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The Fight Within: Experiences of School District Employees Who Advocate for the Rights of Their Own Children with Disabilities Inside the Districts Where They Work, a Heuristic Case Study

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The Fight Within: Experiences of School District Employees Who Advocate
for the Rights of Their Own Children with Disabilities
Inside the Districts Where They Work, a Heuristic Case Study

by

Keri C. Haley

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Special Education
College of Education
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Dedication

I wish to dedicate this dissertation to four young men, including my own, which made this entire study possible. You have all struggled to learn more than many, yet have paved the way for others still to come. Together with your mothers, your biggest advocates, I hope we can make a difference for all children with disabilities. I also wish to dedicate this study to the man who taught me that with persistence, dedication, and a positive attitude anything in life is attainable. My dad only saw me begin this long journey in the doctoral program, but he remained forever in my heart while watching from the heavens above as I stayed committed to my purpose, each and every step along the way. Finally, I want to dedicate this dissertation to my other two children who I hope learned to never give up on their dreams, even when our time lost can never be replaced.

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Achieving high goals does not come without hard work. Nor does it come without the right people who keep you working hard. This dissertation would not be possible if it were not for several people who motivated me by their value in hard work, inspired me to achieve more and accept nothing less, and provided me support and guidance when this moment seemed so far away. And to those individuals, I cannot thank you enough.

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I especially need to thank my mentor and major professor, Dr. Allsopp. Your commitment and passion has inspired me to pursue change in a field which many overlook and others just ignore. "And then there are the Pit Bulls of the group, who know it will take time and effort, but keep on fighting." Who would have thought your simple response to a question would have been my guiding light and will remain so for many years to come. Thank you *Papa Pit Bull*, there's much more to accomplish for children with disabilities, so let's keep on fighting and get it done.

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Abstract

Parents of children with disabilities face a daunting task when it comes to advocating for the rights of their children in school districts across the country. Yet, when these same parents also work inside those school districts, the challenge to balance their advocacy within the expectations of their employment may come with barriers. The intent of this study was to understand the experiences of people who are parents of children with disabilities, as well as educators, and have had to advocate for their own children inside the school districts where they work. Using a heuristic case study approach, this study incorporates the author's own experiences of advocating for her son, along with the experiences encountered by three parents of children with disabilities, who are also educators. Findings indicate parents who are also school district employees experience similar difficulties in advocating for their children with disabilities than parents who do not work for the school districts. Tensions rise between these school district employees and their child's school when the parent/educators feel their child's needs are not being met, communication breaks down between the two sides, and when educators on the inside do not understand the child's disability, the needs associated with that disability, and the accommodations which allow the child to be successful in an educational environment. These parents/educators also perceive repercussions regarding their employment within the school district should they need to advocate for the rights of their children.

Chapter One:

Introduction

In the words of legendary Green Bay Packer football coach Vince Lombardi, “The dictionary is the only place that success comes before work. Hard work is the price we must pay for success. I think you can accomplish anything if you’re willing to pay the price.” This statement serves not only as a purpose for me and my research; it signifies the 14-year journey to ensure the success of a young man named Kristopher. What initially started as a means to find answers, the *fight within* eventually became the battle to safeguard a free and appropriate public education for Kristopher and the assurances due to him under the Individuals with Disabilities Education Act (IDEA).

This research is about paying the price: the price one pays to hold true to a purpose and guarantee that no matter what it takes, how hard you work, and how hard you fight, success will be determined in making sure the children we represent are not left behind.

The story and meaning behind this topic began more than a decade ago. It was a day I will never forget, and obviously have not in the years since 1999 when I received the phone call. I was cleaning the house, the typical daily job for a stay-at-home mom. The phone rang. My son’s pre-school teacher was calling to tell me Kristopher did not, and had not talked to any of the students in class all year. It was January. She insisted it was something more than him just being shy, and that he was losing out on learning opportunities through his lack of communication. She asked if I had ever heard of Selective Mutism. And so it all began.

The revelation was a little shocking, but we had already noticed Kristopher no longer talked to anyone outside our immediate family. He used to speak to his grandparents, aunts, uncles, and other extended family members; used to. We had no idea why. We just knew it happened, and we knew we had to start looking for answers.

Kristopher was born less than two years behind our eldest, Kody, who was outgoing and talkative. Kody and Kristopher were always the pair. Kristopher looked up to his big brother, and big brother always did the talking when his little brother seemed at a loss for words. Problem was the loss for words seemed unusual. Kody's progression through early language development followed what we thought were typical patterns: single words, then three word phrases, followed by simple sentences before the age of three. Kristopher's progression went from single words to three word phrases, and stopped. At the age of three, Kristopher was in pre-school and not developing language skills at the same pace as his peers. He always appeared to struggle to find the right words, even though he was only speaking within the confines of our family nucleus.

Unbeknownst to me at the time, the campaign to help our son would inevitably turn into this dissertation and the quest to help children with disabilities. But the journey has been long for Kristopher and me. What initiated as a parent as an advocate, has evolved into a parent as a teacher, and parent as a researcher. These roles, also lived and explained by researcher Beth Harry (1996), develop what Harry calls the persona of the researcher. These personas contribute to research by allowing the researcher to become increasingly aware of the differing levels of their identity in relation to their research participants. I have always chosen to identify myself as a *parent* first, because that is what I am before any of my other roles associated with children and disabilities.

Perhaps if what followed in the years since the first indication of academic trouble for Kristopher had been easy, the fight to free children from the bind of marginalization may never have occurred. There would be no advocacy on my part, no return to school at the age of 36, and no leaving behind a career in television broadcasting. There would be no today, as it is at this very moment. So perhaps, as my parents taught me, everything happens for a reason. However, there has been many times where I longed for a reason. Why was such a cute little boy saddled with Selective Mutism, a Language Impairment, a significant processing delay, a learning disability, and Social Anxiety Disorder? Why did learning have to be such a challenge for him, no matter how hard he tried? And why did gaining access to appropriate assistance in school always seem so difficult?

The proper identification of Kristopher's language delays was a process delayed in and of itself. Finding the right doctor or therapist was not an easy task, nor was transferring his need for language therapy into the school setting. By the time he entered first grade in a public school setting, he began to fall behind, quickly. His teachers knew he needed more help than they could give, yet no one seemed to have the answer.

Finally, help arrived in the form of an Individualized Education Plan (IEP), or so I thought. The ability to retain speech language pathologists on staff at the school seemed problematic; Kristopher's services got lost in the shuffle, and so did his IEP. I had no idea this was a disservice. I was new to the concept of special education. I did not even have my own copy of the IEP, and neither did the school. With the help of a neighbor who was a school district employee, an investigation into the missing IEP began; and so did my investigation of what I needed to know as a parent of a child with a disability.

In the years which followed, my level of knowledge increased with my own learning and with each and every experience Kristopher and I encountered in the school system. Even though he was receiving special education services for a Language Impairment, he continued to struggle academically. There were concerns about not meeting district benchmarks and earning proficiency on the statewide assessment; there were concerns about possible retention year after year. There were concerns of losing his services for his Language Impairment when he crossed into middle school because he had no other area of eligibility. The district did, and still does, typically eliminate such services for students at that point. Kristopher did not qualify for a Specific Learning Disability (SLD) under the discrepancy model used at that time, as the difference between his aptitude and achievement was 14 points, not the necessary 15 as required. He eventually qualified, years later, when that separation expanded to 22 points.

But even then, his new area of eligibility under IDEA did not guarantee what we thought it should. He was placed in remedial classes in middle school, where he began to question his own existence and I began to question mine. It was here when Kristopher proclaimed, “Mom, I feel like they put me in these classes because I’m retarded.” This single statement alone propelled what became my *fight within*. I had to find a way to fight for my son. I had to keep learning more, finding more, and giving him more. Yet with each step along the way, we still encountered barriers: continued class placement based on standardized assessments despite honor roll performance, a lack of special education services as mandated in his IEP, and teachers not providing classroom accommodations which had proven successful for Kristopher.

Circumstances like these created conflict for me as I had to balance my second career, an educator within the same school district, while also finding the means to advocate for an appropriate education for my son. The continued struggles led me toward my third role as a

researcher for children with disabilities and my desire to advocate for their learning needs. I began to pursue doctoral studies because I promised Kristopher I would fight for the rights of all children like him and that our story would hold greater purpose beyond our own experiences.

Background of the Problem

The rights of children with disabilities are the key focus of federal laws giving all children the right to a free and appropriate education (FAPE). Parents and educators alike are part of the process which provides children with disabilities access to an education meeting their disability related needs. However, obtaining these rights for many families has required an immense amount of action on the part of parents, educators, lawyers, and policymakers. Rights which may seem like a given under the Individuals with Disabilities Education Act, are not easily secured. Parents have had to hire advocates and attorneys (Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania, 1972; Honig v. Doe, 1988) in order to guarantee their children receive an education within the least restrictive environment (LRE), as well as FAPE.

At times these advocates are the parents themselves, the teachers, and the researchers evaluating the means to improve access to education for all children with disabilities. People functioning in advocacy roles such as these are a valuable asset in the quest to provide the best education possible for children who have a history of marginalization. In this study, I examine when these roles meet within a school system; when the roles are tied to a single person who advocates not from the outside as historically done, but from the inside, where voices may remain quiet in order to protect their role as an employee. I am a parent of a child with a disability, a teacher for students with disabilities, and a researcher focused on children with disabilities. Each of these roles serves an individual purpose, which may provide an advantage

for one of the other roles, or provide a level of tension when one of those roles is in conflict with the other.

In the role of a parent of a child with a disability, I have taken an active role in advocating for my son's educational needs from the moment he first went to school. My personal pursuit of higher education is the result of his academic difficulties, both inside the classroom and under the umbrella of education as a whole. In the role as a teacher of students with disabilities, I attempt to provide my students with the best learning opportunity possible, because after all, I understand more about their struggles than they realize. I have also sat on the parent side of the table at IEP meetings, hoping the teachers are pouring their heart and souls out for my son. Being capable of *wearing their shoes*, I am able to relate to other parents and know they expect the same from me for their children. My third role in the field of special education is that of a researcher completing my Ph.D. I was propelled into higher education by my son's story and a desire to advance the field by bridging the gap between research and practice. Much of what I see and experience on the job as a teacher is not supported in the literature or even violates the laws designed to protect special education students: situations such as small group resource classrooms serving more students than a regular education classroom, teachers not providing federally mandated accommodations, and so-called inclusive classrooms which are overloaded with students receiving special education services and only a few students not receiving these services, but many who are experiencing these academic difficulties nonetheless.

Each of these roles serves a unique purpose, affording me knowledge of federal laws and district protocols, as well as a stronger understanding of what it is like to sit on the other side of the table in IEP meetings. Along with the privileges of being an *insider*, living these multiple roles also places me in conflicting positions of advocating for my child with the fear of potential

employment repercussions. I know what should be happening versus what is happening. Armed with this knowledge, there has been numerous times where I knew I needed to speak up on my son's behalf. However, I found myself remaining quiet; worried about the potential professional effects should I make my voice heard.

In the course of my career, I have encountered other parent/educators who have experienced similar scenarios. They have shared with me their paths into special education, which also came as the result of having a child with a disability. They have even disclosed how they have advocated for their child more than they felt should have been required and at the expense of worrying about their jobs.

Many scholars have accessed their personal roles as parents to perform research (Adler & Adler, 1996), while several others, such as Erik Erickson, Jean Piaget, and Charles H. Cooley, have studied their own children. This encompasses a dual research perspective, as a parent and researcher. In my case, my research perspective is three-fold, as a parent, teacher, and researcher. Harry (1996) discusses the multiple roles in which all researchers live when performing qualitative research, such as will be carried out in this study where personal identities become part of their research. Harry identifies the separation between the knower and the known in positivist research as artificial, insisting the two are instead mutually connected in the research process by reality and knowledge. The challenge, she argues, is “not to eliminate, but to document the effects of the personas that influence our behavior as researchers” (Harry, 1996, p. 295).

Living in the role of the parent as a researcher (PAR) comes with advantages as well as implications. In considering the former, a parent acting as a researcher is privileged with a better understanding and a deeper meaning of the world being researched (Adler & Adler, 1996).

PARs are also afforded the unique opportunity of having *insider* knowledge of the settings and behaviors in which they wish to study. This tacit knowledge affects the basic research decisions, such as location, timing of data collection (Harry, 1996), and types of interviews and questions, allowing the researcher to better negotiate the entire research process. In this role the PAR becomes the natural inquirer in the research process, using their knowledge and information to better highlight the children who are the target of their inquiry. The inquiry experiences suggest the experiences accumulated by these PARs can further extend the knowledge/research base. For example Carpenter (1997) suggests that PARs were instrumental in the development of family-focused models of service delivery for students with disabilities.

Serving as a PAR has allowed me complete immersion in the struggles of my child. I know what my son and I have experienced in our several yearlong process of obtaining his right to a free and appropriate education; therefore I have a keen sense of the types of questions to ask my participants, what kind of information might be most relevant for my topic of inquiry, and how to structure the interviews so my participants and I are able to engage in the type of dialogue which has potential for deeper levels of discourse and insight. Using my insider knowledge gives me the ability to connect with the questions which influence this research topic, while at the same time providing the participant a different perspective of me, considering me as *one of them*.

The role of teacher as a researcher is also important to advancing educational reform. In the era of high-stakes accountability, teachers, schools, and districts are held accountable for the programs they implement. They are encouraged to collaborate in the change process of promoting policy and improving the profession (Johnson, 1993). This study allows me to bring about inquiry from the perspective of a parent, teacher, and as a researcher in order to initiate

change by bridging the research-to-practice divide. It also grants me the opportunity to address a call made over the last few decades for more research engineered within the walls of the educational system (Cochran-Smith & Lytle, 1999). Nixon (1987) adds that teacher research plays an important role in a climate of opinion and *taken for granted* assumptions, adding that there is an ever present need for teachers to define their role in the research process as both participatory and critical. Research by teachers also adds voice to the knowledge base from participants whose perspectives have not been heard (Creswell, 2002).

In this study, the voice is my own, as well as other parent/educators such as myself. The research base on parents who are teachers is limited, despite an unknown number of people serving in these dual roles. Likewise, research on people like me, who are parents, teachers, and researchers, is even more finite. The tensions experienced by those navigating these multiple positions have not been exposed, depriving outsiders an opportunity to see and feel their untold stories.

