me that is estimated to take between 60 and 90 minutes.

If you fit the above criteria and might be willing to participate in my study, could you please contact me? In addition, if you know of other families who meet the criteria and might be interested in participation, please pass a flyer along to them and let them know I will be looking forward to hearing from them.

I can be reached by phone at (xxx)xxx-xxxx or at the e-mail listed below. Please feel free to contact me if you have any concerns, questions or would like additional information about this research project.

Thank you,

Donna Smith

Appendix C: Phone Script for Potential Participants

Researcher: “Hello. My name is Donna Smith. I am a doctoral student at DePaul University. I am currently in the process of conducting research for my dissertation. _____ gave me your name and suggested I contact you about the possibility of participating in my study. Do you have a few minutes to talk or would you like me to call at another time?”

If potential participant agrees to talk, I will continue: “In addition to being a doctoral student, I am also a school-based occupational therapist. My research is about the relationship between parents and professionals in special education. I am looking to find parents of children who are currently in the second to seventh grades and who have moderate to severe physical, intellectual or emotional disabilities. Does this sound like a project you might be interested in?”

If potential participant again agrees, I will continue with the following: “My study is focused on the parent perspective regarding the relationship between parents and professionals in special education. In this research project, I am interested in stories about your experiences in order to explore what has worked well for you and enabled you to build healthy and productive relationships with the professionals in your child’s school. I believe your stories have important implications for the field of special education and that we, as educators, have a great deal to learn from your perspective. Participation will require a face-to-face interview with me, and I am anticipating that it will take between one and three hours of your time. The interview will be conducted at a time and location that is convenient for you. After the initial interview is completed, I will be transcribing it word-for-word in order to analyze the content for themes. As my study evolves, I would like to be able to check back in with you briefly in person or on the phone (depending on what is most convenient for you) to make sure the themes I have drawn from your stories are reflective of your experiences as described. Eventually, if you are willing, I would also like to share a draft copy of the information you share with me in order to make sure my interpretations are accurate. How does this sound to you?”

If an affirmative response is received, I will continue: “Thank you! I am very much looking forward to meeting and talking with you. I also want to let you know that I would be happy to cover the cost if childcare is required for our meeting. Would you like to set a date and time to meet now?”

If potential participant agrees, a meeting date, time and location will be scheduled.

If potential participant does not agree, I will say: “That is fine. Would it be OK if I call you back next week to check in? Perhaps we can schedule a date then?”

If a negative response is received, I will continue with the following: “I understand completely. If you happen to know other individuals who might be interested, would you consider giving them my phone number?”

Depending on response, I will share contact information and continue: “Thank you for your time. Take care and have a good morning/afternoon/evening.”

Appendix D: Interview Guide

1. Please tell me about yourself (general history, education, profession, prior experience with issues associated with disability, etc.)
2. Please tell me about your family (single or two parent household, number of children, support systems, etc.)
3. Please tell me about your children...how many, how old, what are their personalities like?
4. Please tell me about your child who has a disability? Please share any details relevant to current educational status such as diagnosis, age at onset of disability, and developmental history.
5. How does your child's disability impact your family? Daily life and connections with friends, neighbors, others in the community? Please feel free to include both positive as well as negative impact (examples may be forming new friendships/networks, financial strain, less time with siblings).
6. Please tell me about your child's school experience. Did he or she start out in early intervention? How did you make decisions about inclusive vs. self-contained settings?
7. Describe your experience in your child's school, with teachers, related service providers, assistants and administrators.
8. Can you describe your child's disability in terms of areas of function where you feel he or she is most able and most compromised?
9. How does the school view your child?
10. How do you make sense of the differences or similarities between the two perspectives?
11. Can you share some thoughts about the value of special education for your child? Have there been any drawbacks?
12. Please tell me about one or two professionals in general or special education with whom you have had positive working relationships, and
13. What is/was it about those relationships that made them "successful" in your mind? What is it that they did that allowed you to trust them/engage in collaboration/feel like a partner?
14. Can you describe particular characteristics or ways of interacting with you that were helpful in constructing and maintaining those working relationships?
15. What is your perceived level of their competence in meeting your child's needs? How is it demonstrated?
16. How necessary are working relationships with the people in your child's school for you? What do you need from and what do you get out of them?
17. One of my goals for this study is to improve the work of professionals in special education. What advice would you have that might be of benefit to the special education community?
18. Could you reflect on what the meaning of positive working relationships between yourself and the staff at your child's school might be in the context of inclusive education?
19. To conclude, could you share with me your hopes for your child's future? Do you trust the school is facilitating progress toward that?
20. Is there anything we have not discussed that you would like to include?