The space I now occupy as a parent, teacher, and researcher is rooted in being the parent of a child with a disability. I believe this reality will help me develop the necessary level of trust between researcher and parent for this study. The road to acquiring the necessary services for my son has never been an easy one. Hence, I have regularly taken on the parent as an advocate role inside the district where I work; the same school district where I sit across the table and tell other parents what services I think are best for their children. Yet this parental advocacy role, I believe, provides me with a stronger sense of sensitivity in decision making and an understanding of the need to create a trusting bond between the family and the educational system. Trusting partnerships have been identified as crucial components to effective educational services for children with disabilities (Colarusso & O'Rourke, 2007; Freiberg, 2006).

Research with families of children with disabilities indicates those partnerships can be established through better communication (Hess et al., 2006). However, the system of special education, with all its terminology, rules, and settings, still holds the power and continues to resist partnerships with parents (Eccles & Harrold, 1993; Henderson & Berla, 1994). Indeed, parents have indicated their relationships with schools may even be viewed as adversarial (Salisbury & Dunst, 1997). Such adverse relationships force some parents to take on the role of advocate in order to protect and provide for the educational needs of their children (Hess et al., 2006). This is a role I have personally taken for Kristopher. It is a role I suspect is also shared by my research participants.

However, living in each of these roles carries with it a certain level of tension. Parents of children with disabilities always want the best possible access to education, which may be at odds with individual school system protocols. Teachers want to provide the best education for their students. Yet, there is an interrelationship between the personal and professional identities which affects the experiences of teachers (Day, Kington, Stobart, & Sammons, 2006), especially when the personal identity involves the continued academic struggle of a teacher's own child. Harry (1996) indicates these competing roles and values are born out of multiple group memberships and paint a complex picture of individual personas. It is my intention in this study to detail the complex picture of my parent-as-educator participants, as well as myself, and understand how those roles influence their experiences with their children in the special education process.

Theoretical Framework

This study is supported by a theoretical framework which integrates the parental development theory, the theory of responsible advocacy, the social cognitive theory of parent

efficacy, and the capital theories in diverse approaches to parental advocacy. These theories provide the foundation for understanding parental advocacy, the tensions involved in adhering to multiple and simultaneous roles as a parent of a child with a disability and an educator, the behaviors and decision making processes which guide parental influence in education, and the social and capital resources which provide these parents the know-how and language to navigate inside the boundaries of the American educational system with respect to the needs of their child with a disability.

Parental development theory. The impact of a disability reaches beyond the child and into every aspect of all those who come into contact with the child's needs, particularly the parents. In order to understand how and why parents respond in particular ways to the developmental and educational requirements of their child, one can look to the parental development theory. The theory, conceptualized by Galinsky (1981) and reframed by Demick (1999, 2002), attempts to explain how children influence the adult decision making process by providing the constructs which support how parents formulate responses and actions to their child's needs. It proposes that parenthood evolves through a sequence of six stages: image-making, nurturing, authority, interpretive, interdependent, and departure. These stages are the result of cognitive and psychosocial development following life events involving their children (Demick, 2002). These life events, such as learning one's child is in need of special education services, force a parent into a state of stress and disequilibrium. The parent must then gain acceptance of their child's disability as they progress through stages of denial, grief, anger, uncertainty, and anguish (Hunt & Marshall, 1999; Public Agenda, 2002).

While grappling with acceptance, parents must then make sense out of their experiences and develop responses, leading to either positive or negative outcomes (Roskam, Zech, Nils &

Nader-Grosbois, 2008). Demick (1999, 2002) refers to this as the person-in-environment system. In negative outcomes, the parental cognitions become inflexible and parenting becomes maladjusted. In positive outcomes, parenthood itself transforms as a parent adjusts their behavior and engages in more flexible cognitive thought processes so they may address the special needs of their child (Galinsky, 1981).

The parental development theory is represented in this study by parents' responses to their child's special education needs. The cognitive and psychosocial adjustments these parents make results in the actions they take toward advocating for appropriate services to address those needs. If and when these needs are met, the parents re-assess and determine their next course of action, whether it be continued advocacy or a state of content.

Theory of responsible advocacy. The theory of responsible advocacy was developed in the field of communication by scholars Kathy Fitzpatrick and Candice Gauthier. The theory is a means to combine the ethical identities of a public relations professional serving as an advocate, with their social conscience; two roles which have been at odds (Cox, 2006). The theory provides "a universally acceptable philosophy on which standards of ethical public relations practice might be based" (Fitzpatrick & Gauthier, 2001). In accordance with this study, the parent serves in the public relations role advocating for their child. Yet the parent also serves the role of an educator, held accountable to their social conscience of adhering to the practices of their employer, the school district.

The theory of responsible advocacy consists of three principles which provide moral guideposts for professionals to adhere to when the advocacy and social conscience roles are at odds: (1) the public relations practitioner must contemplate the advantages and disadvantages of possible action; (2) respect for all persons must be guaranteed; and (3) the public relations

professional must balance all the benefits and misfortunes (Cox, 2006). Fitzpatrick and Gauthier (2001) attest the theory outlines how the public relations professional can serve as an advocate for the child, while simultaneously serving the interests of their jobs within the school district.

The greatest advantage of the theory is its emphasis on advocacy and social responsibility (Sims, 2010; Cox, 2006). This balancing act is supported by ethical principles. Without employing a level of ethics, the public relations practitioner would not be able to serve the interests of their client or society at large. However, this concept can become a disadvantage to the theory, as ethics are individually based and vary from person to person. Thus, an exact balance of advocacy and social conscience cannot be insured.

My research questions intend to understand how my participants perceive their advocacy experience in relation to their positions within the school district; how they balance responsible advocacy for the benefit of their children.

Social cognitive theory of parental efficacy. In order to advocate for one's child in the first place, a parent must possess the belief they can exert a certain level of influence over their child's educational outcomes. This type of parent efficacy has its origins in social cognitive theory, established by Bandura in the late 1970s, and used for research in the social sciences. Bandura (1997) defines perceived self-efficacy as "beliefs one holds in one's capabilities to organize and execute the courses of actions required to produce given attainments" (p. 3). Efficacy beliefs, Bandura (1997) argues, are the underlying forces of parental practices and family development, and are cultivated after the birth of the family's first child (de Montigny, 2002). The level of efficacy is said to promote change of individual courses of action and has been found to predict parental behaviors. This type of parental efficacy is also referred to as

‘parental confidence’ in the field of psychology (Broome, 1993) and transcends teachers as well in relation to student achievement.

Parental efficacy provides a framework in this study in discerning the supports which allow a parent to advocate on behalf of their child with the belief they can make those changes occur. Despite the secondary role the participants serve, that of an educator, these parents advocate from within the larger system.

Social and cultural capital theory. Exerting one’s influence in order to advocate for children with disabilities is also supported by the cultural and social capital theories of sociologist Pierre Bourdieu. Bourdieu identifies cultural capital as one’s familiarity with the dominant culture and knowledge of ‘educated’ language (Sullivan, 2001). The concepts of class-based structures and inequity in the cultural capital theory are bound by three types of capital resources (e.g., economic, cultural, and social) which provide the groundwork for a person’s ability to gain status and power in society. This theory applies to the advocacy of parents who attempt to promote educational success for their children. In order to facilitate advocacy efforts, parents must also access their social capital, which are resources found in social networks and relationships with people. Social capital, as defined by Bourdieu (1986, p. 248), is “the aggregate of actual or potential resources linked to possession of a durable network...” that can be utilized by group members for pursuing action without accessing one’s own economic capital (Carpiano, 2007). The amount of social capital one can generate depends on (1) the size of network connections the individual can assemble and (2) the amount and type of capital of those one associates with. The advantages of being a member of this network are the foundations of solidarity which can generate and maintain one’s place in social class (Carpiano, 2006). Social capital can also be used in conjunction with elements of cultural capital

such as material items, dispositions, and knowledge, which then promote the way a person thinks and acts (Bourdieu, 1986).

The concepts of cultural and social capital are particularly useful in understanding the concepts of parental advocacy. Using Bourdieu's cultural and social capital theories, Trainor (2010) identified diverse approaches to parental advocacy and the rules by which parents apply themselves in the special education process. The findings indicate parents access various social and capital resources to exert influence in advocating for their children's needs in special education relations. These parents are identified as Intuitive Advocates, Disability Experts, Strategists, or Change Agents. Each of these categories reveals important aspects of parental advocacy, access to knowledge via cultural capital and associations among people through social networks, and will be discussed in further detail within the literature review of this study.

Purpose of the Study

Lake and Billingsley (2000) stated little is known about the experiences and perspectives of parents involved in special education conflicts. More so, nothing is known about the experiences of school district employees who advocate for their children with disabilities inside the districts where they work. The literature is void in this area. I, myself, have struggled with the conflict of my roles as a parent and educator, not to mention, the added role of researcher. I always wondered how hard I should push in seeking the services I felt were appropriate for Kristopher's needs. I always wondered if the degree of my advocacy would impact current and/or future positions within the school district. With the opportunity to publish our experiences at my fingertips throughout my five year journey in the doctoral program, I chose to remain quiet on this topic. After all, someone previously indicated the time to tell just was not right. Now as Kristopher exits the public school setting upon high school graduation, it is time

to tell our story. It is time to tell the stories of those who share similar roles. It is time to investigate the meaning of our experiences inside the school districts where we work. It is time to let the *insider* voices be heard.

Research Questions

In order to let these insider voices be understood, the following research questions guided this study:

- 1) What are the experiences of school district employees who challenge their own districts in the interest of their children with disabilities?
- 2) What barriers do these parents/district employees feel they encounter in advocating within their own districts?
- 3) How do these parents and district employees perceive their involvement in advocating for their own children in relation to their job security?

Definition of Key Terms

Advocacy - Speaking or acting on behalf of one's own or another's perspective by presenting, supporting, or defending a position to achieve a result not otherwise available (Turnbull & Turnbull, 1997, p. 294 & 297; Alper, Schloss, & Schloss, 1995, p. 265).

Asperger's Disorder – A disorder characterized by severe and sustained difficulties in social interactions and the development of restricted, repetitive patterns of behavior, interests, and activities (APA, 2000).

Autism Spectrum Disorders (ASD) – developmental disorders affecting verbal and non-verbal language and share common social, communicative, and stereotypical behaviors involving resistance to change in routines and unusual responses to sensory experiences which are evident

before the age of three and adversely impacts a child's educational performance (IDEA Sec. 300.8).

Child with disability – A child evaluated in accordance with the Individuals with Disabilities Education Act as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance) an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services (IDEA Sec. 300.8).

Developmental Delay – for children aged three through nine (or any subset of that age range, including ages three through five), may include a child (1) Who is experiencing developmental delays as defined by the State and as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: Physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (2) Who, by reason thereof, needs special education and related services (IDEA Sec. 300.8).

Heuristics – method of qualitative inquiry which allows the researcher to discover the meaning behind the personal experience (Moustakas, 1990).

Individualized Education Program (IEP) – A written statement, by a team (parent/guardian, one regular education teacher, one special education teacher, and one representative of the school district), for each child with a disability that is developed, reviewed, and revised in a meeting in accordance with the Individuals with Disabilities Education Act (IDEA).

Language Impairment – A communication disorder in which a person has difficulty sharing thoughts, ideas, and feelings completely, including disorders of form, content, and use affecting educational performance (McLeskey, Rosengerg, & Westling, 2013).

Special Education – Specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability (IDEA Sec. 300.39).

Specific Learning Disability – a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia (IDEA Sec. 300.8).

Speech Impairment – Communication disorders associated with articulating speech sounds correctly or fluently which affect educational performance (McLeskey, Rosengerg, & Westling, 2013).

Chapter Two:

Review of the Literature

The most recent data released by the U.S. Department of Education Office of Special Education Programs (2011) indicates American public schools served more than 81 million students, ages 3 to 21, in the year 2011. Of those students, more than six million were students with disabilities eligible for special education services under IDEA Part B. Even though this number is small in comparison to the overall population served, school systems throughout the nation have found it difficult to provide students with disabilities a meaningful educational experience and one which leads to positive post-school outcomes.

Disabilities can impact many areas of a child's intellectual, sensory, social, or physical development. These deficits impinge upon a student's daily living, social inclusion, personal and educational development (Farrell, Elliott, & Ison, 2004). When compared to peers without disabilities, students with disabilities experience a considerable achievement gap in all academic areas (Aron & Loprest, 2012). Scores on the National Assessment of Educational Progress (NAEP) tests indicate 64% of students with disabilities scored below proficiency on the 12th grade reading assessment, compared to 24% of students without disabilities (National Center for Education Statistics, 2010). In math, 76% of students with disabilities scored below proficiency, compared to only 34% of their peers.

Post-school outcomes indicate a gap as well between those with and without disabilities. According to data in the second National Longitudinal Study (NLTS-II, 2004) students served in

special education experience higher dropout rates, higher rates of unemployment, and lower rates of employment. They attend college at a rate half that of their peers without disabilities, about 3 in 10 (NLTS-II, 2004), while only 12% graduate from college (Dowrick, Anderson, Heyer, & Acoster, 2005; Garrison-Wade, 2012). About 75% of them continue to live at home up to two years beyond graduation from high school (NLTS-II).

Improvements have been made for students with disabilities since the era preceding federal legislation mandating a free and appropriate education for all students, whether they have disabilities or not. Prior to the enactment of the Education for All Handicapped Children Act (1975), more than one million children with disabilities were prevented from accessing public education, while those who were able to attend school were either provided ineffective instruction or were segregated from the rest of the school's population (Garrison-Wade, 2012). However, there are continued calls to do more to improve the educational process for students with disabilities (Hess et al., 2006; Roberts & Siegle, 2012). Those voices include parents and advocacy groups, who push the system to close the gaps, both in school and beyond.

This literature review includes an explanation on the beginnings of parental advocacy in special education and its influence in legislative action; teachers and their role in advocating for appropriate services and supports for their students; and parent-school relationships and barriers which prevent successful collaboration among parents and education professionals.

Additionally, literature will be discussed which addresses parents' perspectives in raising children with disabilities including their perceptions and expectations of special education.

Finally, in order to understand the many personas I bring to this study as a parent, teacher, and researcher, I will also address the literature regarding people like me, who conduct research from multiple perspectives in special education.

Parental Advocacy in Special Education

Parents and advocates have played an influential role in altering local, state, and national policies since the Civil Rights Movement (Erwin & Soodak, 2008; Hallahan & Mock, 2003) and the 1954 decision in the landmark case, *Brown v. Board of Education*. Arguing under the equal protection of a “class” of people resulting from the *Brown* ruling, advocates for students with disabilities sought equal protection and treatment under the law as well (Turnbull, 1993). These parents and advocates claimed *not all* students with disabilities received an education, while *all* students without disabilities were provided with such opportunities (Yell, Rogers, & Rogers, 1998).

Prior to the 20th century (*Watson v. City of Cambridge*, 1893), case law allowed for the expulsion from school of a child who was “weak in mind and could not benefit from instruction, was troublesome to other children, and was unable to take ordinary, decent, physical care of himself” (Yell, Rogers, & Rogers, 1998). Such legal mandates barring the right to education persisted into the 1960’s when lawmakers in North Carolina made it against the law for parents of children with disabilities to insist their children attend school (Weber, 1992).

These injustices, accompanied by the Civil Rights Movement, propelled parental advocacy groups to seek out equal protection of students with disabilities as a “class” of people (Yell, Rogers, & Rogers, 1998). Their efforts began to take hold in 1972, when the courts ruled against state policies excluding children with disabilities in *Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania* as well as in *Mills v. Board of Education of the District of Columbia*. These two landmark cases set the stage for the first major legislation to protect persons with disabilities, Section 504 of the Rehabilitation Act, passed by Congress in 1973. Just two years later, one of the guiding principles in educating students with

disabilities was born with the passage of P.L. 94-142, the Education for All Handicapped Children Act of 1975 (EAHCA) and its provision for a free appropriate public education (FAPE) for all students with disabilities.

It was at this time when Congress and the nation began to take note in the plight of children with disabilities:

We must recognize our responsibility to provide education for all children [with disabilities] which meets their unique needs. The denial of the right to education and to equal opportunity within this nation for handicapped children—whether it be outright exclusion from school, the failure to provide an education which meets the needs of a single handicapped child, or the refusal to recognize the handicapped child’s right to grow—is a travesty of justice and a denial of equal protection under the law. (Senator Harrison Williams, principle author of the Education for All Handicapped Children Act, *Congressional Record*, 1974, p. 15272)

In 1990, EAHCA was renamed the Individuals with Disabilities Education Act (IDEA). It was later re-authorized in 1997 to include changes to person first language, and again in 2004 to expand the role of parents in the special education decision making process. Zigmond, Kloo, and Volonino (2009) proclaimed the “multiple re-authorizations of the law have refined, revised, and renewed the nation’s moral pedagogical commitment to providing well-planned, public, inclusive, and appropriate education to all students with disabilities” (p. 190).

The changes in the federal language within IDEA 2004 re-authorization essentially gave parents/guardians the right to serve as equal partners with school personnel in all aspects of their child’s education (Erwin & Soodak, 2008). IDEA outlined areas for increased parental involvement in evaluation, eligibility, and the development of IEPs, discipline, procedural

safeguards, mediation (CEC, 1998; Lake & Billingsley, 2000) and placement in the least restrictive environment.

Prior to the mandate for increased parental participation in IDEA 2004, Public Agenda (2002) found more than a third of parents of children with disabilities who responded to a survey reported problems getting services for their child, even after a disability had been identified. While a majority of parents of children with disabilities in the survey reported positive relationships with their local schools, a substantial number had serious complaints. One in six parents of children in special education reported in the survey that they had considered a lawsuit. For parents who are limited by economic resources, advocacy may become an option when they realize they and their children have rights outlined in current laws and legislation (Alper, Schloss, & Schloss, 1995; Heiman & Berger, 2008; Duquette, Fullarton, Orders, & Robertson-Grewal, 2011). Parents in a study conducted by Duquette, Fullarton, Orders, and Robertson-Grewal (2011) indicated they had considered bringing education attorneys or advocates to IEP meetings, but chose to advocate on their own instead. Parents pointed out they did not feel the threat of legal action would be effective in pushing the professionals who would ultimately provide their child with special education services.

Types of parental advocacy. Trainor (2010) evaluated the home-school partnerships in special education and analyzed the types of advocacy used by parents through their access of cultural and social capital. By studying groups of diverse families from various cultural and socioeconomic backgrounds, Trainor identified four different types of parental advocacy in special education (see Table 1), the Intuitive Advocate, the Disability Expert, the Strategist, and the Change Agent, who all access a variety of knowledge and social connections to advocate for the needs and rights of their children with disabilities.

First, the *Intuitive Advocate*, is characterized as one who capitalizes on the perceptive insights and tacit knowledge they have acquired in understanding the needs and strengths of their child in order to develop a course of action. Trainor (2010) describes such parents as those who rely on “knowing their child.” Despite what comes across as an advantage in understanding more about the child, Intuitive advocacy was not found in the study to be a powerful approach to securing the necessary needs of children with disabilities.

The *Disability Expert* uses knowledge in regards to learning the ins and outs of their child’s disabilities, as they essentially become experts. The group more likely to use this approach to advocacy in Trainor’s (2010) study was parents of children with autism. Disability Experts read online and printed materials, accessed doctors in the field, and joined disability organizations such as Autism Speaks and the Learning Disability Association of America. Parents in this group expressed more stories of successful advocacy than those using Intuitive Advocacy. However, knowing the disability inside and out was not found to be a consistent advantage for these parents. Regardless of their knowledge of the disability, these parents complained school personnel continued to view their children through a deficit lens and that discussions during IEP meetings centered on the child’s challenges rather than focusing on the child’s needs.

Parents who acquired a high degree of knowledge regarding IDEA and their rights to advocate were described as the *Strategist*. Such parents understand the special education process, its paperwork, and what should be happening at school, as well as the services and supports specifically outlined within the IEP. Strategists are viewed by schools as active parents and perceive they are not well liked because they hold teachers accountable for the students’ IEPs. These parents also described a connection between the commitments they experienced in

meeting the needs of their child and wanting to advocate for large scale change in the educational system.

Table 1

Types of Parental Advocacy in Special Education (Trainor, 2010)

Type	Description
Intuitive Agent	Uses perceptive insights of the needs and strengths of their child in order to develop a course of action in advocacy
Disability Expert	Becomes an expert in understanding the ins and outs of their child's disability in order to advocate for appropriate services
Strategist	Develops high degree of knowledge regarding IDEA and the rights afforded to advocate
Change Agent	Understands special education and the function of educational systems; willing to take on role of political advocacy to improve education for those with disabilities

The final role of advocacy identified by Trainor (2010) is that of the *Change Agent*. Despite their frustration with their own experience, these parents will advocate for system's change because they have knowledge of both special education and the functions which operate the educational system. They are also willing to take on a role of global advocacy and political action to improve the educational experience for other children with disabilities, not just their own. Parents in a study by Hess et al. (2006) felt empowered by using their knowledge and past experience to help others. This type of advocacy manifested in sharing of ideas and know-how in accessing services and finding the schools to meet the unique needs of their children. Except for the Intuitive Advocates, Trainor (2010) explains these four approaches to advocacy are not necessarily separate entities, and that parents who accessed advocacy in the other three

categories typically combined more than one approach to successfully advocate for their children.

Development of parental advocacy. The development of parental advocacy in education is also viewed in relation to a parent's evolution through stages of four dimensions. Duquette, Fullarton, Orders, and Robertson-Grewal (2011), define these dimensions as a level of awareness, seeking information, presenting the case, and monitoring. *Awareness*, the first dimension, is the moment when parents realize their child is developing at different academic or cognitive rate than other children. Parents may discover these themselves, or they may hear it from others, such as the child's teacher. Surveys by Public Agenda (2002) found 40% of parents first learned of their child's educational difficulties through their teacher, while 33% realized it themselves, and 13% were informed by a doctor. Most (50%) reported their child's disability was identified by first grade.

The second dimension of parental advocacy is *seeking information*. Parents at this point learn all they can in regards to their child's disability and the special education process through printed materials, networks of other parents, advocacy groups, and professionals. Parents in the Public Agenda (2002) survey complained the process of seeking information was not easy. More than half of the respondents stated they had to find out on their own what types of services were available, rather than receiving the information from the school as they expected.

Once an adequate knowledge base is constructed, parents may progress to the third dimension, that of *presenting the case* to school personnel. It is at this point in time when parents provide rationale for the types of services, accommodations, placement options, and information they feel is necessary regarding their child's disability. Parents in this dimension are also known to attend regular school meetings and any meetings involving the child's IEP.

Once the case has been presented, parents move into the fourth dimension, that of *monitoring*. In this last stage, they will monitor the child's academic and social progress, as well as monitor their child's feelings about the course of special education services. If at any point parents are unhappy with the events, they will return to the second dimension, gather more information, and then proceed toward presenting their case once again.

Research also indicates the level of advocacy carried out by parents may be dependent on the child's disability. Parents of children with significant disabilities have been found to advocate more than parents of other disabilities for curriculum content, instructional services, and educational placement (Ryndak, Orlando, Storch, Denney & Huffman, 2011). In particular, parents have reported feeling frustrated when advocating for appropriate classroom placement in the child's least restrictive environment (LRE) (Ryndak et al., 2011; Soodak & Erwin, 2000). In fact, advocacy efforts the last two decades have mostly focused on securing inclusive educational settings in the LRE and classroom accommodations for students with disabilities (Leiter & Krauss, 2004; Leyser & Kirk, 2004). As a result, recent statistics indicate more than half of all students with disabilities now spend 80% of their day in regular education classrooms (Steinbrecher, McKeown, & Walther-Thomas, 2013).

Advocacy regarding "a place" or a particular classroom setting for children with disabilities began eight decades ago when a group of mothers of children with intellectual disabilities joined forces. The Cuyahoga County Ohio Council for the Retarded Child began to advocate in 1933 against the exclusion of their children from school (Yell, Rogers, & Rogers, 1998). Their efforts resulted in the formation of a special class for their children. From that point forward advocacy groups began to form on local levels, though they did not reach national attention until the 1950's.

Now numerous organizations provide access to disability information while also giving parents a place to express frustration and seek others for support. Without these parents and their years of service as advocates, the decade's long battle to improve education for students with disabilities may not have moved to where it is today.

Teachers as Advocates

Not only has work toward improving a child's education been done outside of school systems, efforts to seek equity for all has also been accomplished on the other side of the table, by those who work inside the school systems. Within the rank and file of educators throughout the world are certain members who push for more, expecting nothing short of success for the children they are committed to help. These are the educators who, with a sense of responsibility, advocate from within the system; they speak up when situations happen at their schools which should not be happening (Athanasos & deOliveira, 2007). "Today's young children need teachers who will become more active in the activities of formulation and implementing change, and sharing a vision for that change" (Dana & Yendol-Hoppey, p. 191, 2005).

Teacher advocates not only attempt to make change in the classroom, they make an impact beyond and into adulthood. White and Weiner (2004) identified teacher advocacy as a predictor of positive post-school outcomes for students with severe disabilities. While Fiedler (2000) explained children who have someone to advocate for their needs are the ones who get the most appropriate services. Such results from advocacy come from teachers' voices and their response to the imbalance of equity for children in special education. In a study on those new to the teaching profession, Greenlee and Dedeugd (2002) ascertained that providing voice to teacher advocates within the literature gives them a sense of power to identify problems and develop their own solutions.

A teacher's move into a role of advocacy not only hinges on their commitment to a cause or a student, but also the strength and talent to locate the "expertise inside oneself" and apply it on behalf of students in need (Richert, 1997). For some teacher advocates, the expert and commitment qualities are born from being the parent of a child with a disability; a natural intuition into the nature of the child. Fiedler (2000) stated "the likelihood is greater for personal involvement as a professional advocate if you can feel the pain and frustration of the child or the child's family" (p. 36). Therefore, an educator who is also the parent of a child with a disability experiences the pain, and can use their personal experience to propel themselves into advocating not just for their own children, but for their students as well.

Yet the extent to which teachers and parents, who are also teachers, advocate for children may have limits bound by institutionalism. In a study of teachers who also served the role as advocates for students with disabilities, Mawhinney and Smrekar (1996) found a timeless level of commitment toward advocacy from their participants, who were also influenced in their actions and decision making by educational policies from their schools. The teachers expressed a strong desire to advocate by standing up for the rights of children with special needs and eliminating the challenges faced by families of those with disabilities. The authors surmised these teachers struggled with the established norms in their dual roles of professional advocacy, stating "teachers are influenced by institutional conventions and educational organizations where they work," (Mawhinney & Smrekar, 1996, p. 492) which may limit the extent of their advocacy efforts. The teachers found themselves conflicted by the policies, rules, and routines they self-imposed on themselves, or were set forth by institutional structures and school cultures. One teacher even commented that her degree of advocacy was restricted by her position as a teacher, and that it would take an outsider to accomplish what she could not.

The findings outlined by Mawhinney and Smrekar (1996) are illustrated not only by seasoned teachers who understand the underlying rules inside school system, but teachers who have not yet had prolonged exposure to institutional barriers. Athanases and de Oliveira (2007) focused on a group of new teachers who graduated from a pre-service teaching program designed to prepare teachers to advocate for children with special needs. The new teachers expressed a strong conviction to speak up and act for the rights of children, but perceived a cost associated with such advocacy. They indicated a conscious awareness of the need to balance advocacy with the associated risks, such as potential job loss should they choose to become a controversial voice and attempt to change policies.

However, changing institutional policies does not come easy, and may require a certain personal perspective in order to lead and implement change. Roberts and Siegle (2012) assert that “part of being a professional is having one’s voice heard and being part of the process (p. 61). In seeking to understand the advocacy experiences of an early childhood educator, Dana and Yendol-Hoppey (2005) identified the connection between a teacher’s perceptions of their own childhood experiences to the leadership roles taken later in life as an educator. The relationship between earlier life experiences and self-identify explains the passion and commitment to advocating for change for those who need someone to be their voice. Yet, since advocacy is rooted in a cause, those who advocate from within must remain persistent and committed to the purpose, as “advocates need to be in it for the long haul” (Roberts & Siegle, 2012, p. 60) because of the barriers associated with institutional change.

Parenting Children with Disabilities

Parenting can be a daunting task for any individual, yet parenting a child with a disability comes with an added layer of uncertainty, coupled with the feelings of incompleteness and loss

(Crastnopol, 2009). Learning one's child has a disability is an especially difficult and stressful event. Yet as the years progress, parents are left to "continually adapt to changing circumstances and needs of the child, with stress being a frequent consequence" (Hughes, 1999, p. 271).

Not only do these parents concern themselves with the daily care which may be needed for their children, they struggle with balancing care and promoting educational, emotional, and social success (Heiman, 2002). Parents can get caught in the cycle of providing too much support, leading their child toward dependency rather than independency; or they may unknowingly leave their child feeling frustrated and hopeless by providing not enough support (Adelizzi & Goss, 2001).

In an article written by a parent of a child with a disability, Crastnopol (2009), a psychoanalytic clinician, discusses the challenges to a parent's identity and sense of well-being when faced with raising a child with a learning disability.