Appendix E: IRB APPROVAL

Donna Smith

From: Motyka, Laura [LMOTYKA2@depaul.edu] **Sent:** Tue 5/15/2007 10:09 AM
To: dsmith@ntdese.k12.il.us
Cc: Monkman, Karen
Subject: IRB Approval of protocol DS040207EDU (Smith, Donna)
Attachments:

Good afternoon,

The requested materials for your project, titled "Hope & Perspective: A Qualitative Study of the Relationship Between Parents and Professionals in Special Education." have been received, and the project has been classified as exempt. Under DePaul's institutional policy governing human research, exempt projects receive an administrative review to confirm eligibility. Once projects are determined to be exempt, researchers on exempt projects are free to begin their work and are not required to submit additional materials or annual updates. As your project has been determined to be exempt, your primary obligation moving forward is to resubmit your materials for prior review and classification/approval if you propose substantive changes to the project. Additional information about DePaul's policy for exempt research is included at the end of this email.

If you have any questions or concerns, please feel free to contact me.

Many thanks for your time, & the best of luck on your research,

Laura Motyka

Research Protections Assistant

DePaul University

Academic Affairs

55 E. Jackson Blvd.

Chicago, IL, 60604

Phone: 312-362-7592

Fax: 312-362-7574

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Donna Smith

From: Motyka, Laura [LMOTYKA2@depaul.edu] **Sent:** Tue 6/19/2007 12:21 PM
To: Donna Smith
Cc: Monkman, Karen
Subject: IRB Review of revised protocol DS040207EDU
Attachments:

Good afternoon,

Please be informed that your recent revisions (change in age group) to exempt project # DS040207EDU, titled "Hope and Perspective: A Qualitative Study of the Relationship Between Parents and Professionals in Special Education" have been reviewed, and the IRB has determined that the project remains exempt. Accordingly, your primary obligation moving forward is to resubmit your materials for prior review and classification/approval if you should need to make substantive changes to the project at some point in the future. If you have questions at some point in the future about whether particular changes need to be submitted, please feel free to contact me.

This review was conducted in accordance with DePaul's newly revised institutional procedures for exempt review, approved by the IRB at its April 2006 meeting. Additional information about the changes is provided below.

Many thanks for your time & the best of luck on your research,

Laura Motyka
Research Protections Assistant
DePaul University
Academic Affairs
55 E. Jackson Blvd.
Chicago, IL, 60604
Phone: 312-362-7592
Fax: 312-362-7574

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Zigmond, N. (2003). Where should students with disabilities receive special education services? Is one place better than another? *The Journal of Special Education, 37*(3), 193-199.

DONNA SMITH

Curriculum Vitae

EDUCATION

Doctorate of Education, Curriculum Studies, Expected 2008

DePaul University, Chicago, Illinois

Master of Science, Occupational Therapy, August 1996

Rush University, Chicago, Illinois

Bachelor of Science, Education, May 1990

Indiana University, Bloomington, Indiana

PROFESSIONAL EXPERIENCE

DePaul University, Chicago, Illinois (Fall Quarter, 2004)

Adjunct Faculty, School of Education.

Niles Township Department of Special Education, Morton Grove, Illinois (6/01 to present)

Occupational Therapist. Responsibilities include evaluation and treatment of children with a variety of physical, cognitive, neurological, behavioral and developmental disabilities.

Mt. Sinai Hospital/Schwab Rehabilitation Hospital, Chicago, Illinois (3/98 to 6/01)

Occupational Therapist in pediatric rehabilitation. Responsibilities included evaluation and treatment of NICU and general pediatric inpatients, outpatients and Early Intervention Program patients as well as evaluations, screening and follow-up for NICU patients.

Mercy Hospital and Medical Center, Chicago, Illinois (11/96 to 3/98)

Occupational Therapist split between in-house pediatrics and school system practice through Mercy Professional Registry. In-house responsibilities included inpatient, NICU program, and Early Intervention. School system practice involved evaluation and treatment of children with severe/profound handicaps and physical and cognitive disabilities.

Neumann School, Chicago, Illinois (8/93 to 6/94)

Special Education Teacher for high school students.

STEP School, Inc., Chicago, Illinois (8/91 to 7/93)

Special Education Teacher for primary and middle school students.

ADDITIONAL PROFESSIONAL AND ACADEMIC ACTIVITIES

- Niles Township District for Special Education, Mentor, Mentor Program for New Teachers, 2004-present date.
- Niles Township District for Special Education, Institute Day Presentation for teacher assistants with Christine Sobieszczyk, Speech-Language Pathologist on *Communication and Sensory Issues in the Classroom*, March, 2008.
- Northwestern University School of Physical Therapy, Invited Speaker for class on pediatric therapy services in the public school setting, December, 2007.
- On-line Paper Presentation, International Visual Literacy Association Conference in Curitiba, Brazil. *Developing and Assessing Critical Thinking Using Visual Images: A Multidisciplinary Perspective*, co-authored with Julia Borst-Brazas and Marjorie Johnson Hilliard, October, 2007.
- Harold Washington College, consultation and revision of manual for Taxi Accessibility Program, July, 2007.
- DePaul University Graduate Conference Presentation, *Hope and Perspective: A Qualitative Study of the Relationship Between Parents and Professionals in Special Education*, October, 2006.