The parents are likely to experience overwhelming compassion for the child but also frustration, anger, distaste, and at times even disdain... The parents will under-protect and overprotect, be sensitive and dulled to the child's pain. They will feel resentful of the child's heightened dependency, and then ashamed of that... resentment. They will be envious and ashamed of envying those with typically-abled children. (p. 475)

Garner et al., (2011) studied parenting children with multiple disabilities and/or behavior problems. Their findings indicate struggles for parents, associating less positive, less consistent, and more ineffective parenting behaviors. However, those results were moderated by levels of education. The authors state that parents with higher levels of education generally had more positive interactions and parenting behaviors. Regardless, difficulties surrounding emotional and psychological adjustments for all parents of children with disabilities remain.

A study on the parental effects of raising a child with disabilities compared to a child without disabilities indicates differences. Daire, Munyon, Carlson, Kimemia, and Mitcham (2011) identified differences for parents of children with disabilities which exceed typical parenting demands. Research indicates difficulty with parenting appears to be dependent on the type of disability affecting the children. Parents of young children with autism have been found to have higher levels of stress than parents of children with other disabilities (Estes et al., 2009; Silva & Schalock, 2012). Parents of children with severe forms of autism must cope with the difficult behaviors of their children in the home, such as tantrums and property destruction (Mattson, 2009). They must also manage the effects of their child's behavior while in the workplace as well, as they may be asked to take time away from work to attend meetings at school, or may even be interrupted during the work day to receive phone calls from teachers regarding their child's behaviors in the classroom. These challenges stress parents and families. Families of children with disabilities must also meet with teachers and school personnel more often than families of children without disabilities, as these meetings typically involve the IEP. These extra meetings compound the layers of challenging experiences these parents manage.

In order to help parents cope with higher than average levels of stress, some authors suggest parents get involved in developing and carrying out their child's interventions (Diggle, McConachie, & Randle, 2003; Silva & Schalock, 2012), wherever those interventions are set to take place. Conversely, Kazdin (1995) reports some parents may be left unable to get involved in their child's interventions because they struggle coping with the stressors placed on the family's economic, social, or cultural resources by the child's disability.

Parents' abilities to cope with the stress of raising a child with a disability are crucial to the child's future development (Spekman, Goldberg, & Herman, 1992). Morrison and Cosden

(1997) suggest there is a connection between parents' coping mechanisms and outcomes for their children with disabilities. Both child and family protective factors, including values, beliefs, and expectations have been found to mitigate the impact of the child's disability, both on the child and the family (Bailey, 2001; Keogh & Bernheimer, 1998; Dunst, Hamby, Trivette, Raab, & Bruder, 2000; Dunst, Lowe, & Bartholomew, 1990). Studies suggest a child's ability to remain resilient in the face of difficulties associated with her disability is dependent on the supports within the family and the available resources necessary for promoting positive development (Ungar, 2011; Walsh, 2006, 2007). Adults with learning disabilities have even reported the importance of having someone, like a parent or mentor, who believed in them and provided emotional support to cope with the difficult experiences during school (Gerber, Ginsburg, & Reiff, 1992).

Heiman (2002) studied parents of children with intellectual, physical, or learning disabilities and the social resources and supports which promote resilience through optimism and acceptance. Parents in the study expressed issues of frustration and an initial negative emotional response to the diagnosis of a disability, but eventually gained a level of acceptance of the child's disability and a belief in the child's future by accessing various avenues of supports within the community and their extended families. Improved outlooks therefore transcended risk factors associated with disabilities, and instead served as protective factors in developing resilience and family coping mechanisms.

Parent Perceptions of Special Education Outcomes

No matter the disability, nor the degree of advocacy, parents of children with disabilities want their children to have a successful learning experience. They carry with them perceptions of how those learning experiences should look and feel. They also carry with them the

expectations that they should be part of the special education decision making process (Hess et al., 2006). After all, their right to participate is mandated by law. Valle and Connor (2010) report the attitudes and beliefs of those who actually implement the law have everything to do with whether it is carried out, indicating a divide between what parents expect for their children's special education services and what may actually occur. Previous research by Lawrence (1995) has identified differences between parents and professionals when it comes to perspectives on the parental role in education. Variances between parents and educators in the study were more pronounced in a child's early and later years in school with the differences negatively impacting effective collaboration.

According to Carpenter (1997), in the years following IDEA 1990, research began to establish a shift toward the parental perspective in relationships with educators, as parents of children with disabilities were beginning to take control by "identifying needs within their family, planning their intervention strategy, putting this into action, and then reflecting on the outcomes" (p. 392) before determining further courses of action. Therefore with identified discrepancies in points of view and a conversion by parents toward more authority, Horowitz, Kaloi, & Petroff (2007) called for researchers to study the perceptions of parents whose children had difficulties in the special education process.

In a study of parental perceptions, Stoner et al., (2005) found that parents of children with autism perceived the level of trust established with educational professionals was dependent upon the degree to which they had to fight the system for services for their children. Parents in the study felt that conflict resulted when they had to fight for the services they believed their children needed. Once the trust eroded between the two parties, parents reported they had to remain cautious and monitor all services on their children's IEPs. If parents believed educators

had the child's best interest at heart and the expectations within the IEP were met, a foundation of trust was established and conflict subsided.

Trust has been identified within the literature as important in collaborative efforts between parents of children with disabilities and educators. It is a necessary component in the development of reciprocal relationships (Angell, Stoner, & Shelden, 2009) and effective partnerships between parents and educators (Soodak & Erwin, 2000) as well as the maintenance of such relationships (Dunst, Johanson, Trivette, & Hamby, 1991). Conversely, distrust may negatively impact the alliance with school personnel and the services designed to support children with disabilities (Gewertz, 2002).

A study by Angell, Stoner, and Sheldon (2009) focused on the perspectives of mothers of children with disabilities and identified three factors which contribute to building trusting partnerships between schools and parents, family factors, teacher factors, and school factors, each with its underlying themes associated with the development of trust. Themes related to the family with respect to building trusting partnerships including the family's initial disposition and willingness to trust others, previous experience with educators which may cause them to trust, or not, and verbal or non-verbal communications from children as parents tried to read and listen to indications of how well things were going at school. Themes related to the teacher included the authenticity of care toward the children and the parents, frequent and honest communication, and the teacher's ability to provide appropriate accommodations and modifications in the classroom based on their knowledge of the child's disability. Themes related to the school included the overall school climate toward parents and children with disabilities, parental satisfaction with related service individuals, and the willingness of the school personnel to include the parents as team members in the education of their children. Overall, parents in this study believed

collaboration was important for establishing trust between themselves, teachers, and schools. Without collaboration, they were less willing to trust those charged with providing an education for their child's needs.

Understanding parent perceptions of special education interventions and outcomes is also important in discerning why parents may or may not perceive school personnel as their partners in education. Katz-Plotkin (2009) interviewed both parents and students from schools in the San Diego area to gauge how parents and students perceive the overall effectiveness of special education interventions and the outcomes. Parents were generally pleased with their children's academic gains over the duration of their special education services, yet they spoke of frustration with the IEP experience and urged caution for parents new to the special education process. They encouraged parents to take action early upon signs of learning troubles and never give up when met with challenges. Students echoed similar advice for students new to special education as well informing them to keep on trying.

Parental involvement has become an important part of the special education process since the inception of IDEA 1990. Yet divisive perceptions between schools and parents remain. Parents value trusting relationships, which are essential in building collaboration. Trust is therefore established when educators listen and meet the needs of students with disabilities in the classroom.

Parent-School Relationships

Overall parents play an important role in the collaborative relationships with the educational system. Teachers rely on them to send children to school with needed supplies (e.g., pencils, paper, and for some children a change of clothes). Schools rely on them as volunteers to make copies in support of classroom teachers, prepare for school-wide events, and participate in

the parent-teacher-student associations (PTSA). In particular, parents of children with disabilities find it vitally important to become involved in the educational experiences of their children (Trainor, 2010). They value positive relationships with the people who provide services and supports for their children in the school settings (Hess et al., 2006). However, those relationships have not always been described so positively (Stoner et al., 2005). For some parents, schools “represent places that are intimidating and hostile” (Mawhinney & Smrekar, p. 490, 1996).

Parent-school collaboration began to re-shape after IDEA 2004 granted parents a more active role in the special education process. Since then the relationships between parents and professionals have been of particular interest to researchers (Valle, 2011).

It is well established that parental involvement in a child’s education can be beneficial (Epstein, 1996; Jeynes, 2003) including enhancing the child’s academic outcomes (Fan & Chen, 2001) regardless of whether the child has a disability. A longitudinal research study (Flouri, 2006) identified a link between parental involvement in the elementary school years and the child’s educational attainment into their 20’s. Yet according to Valle (2011), the literature points to shortfalls in parent and school collaboration since the inception of IDEA 2004.

When parents and school personnel have differing perceptions on the meaning and functions of parent involvement, misunderstandings may develop and tensions may rise (Lawson, 2003; Lightfoot, 1978). Differences inevitably arise among parents, school officials, and other professionals involved in the design and implementation of appropriate programs for students with disabilities (Lake & Billingsley, 2000). These conflicts can undercut parents’ faith in schools and strain relations for those on all sides of the table.

Schools follow legislative directives and attempt to create systems that standardize the process of identifying and placing children in special education as a form of special education ‘assembly line’. The advocates or families, attempt to support their children’s individual needs, seeking justice in the form of equal opportunities for their children (Hess et al., 2006, p. 155-156).

Despite participation and advocacy by parents, their efforts have often been thwarted by structural barriers and/or disregarded by school personnel (Harry & Klingner, 2006). These actions have resulted in inappropriate placement and service delivery for children with disabilities, rather than needs-based decisions.

Even though a majority of parents in the Public Agenda (2002) survey reported general satisfaction with the special education services their children receive, parents of students with varying degrees of disabilities have a different outlook on their levels of satisfaction. In a study by Hernandez, Harry, Newman, and Cameto (2008) parents of students with mild disabilities reported more displeasure with their child’s special education services than parents of students with more significant disabilities.

Parents have expressed their confusion and frustration with the barriers that are part of schools which prohibit positive collaboration. They have indicated the feeling of being “left out of the process” (National Council on Disability, 1995) because they do not understand the technical special education language. And they have expressed being “disenfranchised and alienated from educational systems designed to help their children” (Kroth & Edge, 1997, p. 14). Parents in the literature have complained about school meetings which are scheduled at times when they cannot attend (Linan-Thompson & Jean, 1997); receiving little opportunity to provide input when making decisions about their child (Harry, Allen, & McLaughlin, 1995); complicated

information regarding their rights written in advanced and sometimes legal language (Harry, 1992; Leung, 1996; Linan-Thompson & Jean, 1997); lack of available class programming options for students with disabilities; and ill-prepared special education teachers (Hess et al., 2006).

Another barrier to positive parent-school collaboration may be the difference in perceptions, as educators may think they understand the family perspective, when they do not. Failed collaboration between the two sides may result due to “the educator’s lack of understanding of family culture or unwillingness to investigate the meaning behind certain behaviors” (Hess et al., 2006, p. 148). Kalyanpur and Harry (2004) maintain that little attention is given to the voice of families, when the decision making processes exist within the boundaries of the professional community without including parents. Indeed, there is a need to empower families of children with disabilities with respect to the education of their children and to give them a voice for action (Hess et al., 2006).

Multiple Roles of the Researcher

The literature is particularly void with respect to the experiences of parents of children with disabilities who are also educators and researchers. My exhaustive search through the university databases and online search engines was only able to account for very few people who serve in these multiple roles. Beth Harry, Ph.D., Carol Gross, Ed. D., and Katherine Koch, Ph.D. are authors who share common ground as a parent of a child with a disability, and all three have written about their experience, whether directly or indirectly, within their role as a researcher.

Beth Harry, mother of a child with cerebral palsy and an intellectual disability, is a professor at the University of Miami. Prior to her entrance into higher education, Harry taught English in Toronto, Canada. She entered the field of special education when she founded the

Immortelle Center for Special Education in Trinidad and later went on to earn her doctorate in special education from Syracuse University.

In the book, *Melanie, a Bird with a Broken Wing: A Mother's Story*, Harry (2010) gives readers personal insight into her experiences in raising her daughter and finding appropriate care. She uses the inspiration of her daughter's short life as the basis for her position as a researcher in special education.

Melanie's impact on my professional life has been immeasurable. My focus as a researcher and teacher of special education has been indelibly marked by my experience with her. I begin every course with a personal introduction that includes the lessons I learned from her, and I encourage undergraduate and graduate students alike to believe the messages of their hearts as they make professional decisions (p. 205).

Harry (1996b) also discusses the impact of each of her identities as a parent, educator, and researcher in her article, *These Families, Those Families: The Impact of Researcher Identities on the Research Act*, and how those roles converge in her research.

Also living in multiple roles as a parent, teacher, and researcher is Carol Gross, assistant professor at Lehman College. In her article, *Parenting a Child with Learning Disabilities: A Viewpoint for Teachers from a Teacher and Parent*, Gross (2011) narrates the struggles ensued when her adopted son began to show signs of learning disabilities. She offers readers the perspective of both a parent and a teacher. At the time Gross was a teacher in early childhood and found her son's learning challenges difficult to accept, because as she stated "she didn't know what learning disabilities looked like", nor was "even sure they existed" (Gross, 2011, p. 87).

Gross now incorporates her experience in learning to understand her son and his educational needs to teach graduate level teachers how parents may feel when they have children with unique learning needs.

Katherine Koch incorporates her role as a parent and teacher of a child with disabilities in her dissertation titled, *Dual Role: Parent and Teacher of Children with Disabilities*. Inside her research study, Koch (2011) reveals her struggle of parenting a child with Autism Spectrum Disorder (ASD) and Attention Deficit/Hyperactivity Disorder (ADHD) and obtaining appropriate services for his needs within the school setting. The challenges which ensued between Koch and her son's school led her to become a teacher and go on to complete her Master's Degree in Special Education and doctorate in Education. She took her experiences of living in the dual role of a parent and teacher of children with disabilities and geared her research toward others in such unique positions. Koch (2011) reports that parents of children with disabilities, who are also educators, seek out and support each other in their academic endeavors for their children, as well as support and advocate children with disabilities, who are not their own, on a more conscious level than teachers who do not fill the role of parenting a child with a disability. This appraisal was supported by the parents, who were also teachers and who had to fight for services themselves for their own child, leaving them more inclined to help other parents learn to navigate the world of special education.

The concept of parent as researcher stems from Adler and Adler (1996) when they introduced the parent as a researcher paradigm. In essence, this methodology of research allows the parent insider status into an area where outsiders would not yet understand the norms, values, and sets of behaviors. This places the parent-researcher in a dichotomy of separate standards: "the public arena of the research role; and the private arena of the parental role" (Adler & Adler,

1996, p. 55). In response to the parent as researcher paradigm and specific to parents of students with disabilities, Carpenter (1997) proposes a parent inclusive pattern of research designed to empower parents of children with disabilities, stating, “They are the natural inquirer within their family, seeker of knowledge and information that will illuminate needs within their family and specifically in relation to their child with a disability” (p. 396).

The opportunity to conduct research using insider status concerning issues of a personal nature is supported elsewhere in the literature. Authors such as Carolyn Ellis and David Karp have contributed to research writing about their own very personal experiences. In her account of losing a loved one, Ellis (1995) revealed the inner feelings associated with her loss. Karp (1996) used his personal insight to tell the stories of men and women suffering from depression.

Similar to other authors and researchers before me, this study will draw upon my own personal experience as a parent of a child with a disability, a teacher, and a researcher of children with disabilities. Those identities inform my roles within special education and place me in a distinctive position to conduct this research study from three different perspectives all associated with children with disabilities and something which has not been accomplished before.

Summary of the Chapter

Children with disabilities and their families have faced an uphill battle throughout the course of educational history. They have been denied the right to an education; have been placed in settings awash with inequities; and now face challenges in the decision making processes afforded to them by legal mandates under IDEA and FAPE. For those who advocate for children with disabilities, the challenges may seem insurmountable at times, but as quoted from Vince Lombardi in the opening of this dissertation, “hard work is the price we must pay for success.” Parent advocates have put in the hard work, organizing advocacy groups and pushing legislators.

They have developed a sense of parental efficacy, similar to Bandura's social cognitive theory, in their approach to making change and the belief in their abilities to do so. Hence, their successes have come in the form of free and appropriate public education for all students and the development of federal protection for students with disabilities.

But as the literature indicates, problems still exist; parents are still frustrated and conflicts still abound (Gewertz, 2002; Katz-Plotkin, 2009; Lake & Billingsley, 2000; Public Agenda, 2002; Stoner et al., 2005; Trainor, 2010) when it comes to parents' roles in the development and delivery of their children's educational services. Many parents find themselves advocating for their child's needs through various means (Duquette, Fullarton, Orders, & Robertson-Grewal, 2011; Trainor, 2010). They make their decisions and chose their actions based on the needs of their child at the time, an example of the parental development theory previously outlined in Chapter One. Some hire attorneys, many more choose to fight the system on their own (Duquette, Fullarton, Orders, & Robertson-Grewal, 2011). Trainor (2010) outlined four types of parent advocates, the *Intuitive Advocate*, the *Disability Expert*, the *Strategist*, and the *Change Agent*; each with its own approach to accessing Bourdieu's (1996) social and cultural capital theory, and each addressing the needs of children with disabilities.

It was a discussion on Trainor's (2010) research which led to the topic of this study. A conversation ensued regarding the *Change Agent* and how it related to my position within the school district; that of having insider knowledge which I used to navigate the procedures and protocols to advocate for services and accommodations for my own son. I also felt the *Change Agent* described people like me, those who are parents of children with disabilities who have had to advocate for their own children inside the districts where they work.

Thus, having insider knowledge may not make advocating any easier from the inside, than from the outside. Schools are institutions, complete with barriers which support their very foundations. Parents on the outside experience difficulty, and so do advocates on the inside (Athanases & de Oliveira, 2007; Mawhinney & Smrekar, 1996). Teachers fear on-the-job repercussions should they become too vocal or push the wrong buttons in their advocacy efforts.

As outlined throughout history, institutional change does not come quick nor does it come easy, and advocates, parents, and teachers alike, must remain vigilant (Dana & Yendol-Hoppey, 2005) and allow persistence to endure. Yet the ethical dilemmas which arise when these advocacy roles become entwined highlight one of the supporting frameworks of this study, the theory of responsible advocacy. The identity conflict associated with the theory commences when one must advocate for their child, while at the same time adhering to the expectations of one's employer. Parents who were also teachers in the study by Koch (2011) indicated they were better able to handle their role conflict by empathizing with other parents of children with disabilities while teaching. They considered themselves a "package deal" because they could offer perspectives from both sides.

This study intends to portray the experiences of parents; not just those identified in the literature who express a sense of frustration, alienation, and isolation by the system (Hess et al., 2006), but those who have never been allowed to tell their stories. The research base is well versed in regards to parental advocacy, yet it is empty on the parents who are educators too, who have had to advocate from within the walls of the system.

The next chapter in this study addresses my research method and outlines my procedures for identifying participants, collecting, analyzing, and presenting the stories of parents who have quietly experienced the *fight within*. These procedures are designed to answer the study research

questions by uncovering the experiences of school district employees who challenge their own districts in the interest of their children with disabilities, as well as identifying how these parents and district employees perceive their involvement in advocating in relation to the job security, and the barriers they encounter in doing so. Exposing these issues will also help me understand the meaning of my advocacy for my son and how those experiences have shaped me as a parent/educator/researcher.

Chapter Three:

Methods

Research in the social sciences can be either personal or impersonal. In the case of this study, I focus on the personal: my personal experience, as well as the experiences of those who serve similar roles as me. This cannot be accomplished from an objective position. Ellis, Adams, and Bochner (2011) state “that different kinds of people possess different assumptions about the world” and insist “subjectivity, emotionality, and the researcher’s influence on research” (p. 2) do exist when researchers focus on personal aspects.

This study intends to understand the experiences of parents who work for school districts, yet advocate for their own children with disabilities inside those very places where they work. I am one of those parents. I have experienced the institutional barriers discussed within the literature. I have had to become the *Strategist* and the *Change Agent*. I have called for change from within the institution, only to fear future outcomes. As a result, I bring multiple perspectives to this study as I also explore the experiences of people who are parents and educators just like me.

The primary instrument in qualitative research is the researcher herself. I am both the researcher and participant, two roles which cannot reasonably be separated. Therefore I define my role within this study as that of a researcher/participant rather than an objective observer. In doing so I bring certain biases associated with my personal experiences as a parent of a child with a disability, a teacher of children with disabilities, and a researcher of those with disabilities. I attempt to illuminate how I have addressed the dualism of being both researcher

and participant in my description of this study's methods. Additionally, I discuss the delimitations of my approach in Chapter Five.

Heuristic Case Study Design

Educating children with disabilities is a tension filled environment for all parties involved in the process. Some parents understand those difficulties more than others since they also fill the dual role as a parent and an educator of children with disabilities. For those who live in these roles, they experience compounding factors which challenge the manner in which they negotiate those positions. Currently the literature concerning parents of children with disabilities who also work in the field of education is extremely limited. This study intends to explore this untapped area, as I attempt to understand the lived experiences of individuals, including myself, who fill multiple roles as an educator and parent of a child with a disability.

In order to share the lived experiences of myself and others who live in these multiple roles within the educational system, I investigate the research questions using a combination of qualitative case study and heuristic inquiry. With roots in the Greek word *heuriskein*, meaning to discover or find, heuristic inquiry is a method which focuses on the research and the self, connecting the two, and allowing the researcher to discover the meaning behind the personal experience (Moustakas, 1990). This qualitative method invites participants to become part of the meaning making by sharing their experiences. In essence, the research participants become co-researchers, developing a story through the use of dialogue and documents which is then synthesized by the primary researcher.

The opportunity to synthesize the experience of others will be evaluated through case study research. "Not considered a methodological choice, but a choice of what is to be studied" (Stake, 2008, p. 119), case study research delves into the meaning of experiences by allowing the

researcher to focus on the case and provide analysis through storytelling from the researcher's perspective of the participants.

In combination, a heuristic case study "is able to shed light on the phenomenon, allowing the reader to extend their experience, discover new meaning, or confirm what is known" (Brown, 2008, p. 3).

Rationale of Case Study

Case study research has received extensive attention from three research voices, Yin, Stake, and Merriam, each with its own perspective regarding case study methods because "there is little consensus on what constitutes a case study or how this type of research is done" (Merriam, 1998, p. 26). Therefore Brown (2008) categorizes the positions of these three case study exemplars as existing on a continuum, with Stake on one end, Yin on the other, and Merriam in between. I briefly describe the uniqueness of each perspective, followed with an explanation of the components of case study research I use in this study.

Yin, described as a methodologist, is known for adherence to prescribed procedures and the development of an outline for guiding the research design and the processes for conducting the case study itself (Brown, 2008; Hocutt & Fowler, 2009). Yin focuses on a devotion to protocols in rigorous data collection, steps for analysis, and the approach for the reporting of findings. Yin's approach to case study is concentrated on the details of the process. Such attention to specifics maintains a high degree of quality, giving case study "credibility by thoroughly triangulating the descriptions and interpretations, not just in a single step but continuously throughout the period of study" (Yin, 2003, p. 443-444).

Far different from Yin in his concept of case study is Stake, with attention not in the specific structure, but rather in the choice of the case itself, using a more interpretive approach (Stake, 2008). His vision of case study places the emphasis on the researcher in seeking more

than just the ordinary (Stake, 2008). The researcher then takes on the task of providing explanations and rich descriptions of the experiences of the participants, allowing the reader to construct a view of the phenomenon and interpret their own meaning. “The purpose of case study is not to represent the world, but to represent the case” (Stake, 1994). This perspective also identifies the significance of the researcher’s role in contextualizing the experience and issues related to the research questions, while providing an extension in the presentation which the reader may then understand.

In between the contrasting perspectives of Yin and Stake is Merriam’s holistic approach which emphasizes attention to the phenomenon. Referred to as an educator by Brown (2008), Merriam supports case study in education as a means of allowing a practitioner to research a phenomenon that is problematic (Merriam, 1988); hence it is typically utilized by researchers with intrinsic interest in the case. The phenomenon which is studied may arise from a multitude of options, including a person, process, event, program, institution, or a social group with the researcher serving as the primary instrument in the collection and analysis of data. The feature of Merriam’s case study style is the outlining of the case or phenomenon with boundaries, identifying what will and will not be studied. Merriam does not approach the case study phenomenon by subscribing to any particular method of data collection, as does Yin, because of the “particularistic, heuristic, or descriptive” (Brown, 2008, p. 3) nature of case study. Her approach allows for the storytelling aspect of the case, but from the researcher’s perspective of the participants. This is done in an intensely descriptive and inductive manner so readers may experience the events themselves and draw their own conclusions.

Guba and Lincoln (1981) indicate it is the rich, “thick” description of a case study which builds the reader’s tacit knowledge. Merriam (1988) defines a set of preconditions which may

guide the researcher before setting out on a course for using case study as a research. First, the focus must be grounded in humanistic outcomes. Second, the information obtained is subject to scrutiny based on credibility rather than truth. Merriam's case study is an appropriate method within the field of educational research when the intent is to better understand the uniqueness of the phenomenon. In the context of this study, uniqueness is one of the driving forces behind the phenomenon of interest to me. Case study research is optimal when the goal is to describe the human experience. As indicated in the previous chapter, the current literature base is void of any analysis describing the experiences of school district employees who advocate for their own children with disabilities.

In this study, I describe the experiences of a group of educators who not only advocate for the rights of their children with disabilities, but must also fight for those rights within the district where they work, launching parental advocacy from inside the system as not reported within the literature. Merriam indicates case study can be descriptive or even heuristic (Brown, 2008). And that "a heuristic case study is able to shed light on the phenomenon, allowing the reader to extend their experience, discover new meaning, or confirm what is known" (Brown, 2008, p. 3). In order to highlight an area of intrinsic interest, I use heuristic inquiry in combination with case study, adhering to not just a single approach, but to a blending of elements from Yin, Stake, and Merriam.

Rationale of Heuristics

Much like case study, heuristic inquiry is storytelling as well, but from an individual perspective allowing the researcher to focus on the self, other, and the world (Moustakas, 1990). The purpose of heuristic research is to conduct deep, inward reflection of the feelings about one's own experience, creating a social transformation within the researcher to discover

meaning. There is no intent to generalize, nor generate theory, but rather to identify meaning through tacit knowledge, intuition, and self-searching. Observations are of only thyself and the connection of the inner “*T*” with the outward experiences of the cases (Sela-Smith, 2002).

The key concept in heuristic research is the development of tacit knowledge. First conceptualized by Michael Polyani (1966), tacit knowledge is more than an explicit part of our awareness; it is knowledge which exists in the background of consciousness (Gertler, 2003) and when combined with more surface level knowledge, allows one to focus on the specifics and actions during life experiences. Elements which one can describe are observable and stand out when recalling an experience. However, tacit knowledge is the intuition of “knowing what we know”, which is “more than we can tell” (Polyani, 1983, p. 4). Polyani (1966) states one can teach a child the skills of how to ride a bicycle, from pedaling to steering to braking. Yet the self-awareness of how we balance our bodies over two wheels is an experience which cannot be fully described. Those feelings associated with intuition connect the parts of implicit and explicit knowledge providing a picture of the whole experience. Tacit knowledge is the deep dimension of experience, feeling, and meaning (Sela-Smith, 2002). Gertler (2003) calls this combination the “undefinable tacitness of being (there)” (p. 75), which can only be acquired through experience. There are emotions, memories, and images which evolve from an experience and attach to tacit knowledge. Maskell and Malmberg (1999) argue tacit knowledge “can only be produced in practice” (p. 72). Consequently, it is the intention of this study to connect what was experienced in practice with the multiple sets of memories, emotions, and actions to gain an understanding of the experiences of school district employees who advocate within the school district where they work for the rights of their own children.

The lived experience may also be researched through methods such as phenomenology. Van Manen (1990) describes phenomenological research as interpretive with a certain degree of depth and richness. It explores the world pre-reflectively, as it is experienced and presents itself to consciousness. Hence, whatever lies outside of consciousness is not part of the lived experience. Understanding post-lived experiences is the purpose of this study. The intent is to uncover the deeper meanings within each participant's experience in advocating for their children, as well as that of my own experience. Simply reporting on those past and current experiences would not expose the difficulties presented in advocating for one's child from inside the boundaries as an employee within that same school district. There are feelings associated with each experience. My research questions intend to dig beyond the facts of what my participants recall in order to describe the essence of their conflict.

Moustakas (1990) insists heuristic inquiry be conducted by individuals with intrinsic interest in the research and its questions. The methodology allows a researcher to gather "detailed life experiences related to the qualities and constituents of the phenomenon under investigation" (Moustakas, 1990, p. 24). Moustakas (1990) describes the search for a topic as one which requires inner receptiveness. It begins with initial engagement and the inner search to develop the research question(s). What evolves is a research problem which is autobiographical, may be consciously or unconsciously considered incomplete, and holds social significance for the researcher (Sela-Smith, 2002). The initial engagement phase is not complete unless the researcher is willing to passionately commit to the theme and the inner growth which comes as a result of a new and transforming experience.

In my case, I had to be willing to disclose personal aspects of my experience and that of my son's which have remained behind closed doors under lock and key. Determinations had to

be made whether to unveil the whole experience or just parts of the whole, for the protection of my own emotions, but most importantly for the potential psychological effects of bringing an experience buried in Kristopher's subconscious to consciousness.

In order to accomplish the insightful nature and understand the story of a human experience, Moustakas (1990) suggests the researcher-participant surrender to the six phases which lead to the meaning within the research design: initial engagement in the topic, immersion into the research questions and data, incubation, illumination, explication, and the concluding creative synthesis.

Initial engagement. Investigations in heuristic research, according to Moustakas (1990), begin with a critical area of interest on the part of the researcher. The purpose of initial engagement is for the researcher to identify an area of intense passion or concern and its connection within social contexts. This process invites self-dialogue as well as autobiography in relation to significant relationships and their social meanings. It is in this phase where tacit knowledge allows a question to linger, leading to commitment on behalf of the researcher and the formulation of the research questions. In my case, this dissertation topic was an issue which lingered throughout my involvement in the doctoral program. I dabbled with its impact on my life earlier in my coursework, yet hedged at full-scale research commitment, particularly in response to an outsider's view of me. A professor of mine said I looked conflicted at the time and appeared to have reservations whether I should even pursue this topic. Ironically, I felt I was more at odds with her observation of my feelings than with my desire to follow this line of inquiry. So as it was, my thought process on this topic was put to rest. But the idea continued to linger, until a simple discussion developed regarding parental advocacy and my long-standing

desire to research parents just like me; those who had to advocate from within the educational system and whether their experiences were similar to mine and Kristopher's.

Immersion. Once the topic and questions are identified and defined, the researcher moves to the second phase, that of immersion. This phase places the focus on the self, consciously and unconsciously, in every state of being. "Everything in his or her life becomes crystallized around the question" (Moustakas, 1990, p. 28), as the researcher begins to submerge themselves in the question and its connection to every facet of life. There is not only association of the inner experience, but a continuous focus on the outer experiences of people, places, and meetings for understanding of the phenomenon. If full immersion is realized, the question will come alive within the researcher (Sela-Smith, 2002). For me, my research questions lived with me in my multiple roles. I am immersed in it as a parent, an educator, and a researcher. It has consumed every aspect of my life, while awake and asleep. These roles have defined who I am, yet have also left me to seek understanding of my experience and in relation to the larger phenomenon. Once the data collection process began, immersion dominated my life unlike any moment before this inquiry. I interviewed, transcribed, and reviewed all the data over and over again, a minimum of seven times per interview. I became consumed with the data and began to think about the importance of each piece and its relation to the overall experience. Immersion does not come with a timetable; therefore I continued to examine the data until I understood all the pieces. For me, I lived this topic on a daily basis, while at work because it was part of my job and while at home as I immersed in the data.

Incubation. Once the questions and the topic come alive within the researcher, a detachment period follows, which Moustakas (1990) refers to as incubation. This phase is defined by a departure from the intense focus on the questions, allowing tacit knowledge and

intuition to clarify what previously may have been beyond immediate awareness. Here the researcher is no longer directly associated with the question. Instead, the incubation period is used for processing the unconscious awareness to allow for a new understanding and forming an answer to the question. This progression unfolded after I conducted and transcribed the last interview from each co-researcher and spent time repeatedly inspecting all the data. Of great importance in this step is the ability to disconnect from the thinking process and allow the mind to clear for a renewed perspective. My work schedule and its demands allowed me to disengage from immersion on a daily basis and focus my thinking away from the research topic. Hence, I would immerse by night, incubate by day, and re-immense by night.

Illumination. The next step in the heuristic process begins naturally, but only when the researcher is receptive to tacit knowledge and intuition, allowing it to breakthrough into consciousness. Illumination serves as an awakening of new awareness of old understandings (Moustakas, 1990). It is not a planned experience; it is spontaneous; it brings about disassociated aspects of the self and provides new meaning (Sela-Smith, 2002) by allowing the heuristic researcher to realize things which had always been present, but were buried from conscious awareness. Illumination is described by Sela-Smith (2002) as the moment when wholes or clusters of wholes break through into consciousness forming themes which are fundamental to the question. The illumination process follows a time of rest, so the researcher is open to new ideas which may underlie the meaning of the experience. Once I returned to the data following a period of detachment, I re-immersed and listened to the interviews and repeatedly reviewed the transcripts, co-researcher journals, all documentation provided by the co-researchers, and my own notes in my reflexive journal. As I reviewed all the data, I began to take extensive, detailed notes pertaining to the qualities and themes of the interviews from each

co-researcher and the documents they provided. Such a methodical data review process occurred when I returned to my data for the fourth, fifth, and sixth time and allowed concepts and ideas, which were not as obvious in earlier portions of the phase of immersion, to illuminate and emerge from my own sub-conscious thoughts. During those moments between repeated listening to the transcripts, new thoughts emerged and led me to make connections through the next phase in the heuristic process.

Explication. According to Moustakas (1990), once the consciousness has awakened from its interaction with the tacit dimension, the time comes for the examination and explication of the descriptive qualities and themes which have emerged. For this phase to occur, the researcher must be devoted to their own thoughts, feelings, beliefs and judgments which were obtained from conversations and dialogues with others. In turn a re-organization of what occurred during the incubation period leads the researcher to explicate the major segments of the phenomenon and organize them into a depiction of the experience. The explication phase materialized following the note-taking process during illumination. My notes and thoughts were examined, and I was able to make connections and develop diagrams of my thinking in relation to the data and research questions. After following these steps for each co-researcher, I began to conceptualize the written portraits.

Creative synthesis. A researcher's adherence to the heuristic process leads her to the final and culminating phase; that of the creative synthesis. Achieved through the interaction with the tacit dimension, intuition, and self-searching, the creative synthesis evolves when the researcher is familiar with all the data, its qualities and meanings, and has explicated the details behind the experience (Moustakas, 1990). The creative synthesis develops in three forms: the individual written depictions for each case, a group or composite depiction, an exemplary

depiction of two or three cases which illustrate the group as a whole, and the final product which may be expressed through the use of a narrative, a poem, drawing, or painting. It takes on a life of its own as the creator and creative synthesis synchronize as one (Sela-Smith, 2002). Intuition, relied upon so heavily throughout the heuristic process, once again played a role in the birth of the final creative synthesis. My creative synthesis evolved in an unexplainable and truly amazing moment of uncommon creativity, leading me to create a poem using the words and phrases from my co-researchers.

What better means of inquiry could there be to address the research questions in this study than by someone who has personally experienced the scenarios behind the research questions? I have personally experienced the *fight within* as I have advocated for my son and his educational needs. I have wondered if we were alone.

Theoretical Lens

As a person who enjoys numbers and mastering elements of mathematics, it would be easy to say I align myself with the world of positivist research. After all, much of my time in education and previous research interests has focused on student behavior and behavior interventions. But also as someone with an undergraduate degree in the area of psychology, I prefer to view my world in questions surrounding the ‘*why*’ and the ‘*how come*’, (e.g., why is a student behaving like this in one classroom situation, but not the other?; or, how come the gains of students in my math resource class equaled or exceeded the gains of students in regular education settings on the statewide standardized assessment?). I enjoy getting to the root of what is seen by surface level thinkers. I want to know the underlying reasons behind actions and behaviors. My theoretical lens is more socially constructed in post-positivism, than objectively determined by positivism. Accordingly, as stated by Noor (2008), this subjective view of a

social phenomenon requires a qualitative approach, not a quantitative one. Choosing a qualitative approach to understanding the nature of my research questions allowed me to explain the complex, real-life situations of my participants. It also granted me the opportunity to probe a particular area of interest with significant depth and care.

In order to explore the social phenomenon outlined in this study, I address the following research questions:

- 1) What are the experiences of school district employees who challenge their own districts in the interest of their children with disabilities?
- 2) What barriers do these parents/district employees feel they encounter in advocating within their own districts?
- 3) How do these parents and district employees perceive their involvement in advocating for their own children in relation to their job security?

Selection of the Cases

Critical to the understanding of the experience of school district employees who advocate within the system for their own children with disabilities is the selection of those employees. It is their experience which may exemplify a component of parental advocacy not yet seen within the literature. Therefore, proper participant selection was crucial to uncovering the phenomenon within this study. Participants, referred to as co-researchers by Moustakas (1990), were selected from school districts in the southeastern United States through purposive sampling. Purposive sampling is described as a means of gaining more insight and in-depth understanding of the participant's experience (Chen, 1981; Patton, 1990), allowing researchers to think through the cases from which they learn the most. Cases are opportunities to gain an understanding from a phenomenon (Stake, 2008); therefore large samples may not afford a researcher the time and

resources to conduct an intensive study. As a result, qualitative research samples are small and methodologically unfit for random selection, leaving purposive sampling as the means of representing the phenomena. Stake (2008) defines the need for a small number of participants in case study research in order to identify those which are accessible in order to immerse oneself in the phenomenon and learn as much as possible from the experience of others in accordance with the research question(s). In order to understand the phenomenon of the experiences of school district employees who advocate for their own children with disabilities, persons meeting these qualifications were unique in respect to the defining characteristics of this study. Therefore the sample size was too restricted to allow for random selection. This form of non-probability sampling method is used by anthropologists, who maintain that purposive sampling:

“are logical as long as the fieldworker expects mainly to use his data not to answer questions like ‘how much’ and ‘how often’ but to solve qualitative problems, such as discovering what occurs, the implications of what occurs, and the relationships linking occurrences” (Honigmann, 1982, p. 84).

Three participants were selected for this study using a more defined method of purposive sampling proposed by Patton (1980), called the critical case. Critical case sampling allows the researcher to purposely select cases which can “yield the most information and have the greatest impact on the development of knowledge” (Patton, 2001, p. 236). In this case, districts are aware of the efforts made through advocacy for children with disabilities. However they may not be aware of the experiences of such advocates within their own organizational system who must address the needs of their own children from the inside. Therefore such individuals were selected so their experiences could provide a deeper understanding of the specific phenomenon of interest in this study. While readers are unable to make broad generalizations with critical

case sampling, they can make logical generalizations based on the importance of the evidence produced in critical samples (Patton, 1990). Patton (1980) equates the selection of critical samples to Galileo and the study of gravity. In order to determine whether the weight of an object changed the rate of speed at which it would fall, Galileo chose to use a feather as a critical case to make generalizations, rather than finding random objects of different weights.

As with any form of research, attrition was a consideration in the research design. Consequently no more than three co-researchers were selected for the purpose of this study, allowing for the possibility of a co-researcher to withdraw while also maintaining realistic expectations for completion. Obtaining more than three co-researchers could have presented time limitations and restricted full immersion of the experiences, from a heuristic stand point. Time limitations were also a concern within this study due to my role as a current educator. My job responsibilities frequently require time beyond the typical eight-hour work day, leaving limited room for research. Identifying too many co-researchers would have expanded the time to conduct interviews, impeding on the guidelines for reflection in heuristic case study research. The analysis and meaning making could have been impacted if too much time elapsed between the interviews in each case.

Criteria for Co-researchers

Purposive critical case sampling requires that specific criteria be utilized in the selection of study participants. Co-researchers had to be current employees of a school district in the southeastern United States. They also had to have a child with a disability, currently or previously, served through an Individualized Education Program (IEP) in any year following the enactment of IDEA 1990. The services of the IEP must also have occurred within the same school district where the co-researchers worked. Parents who had a child without a disability or

those only with accommodations under the Section 504 of the Rehabilitation Act were not considered for this study. These requirements formed the bounded system as outlined in Merriam's (1988) approach to case study research and created the critical case sample criteria which most closely aligned with my own experience of a school district employee having to advocate for the needs of my own son. Finding co-researchers with similar roles as a parent and an educator helped me explore my own experience and identify whether I was alone in my advocacy efforts or shared similar experiences with others. Current, rather than previous, employees were sought in order to lessen the distance between their memory of the experience and the experience itself. The co-researchers needed to also work in an instructional setting, such as teacher, administrator, or paraprofessional. Such persons are innately connected to educational policies by the sheer nature of their job duties. However, the inclusion criteria did not require participants to have previous experience working within special education. Doing so may have refined the available population, leaving case selection and identification impractical within the time limits of this study. Even though para-professionals are not certified educators, they are exposed to the rules and regulations in special education and have a certain level of acquired knowledge. That knowledge also placed them in this relational space in which I intended to investigate, therefore they were included within the selection criteria. Of importance on this note is that my own entry and advocating in the world of education began as a paraprofessional, prior to returning to school to complete my bachelor's degree and progress into the teaching profession.

While parental advocacy may be enhanced through in-depth knowledge of special education practices (Trainor, 2010), it is the actual experiences of advocating from the inside out which were the focus of this study. These individuals work in positions which allow them

access to knowledge of the inner workings of educational systems. The knowledge they acquired in these situations may be considered *privileged* in accessing information and personal connections (Trainor, 2010) within their school district, which may have benefitted their advocacy efforts for their own children.

All three co-researchers were known to me through professional relationships developed within the workplace. I was familiar with them, but not as familiar with the stories which brought them and their children into special education. Development of such a relationship can be beneficial to the research process as it adds to the interactions of the researcher and co-researchers, providing me insider access to the type of information to ask (Kaler & Beres, 2010). It also afforded me trust and rapport which I did not have to spend time acquiring within interview sessions. Polkinghorne (1983) indicates the opportunity to acquire in-depth information is best when inquiry can take place within relationships already established in the field. Two of the three co-researchers worked in more than one state and carried out their advocacy efforts for their children there. The variation of experiences in different districts did not limit the context of the co-researcher perceptions to a single area within the country.

Upon approval from the Institutional Review Board (IRB Study # Pro 00013966), all co-researchers were provided with informed consent prior to the commencement of the data collection process (Appendix A). The purpose and description of the study was explicit: including providing the co-researchers my contact information in the event they had questions, informing them they may withdraw at any time during the course of the study, and asking them to review the transcribed data and my written account of their experiences in advocating for their children.

Due to the nature of exploration in this study and the need to allow opportunities for co-researchers to express themselves within dialogue, the anonymity of my co-researchers and their children was of utmost importance. Parental involvement in advocating for their own children in relation to perceptions of job security was one of the research questions. Therefore co-researchers were given the opportunity to identify their own pseudonyms for themselves as well as their children so they may not be identified throughout the course of this study, or its written presentation, while at the same time remaining free from the worry of repercussions and comfortable enough to fully detail the accounts of their experiences. Once pseudonyms were identified, all data collected used those pseudonyms. Names of any and all schools and/or school districts, personnel, or other identifying information were removed within the interview transcriptions and blacked out on any written documentation in order to maintain a high level of confidentiality and protection from unintended implications.

Great care was also given beyond the pseudonyms. I knew these participants, they knew me, and some of them knew each other. Consequently, I also had to ensure anonymity across participants. I did not discuss any aspect of this study with any of the participants while in our workplaces and asked them not to discuss their participation with anyone else. Contacts and conversations with the participants, aside from the interviews themselves, were made using personal contacts (e.g., cell phone numbers, personal email, etc.).

Myself as a Researcher and Participant

Moustakas (1990) states all heuristic inquiry begins with the internal search to discover; a passion and desire to pursue research through a question which is connected to the researcher's self and identity. My son and I have lived an experience, which at the moment felt like none other. We struggled, we fought, and we pushed for what we believed best suited his learning

needs. As the need to push harder intensified, I wondered whether we were truly alone, or if there other parents of children with disabilities in the school district who found the experience of advocating from within equally as challenging. For it seemed, as I perceived it as an educator, that parents of children with disabilities who did not work in the school district quickly became the *squeaky wheel that got the grease*. They appeared to have no fear in climbing the ladder to demand specific services for their children. And at many times it seemed they got exactly what they demanded. But could I have approached my concerns in the same manner? Would my involvement in advocating for my son have impacted my job security? And was my experience part of a single phenomenon or that of an inherent issue for parents in my position? I began to question my very existence in special education, as a parent and educator. In order for me to examine the meaning of my experience, it became evident I needed to study the experiences of others in my shoes. Did they experience similar barriers or derive any benefits of being a school district employee? As a result, my own participation within this research study is that of a researcher and participant. First, my dual role in this study allowed me to access elements of tacit knowledge which aided me in the interviewing process with my participants. It provided me with a greater initial understanding of the situation in order to develop the interview questions and protocol. Second, my parallel insider status allowed me to spend less time understanding the complexities of my participants' cases, and more time discerning the meaning of their experiences within the context of my research questions in the heuristic case study process. The characteristics of heuristic research, according to Moustakas (1990), require the researcher to immerse one's total self and elicit a preoccupation if you will, with the research process and its driving questions. The autobiographical nature of the heuristic method intimately connects the researcher to the question, uncovering as many meanings as possible behind the

human experience. Consequently, the best design for this purpose is that of heuristic case study, as a researcher and a participant.

Collecting the Heart of Their Stories

Acting as a researcher and participant lends itself to certain biases. I already view the world as I have experienced it, as a parent, teacher, and researcher in special education. In Yin's assessment (Brown, 2008), one must identify personal bias, as I just did, and remain aware of how it lends itself to the data collection process. Consequently, a researcher must be transparent and assert oneself to rigorous data collection and analysis procedures, followed by thick, rich descriptions of the cases as required by case study and heuristic research designs.

These designs are meant to be information rich. In order to succeed in this task, I needed to seek out the inner meaning of the experiences of myself and my co-researchers. I needed to probe directly and deeply into the events which previously took place for all so I could achieve the proper descriptions. Therefore interviewing was the primary means of collecting the data to answer the research questions of this study. Merriam (1988) concludes interviewing is the key element of case study, dispensing knowledge when researchers cannot witness the events in someone else's world. It is a means of providing "access to the context of people's behavior and thereby presents a way for researchers to understand the meaning of that behavior" (Seidman, 1998, p. 4), giving us an idea what is on someone else's mind (Patton, 1980).

Interview process. As characterized by Moustakas (1990), the interview, immersion, incubation, illumination, and explication process took place in a step-by-step manner, one person at a time. Co-researchers were interviewed in a series of three separate interview sessions, spanning a three to four week time period as prescribed by Seidman (2006). The interviews lasted 60-90 minutes each and consisted of general semi-structured questions aimed at probing

for details and allowing the co-researcher's story to evolve in relation to the research questions. It was at this point where the intuition of my insider status was able to assist me in knowing what types of follow up questions to ask, which Moustakas (1990) indicates should not be framed in advance because "genuine dialogue cannot be planned" (p. 47). One person at a time was interviewed over the course of a few weeks. Doing so afforded each co-researcher the opportunity "to mull over the preceding interview but not enough time to lose the connection between the two" (Seidman, 2006, p. 21). As well, this allowed me the prospect for thoughtful immersion, reflection, and tacit understanding of each individual experience. It also provided me the necessary time to transcribe the interview itself and develop further questions before returning to the field.

Procedures for collecting data with participants are emphasized in Yin's methodological approach to case study. Therefore, I carried out the step-by-step portion of the interviews with the assistance of an interview guide (Appendix B) as suggested by Patton (1980). The guide was an important data collection tool designed to make sure I sought the same basic information from all co-researchers, yet it was flexible enough to allow me to create a conversational approach consistent with heuristic inquiry and the freedom to probe for further information to illuminate a particular subject. The interview sessions were framed to focus on the experiences and different roles of the co-researchers as parents and educators. The first interview was designed to capture the history and details of the co-researchers past experiences in advocating for their child. The second interview investigated those experiences further from the role as a parent, while the third interview focused on the co-researcher's role as an educator. The questions served as my guide for each of the three interview sessions, while my intuition led me to determine which follow up questions needed to be asked.

All interviews were recorded using an Olympus WS-710M digital voice recorder and two back up recording devices, the voice recording application on my cell phone and the audio recorder on my laptop computer, in the event of a malfunction. The interviews took place in mutually convenient locations, where the co-researchers felt at ease enough to share the in-depth details of their experiences. All interviews with the first co-researcher were conducted at her home. The interviews with my second co-researcher were conducted at a local restaurant and a public library. The three interviews with co-researcher three were held at a local restaurant. Noise levels in any of the locations did not impede on the quality of the audio received. Data was transcribed following each interview and prior to returning for successive interviews. All co-researchers were provided either an electronic or paper copy of the transcription, per their request, and asked to verify its accuracy as a form of member checking.

Each interview was transcribed by me using Dragon Naturally Speaking speech to text software immediately following every interview. The transcription process involved me listening to the audio from the voice recorder and then repeating the words myself into a microphone on my computer while the software transcribed my voice. I ensured correctness of the transcription throughout the immersion and analysis phase as I listened to the audio recordings while reading the transcriptions six more times. I found self-transcription to be particularly important within the heuristic process as I had to listen to the audio from the interview and speak it into my computer, while reading the words which were appearing in the written text. This multi-sensory mode of transcription improved my connection with the data, because I not only had to listen to the spoken words, I had to think about what was said, repeat it into the microphone, and read along with the appearing transcript for accuracy.

Pre-interview questionnaire. Prior to conducting the first interview within each case, I met each co-researcher to explain the study, provide consent forms, and allow them to ask questions. I also asked them to complete a pre-interview questionnaire (Appendix C) to complete on their own and return to me before the first interview session began. The intent of the pre-interview questionnaire was to acquire background information which would assist in developing the individual case depictions while also saving time within the interview sessions themselves for further exploration of the co-researcher's experiences. Demographic information regarding the age of co-researchers at the time of their child's placement into special education was collected, as well information regarding their child's current and previous areas of eligibility, other children of the co-researchers, the co-researcher's ethnicity, the number of states and/or districts their children attended, and previous positions the co-researcher's held within their school districts. The information obtained helped build the background portraits of each case. No additional demographic information was asked as it did not hold relevance in relation to the research questions.

Co-researcher journals. Prior to the commencement of the interview process, co-researchers were asked to record thoughts and ideas they would like to share the next time we met. Co-researchers could accomplish this through any combination of the use of a journal, an electronic blog, or by recording themselves using the electronic recording option on their cell phones. Regardless of the options, all co-researchers were provided with a spiral notebook to use. Since the co-researchers were asked to perform this portion of data collection at their convenience, the alternatives were designed to increase the likelihood of active participation in this form of data collection. The first co-researcher asked to record her thoughts electronically using her cell phone. However, she did not access this or any of the other options. The second

co-researcher used the spiral notebook to journal her thoughts, while the third co-researcher also used the spiral notebook as well as her own personal journal.

Researcher reflexive journal. Likewise, I kept my own journal throughout the entire course of this study, documenting thoughts and information as it came to mind. At times this occurred on a daily basis, and at other times days passed between journal entries. It depended on where I was within the process, whether it was data collection, analysis, development of the written case depictions, or in between cases. I began documenting notes associated with the research process, my own progression through Kristopher's last IEP meeting, and previous experiences of my own which came to mind once this study was approved. As the interview process began with my first co-researcher, the reflexive journal served as a means for me to write down my memories of personal experiences which came about as a result of the dialogue in the interviews. I found the conversations with my co-researchers triggered memories and new awareness of my past in fighting for Kristopher. According to Moustakas (1990), the researcher must "attend to their own awareness, feelings, thoughts, beliefs, and judgments" (p. 31) which develops as a result of discussions with co-researchers. As such, the reflexive journal helped me reconnect with physical and emotional reactions from experiences which were unconsciously buried by time and choice. It also allowed me to record observations regarding the setting, the participant, and non-verbal communication during my conversations with the co-researchers, including the nuances from the interviews. I even recorded my thoughts as I embarked on the immersion and incubation phases within each case.

In addition to the reflexive journal, I myself answered the interview questions from each of the three interview sets. I did this so I could better access pieces of my own story based on my responses to the same questions. I carried out my own question and answer session

following the conclusion of the third written case depiction and prior to data analysis for the group depiction. This allowed me to analyze common themes across all members including myself. All these pieces led toward the process of discovering meaning in the analysis phase.

Qualitative data collection in this manner may come at a price, as qualitative research topics which are emotionally laden may have a powerful effect on the researcher (Rager, 2005). Prior to the commencement of this study, one participant and I coincidentally shared a similar, yet equally traumatizing experience concerning our children. The circumstances were so incredibly identical in the events, as well as the emotions for both boys and us. Listening to her articulate the situation brought back feelings and painful images of a time I wanted to forget. As it did, I once again felt my body start to shiver and feel ill. I wanted to cry, I wanted to throw up, I did not want to relive any of it, but I did. I had no choice as I listened to her tell me the story.

Rager (2005) points to the power of a reflexive journal in helping the researcher see the patterns of emotional reactions, as well as cope with the feelings which arise in consciousness yet again. My reflexive journal captures the struggles I encountered as I approached having to answer the interview questions myself. This portion of the heuristic approach was more emotional and painful than I imagined. I found myself unable to even tell my own story for fear of facing what I was about to uncover. I even remarked in my journal how I quickly found myself unable to do what I had asked my co-researchers to do. When qualitative research begins to impact the researcher such as this, Rager (2005) suggests peer debriefing and counseling as a means for coping with the emotions. As a result, I had to reach out to someone whom I trusted and felt confident would help me find the courage to take the difficult step forward and describe the reason behind mine and Kristopher's story.

Artifacts. The heuristic and case study approaches rely on more than just interviews. They are supported by other artifacts which provide sustenance to the co-researcher's perspectives. Several artifacts became part of the data collection process: IEPs, psychological reports, parent and teacher conference notes, emails, and other pieces of documentation the co-researchers wished to voluntarily provide. During the explanation of the study with each co-researcher and before the interview process began, I asked each of them to provide any documentation they were willing to submit for data analysis. I made copies for myself and returned all original documentation. My first co-researcher initially provided a folder with multiple IEPs, psychological reports, her own written records prior to IEP meetings in years past, and teacher conference notes during our first interview session. She supplied me with two more IEPs during our subsequent meetings. Co-researcher two provided me copies before our first interview from a three-ring binder which she used to maintain and organize documentation throughout her son's educational career. Co-researcher three went to her son's school, requested a copy of all IEP related documentation in her son's cumulative folder, and gave it to me during the second interview. I myself had access to every IEP, psychological report, formal assessments, and emails I had kept since Kristopher's entry into special education. Each piece of data provided to me by my co-researchers confirmed potential challenges incurred within these cases or provided other perspectives of the parent-educator's advocacy related experiences. As Moustakas (1990) explains, the heuristic researcher must gather "detailed descriptions, direct quotations, and case documentations" (p. 38) from multiple sources to build the case depictions. However, interpretation of meaning of the data in relation to the line of inquiry relies on the insights of the researcher (Merriam, 1988).

Data confidentiality and storage. Since confidentiality was of utmost importance for my co-researchers, I adhered to stringent methods of collecting and storing data, emphasized by Yin (Brown, 2008). Each participant selected their own identifying pseudonym, which were used on all sources of data, both paper and electronic. Paper data sources (pre-interview questionnaire, documents, printed transcriptions, and journal notes) were kept in individual folders in a locked file cabinet. Consent forms were kept separate from other documents in the file cabinet. Electronic files of all data were stored in a database on an external flash drive, as well as on a backup CD, and kept in the locked cabinet. Additionally, recorded interviews were transcribed and stored on the external flash drive. The original recordings were then deleted from the digital voice recorder. The flash drive and backup CD were also stored in the locked file cabinet at my home and will remain there for three years following the completion of this study when the files will be destroyed.

Data Analysis and Back Again

Data collection and analysis in a heuristic case study is an ongoing, unified process which continues until the creation of the final product, the creative synthesis. Patton (1990) indicates there is a long-standing debate related to qualitative methods and approaches, and how the interpretive nature fits into the larger picture of the social sciences. Heuristic inquiry relies heavily on the interpretations of the researcher. Therefore without formal rules on how to make meaning of the data, Moustakas (1990) provides a heuristic guide for the researcher, outlining the important aspects of undergoing a step-by-step process of analyzing, evaluating, and presenting the culminating products.

In particular, the most central element of the analyzing process, according to Moustakas (1990), is the back and forth nature of examining the data (e.g., interview transcriptions, journals,

documents, and reflexive journal), looking for patterns from the in-depth interviews, consciously reflecting on the data, taking notes, setting it aside for a period of time, and then returning to the original data once again. A visual representation of my data analysis process is seen in both Appendix D and E. It is at this point when intuition and tacit knowledge take over and bring thoughts, which rest in the subconscious, to the surface. Moustakas (1990) indicates this is a place where the researcher must arrive, as it cannot be forced. These steps, outlined previously in this chapter, complete the immersion, incubation, illumination, and explication phases of heuristic inquiry. The researcher then becomes fully conscious of his/her own thoughts, feelings, and meanings of the phenomenon, permitting the culmination of an individual depiction of the co-researcher's experience and eventually the final creative synthesis. I carried out the steps of this process by visiting the interview audio recordings a minimum of seven times, as well as analyzing the documents on several occasions within the immersion phase. My degree of immersion throughout this study allowed me to develop a group depiction and then create a final synthesis which emerged from deep within my own being.

Interview data analysis. I transcribed the audio into a word document immediately following each individual interview by speaking into a microphone using the Dragon Naturally Speaking speech to text software program and repeating the words of the co-researchers. A progression of my interview data analysis is outlined in Appendix F. I verified the accuracy of the transcription by listening to the audio recordings a second and third time while looking for errors in the written transcription. I then gave my co-researchers copies of the written transcripts as a form of member checking. These steps were repeated following each interview within each case. After conducting and transcribing the third interview and providing the co-researcher with their last copy of the transcription, I began to further immerse in the data. Immersing in the

interviews involved returning to listen to all three interview recordings back to back, while reading along with the corresponding transcripts for a fourth, fifth, sixth, and seventh time. On the fourth visit with the interview data, I only listened intently and read along. I began to take simple notes on the written transcripts the fifth time I listened to the recordings and then expanded on those notes when I listened and read for the sixth time. Themes which began to emerge were written on sticky notes and placed onto a poster board to allow for reflection and refinement as I continued to move back and forth with the data. My seventh and last visit with the interview transcripts involved color coding the themes according to their relation with the three research questions. This last step of immersion also involved cross-checking the emerging themes with the interviews and further enhancement of those themes. For example, some themes which initially materialized within the note taking process were either eliminated due to lack of supporting data or names of themes were relabeled to better represent the concepts which emerged. Themes were then finalized following meetings with two peer reviewers and resulting discussions on the connections to the data. The immersion, incubation, illumination and explication phases occurred for me on a daily basis. I immersed in the data in the evenings and experienced the incubation period during the day while at work. Each time I returned to the data following the fourth, fifth, and sixth visit with the transcripts, illumination and explication would naturally occur leading me toward identifying themes and making connections.

Document analysis. The documents which the three co-researchers voluntarily provided were analyzed after I received them. Co-researcher one provided me the majority of her documents at our first interview, and followed up with more documents on subsequent interviews. Co-researcher two gave me everything she had following our first interview, and co-researcher three provided me copies all the documents from her son's cumulative folder during

our second interview. I combed through the numerous documents in between interview sessions with all co-researchers, initially thinking the documents would lead to further questions within the interviews. Instead, I found that the psychological reports, IEPs, parent and/or teacher conference notes, and any other documentation helped me better understand the co-researcher's overall experiences in special education while also providing a foundation for their individual depictions. I read each and every piece provided to me, in progression from the earliest documentation to the most recent to allow for better understanding of the child's evolution through the special education process, and blacked out all identifying information at the same time. I organized all the documents, interacted with the data by taking notes, and highlighted information which pertained to the themes which were emerging from the interviews.

Journal analysis. Each co-researcher was provided a spiral notebook upon receipt of the consent forms and asked to write down ideas and thoughts which came to mind prior to the first interview and in between the successive interviews. All three co-researchers were also given the option to record their notes using the voice recorder function on their cell phones or employ a blog. Co-researcher one preferred to use the cell phone, but did not access it or the journal notebook. Co-researchers two and three used the journal notebooks. Co-researcher two gave me her journal three weeks after our last interview. Co-researcher three gave me pages from her notebook each time we met for interviews. The intended purpose of the journals was to capture experiences which may have come to my co-researchers minds in between interviews. Co-researcher two mostly used the journal as a means to vent her frustrations in relation to her son's special education experiences. Co-researcher three utilized the journal in accordance with my intentions, documenting her pieces of her experiences which were not discussed during our interviews. I analyzed both of their journals within my immersion phases and incorporated the

available information into the development of the individual themes and then color coded the data in relation to those themes. I was able to use very little information from co-researcher two's journal, however co-researcher three's journal provided more usable information.

Researcher reflexive journal. As previously mentioned, I documented my own thoughts, feelings, memories, and reactions throughout the course of this study. Once I completed the third interview in each case and began immersion, I incorporated my journal entries up to the date which I began the case analysis, looking for elements relating to the individual themes. I separated my journal entries according to the case I was working with at the time. When I moved to the next co-researcher, I began a new set of journal entries and repeated the analysis process for the reflexive journal. Following the completion of the third case, I gathered all my journal entries from the beginning to the end, and analyzed their importance in relation to the themes associated with the group depiction.

Pre-interview questionnaire. The pre-interview questionnaire was returned to me by each co-researcher upon the first interview. The purpose of the questionnaire was to glean important background information without detracting from the interview time frames. I analyzed this information as well within the immersion phase and used it to understand the essentials of my co-researchers and their children's backgrounds in special education. The information also helped establish specifics in developing the individual case depictions.

The multiple iterations of data analysis from the five different sources as mentioned helped me understand the meanings of the phenomenon and achieve verification of the stories within the case studies (Moustakas, 1990). Polanyi (1969) describes this reflective process as a rigorous series of steps which must occur in order for the researcher to make the final judgment on the underlying meanings. I was able to make final judgment on the individual case themes by

placing my thinking on sticky notes and using a tri-fold display board to make connections among the themes. After I made those connections, I began to code the interviews during my seventh round of immersion, highlighting the transcripts with colors associated with my three research questions.

Once I felt the resulting themes matched the data, I met with two peer reviewers, an educator and a researcher in order to reduce concerns with bias. I elected to meet with two reviewers in order to address two of my roles within this study, that of an educator and that of a researcher. When meeting with the peer reviewers I provided a chart outlining my themes and explained the pieces of data which I believed supported the development of my themes in relation to my research questions. On two separate occasions, once in the first case and once in the third case, I altered themes based on suggestions within the peer review process. In both instances my peer reviewers proposed I re-label the themes to better represent the information we discussed. After the peer reviewers felt my interpretations and thinking matched my data, I began to write the individual depiction highlighting the themes which emerged.

As soon as I reached the completion of each individual depiction, I asked myself whether the depiction of the experience adequately defined the data from which it was developed, and whether it retained elements critical to the experience (Moustakas, 1990). Once I felt assured the depiction accomplished that task, I then carried out a form of member checking and shared it with my co-researchers, confirming its completeness and accuracy. Any inaccuracies were discussed with the co-researchers, corrected, and shared once again until complete accuracy was confirmed. My first co-researcher was concerned about her use of the words “like” and “you know” and other forms of redundant language. It was decided to eliminate those words and use

ellipses to allow for better readability. Co-researcher three expanded on a few of her statements and clarified another. Otherwise no other changes were made within the individual depictions.

I followed this back and forth nature of immersion, incubation, illumination, explication of the data, and the development of the case depiction for each co-researcher one at a time. After carrying out this process for each co-researcher, I gathered all the individual depictions in accordance with the next step in the procedures set forth by Moustakas (1990) and returned to a state of immersion. I analyzed the themes across the individual cases, immersed in the interview transcripts once again, and returned to themes to finalize the common threads which tied the individual cases together. This phase was once again followed by a periods of rest which allowed the meaning of the experiences to arise in consciousness. At this point, a composite depiction was created using the components and core themes which represented the experiences of the group as a whole. The phases leading to the group depiction came easily as I found myself thinking about common themes as I progressed through the individual cases.

Typically a heuristic case study concludes with one last depiction prior to the culminating creative synthesis, as the researcher is to enter into one final state of immersion with the raw data and the individual depictions. The researcher is to select two or three co-researchers from which to draw upon autobiographical information gathered throughout the study. All the information is then to be crafted into an individual portrait “in such a way that both the phenomenon investigated and the individual persons emerge in a vital and unified manner” (Moustakas, 1990, p. 52). These individual depictions are then presented as one single representation. Due to the sample size in this study, selecting two or three co-researchers to represent the group would have meant using the most of the entire group. It was my determination the group had already emerged in a unified manner in the group depiction, becoming one voice. Therefore separating a

case or two from that single voice for the exemplary depiction meant defying the purpose set forth by Moustakas.

The final step in analyzing and presenting the research phenomenon is realized when the researcher uses artistic talents to construct the final creative synthesis. This concluding depiction, comprised of a narrative, poetry, artwork, or verbatim conversations, is meant to portray the co-researcher's story. In this culminating research experience, the researcher has "free reign of thought and feeling that supports the researcher's knowledge, passion, and presence" (Moustakas, 1990, p. 52) to fashion an artifact which draws upon the identified themes and essential meanings of the data. Moustakas (1990) defines heuristic research as a demanding process, which "requires a passionate, disciplined commitment to remain with a question intensely and continuously until it is illuminated or answered" (p. 15). In this inquiry, my final synthesis was not planned. It came as a result of countless hours immersing myself in the words of my co-researchers. It was those very words which spoke to me and led toward the concluding product using a version of poetry called a found poem. The nature of a found poem is further explained prior to the creative synthesis near the end of Chapter Four.

Credibility and Trustworthiness

The selection of the heuristic, case study may provide concerns for those seeking truth through the paradigm of positivism. However, the interpretive nature of qualitative research requires the researcher to make judgments about what is true by analyzing and interpreting data in relation to the phenomenon (Patton, 1980), leaving the scientist to "make the ultimate judgment" (Moustakas, 1990, p. 33) because they are the one who returns to the data time and time again verifying its meaning. The trustworthiness of the data collection and the individual

depictions was checked each time I returned to my co-researchers for member checking and sharing of their case portraits.

With an emphasis on the interpretive nature of qualitative case study research, Stake (2008) maintains the essence is in the case selection. Cases were selected in this study using purposive, critical case sampling. This non-random sampling method may create concerns regarding similar perceptions of the co-researchers because they all represent an extremely narrow, yet similar population. However, Polkinghorne (2005) states that “participants and documents for a qualitative study are not selected because they fulfill the representative requirements of statistical inference but because they can provide substantial contributions to filling out the structure and character of the experience under investigation” (p. 139). The unit of analysis is the experience. Therefore in order to explore and understand an experience, participants who have had the experience were needed. The cases are defined and bounded. The intent was to implore cases which are information rich, where researchers and readers alike can learn the most concerning a central idea or issue (Polkinghorne, 2005). Merriam (2002) states the researcher is not concerned with “how much” or “how often”, but rather “the meaning of a phenomenon from the perspectives of the participants” (p. 12).

Meaning making in qualitative inquiry is subjective, opening the design to questions of credibility. Careful attention to the conceptualization processes can allow a researcher to eliminate concerns about truth. Merriam (1988) suggests doing so by employing six strategies in qualitative research: triangulation, member checks, long-term observations or interviews, peer examination, involvement of the participants, and clarifying the researcher biases. Triangulation in this study is based on accessing and analyzing multiple forms of data in relation to each other (Merriam, 1988; Patton, 1990), interviews, journals, a questionnaire and other documents.

Member checking of transcriptions is accounted for each time the co-researcher was given an opportunity to verify the accuracy of the interview transcriptions as well as the written depictions. Prolonged engagement using a three-step interview process (Seidman, 2006) enhances credibility as well, since I had the opportunity to confirm or disconfirm the information in each successive interview with each co-researcher. The researcher may cross-check the co-researchers' notes in their journals as well. Peer reviewing, according to Merriam (1988), is accomplished by asking colleagues to evaluate the researcher's findings as they become apparent from the data. This strategy served as a check against biases which may have clouded my own interpretation. Two peer reviewers were used within this study, an educator and trained researcher. Co-researchers also became part of the credibility process as I shared the depictions and asked whether the results of the intense reflective process were credible and accurate. Moustakas (1990) indicates validation is achieved because the researcher returns to the data on numerous occasions to verify whether the themes and qualities portray an authentic depiction of the phenomenon.

These themes and concepts are the result of concentrated sifting, exploring, reflecting, and judging of each piece of data. The heuristic researcher is constantly appraising the significance to achieve "a valid depiction of the experience being investigated" (Moustakas, 1990, p. 33). As I concentrated on the data within each case, I found myself changing and refining earlier appraisals. I continued this extended analysis of the data until I was sure each of my themes accurately represented all the information obtained from each piece of data. The resulting themes were discussed with two peer reviewers for each case analysis to eliminate potential bias. Within the peer review process and subsequent discussions of the data, two

themes were further analyzed and adjusted to align with the data for co-researchers one and three.

The last element of establishing credibility within a case study is for the researcher to clarify their assumptions. My assumptions surround the multiple roles I serve as a parent of a child with a disability, a teacher in special education, and a researcher in special education. I outlined my theoretical perspective previously in this chapter so the reader can understand how and why I make meaning. Yet the meaning of these experiences only came to me through a rigorous, step-by-step process infused in heuristic inquiry. Moustakas (1990) maintains the primary researcher is the only one who can validate the meaning because it is derived from my own interaction and interpretation of extensive analysis of the data.

The process of qualitative research is highly intuitive, and readers may even question how to generalize what they read to a larger setting. This desire is linked to traditional scientific experimentation, not humanistic inquiry (Patton, 1980). Thinking and theorizing over the data is the process by which qualitative inquiry “provides the richly interpretive narrative that is the heart of the case” (Brown, 2005, p. 4). Context plays an important role in interpretive research as the inquiry uncovers an experience, not a correlation to a cause (Corbin & Strauss, 2008). Therefore, the intent is not to generalize the findings for all, but to allow the reader to feel the experience and generalize within the context of a unique group of people who advocated for their children inside the school district where they worked.

Summary of the Chapter

The stories of parents like me are stories untold. This chapter has outlined how I uncovered the experiences of those who advocated for their own children with disabilities inside the school districts where they work. I used a heuristic, case study design to uncover what lies

inside the walls of “the system” and examine their perspectives of challenging the districts where they work. Three co-researchers, selected through purposive, critical case sampling joined me in this journey. My chosen research method and its procedures not only allowed me to understand the experiences of my co-researchers, it also led to an understanding of my own experience through the meaning making progression of heuristic inquiry.

The case study design, using frameworks from Yin, Merriam, and Stake guided me through the collection of interview data and the accumulation of documents and journals from my co-researchers, so I could paint an information rich depiction of each case and each experience. I underwent an intense relationship with three co-researchers and the information they revealed. Readers will come to know these co-researchers, and feel the purpose and passion in their advocacy for their children as they read the case studies in the next chapter. I also came to know them, and came to better understand myself, as I reflected upon my own thoughts and emotions, coming to a holistic understanding of the meaning of my advocacy for my son. I may now answer my questions: Was our experience just our own? Or have others experienced the same? The next chapter begins to uncover their stories and unleash their voices.

Chapter Four:

Our Stories, Our Voices

The purpose of this study is to uncover the experiences of parents, who are also educators who advocate for the rights of their own children with disabilities within the school districts where they work. These parents, including myself, serve more than one role in their school districts: parent of a child with a disability and teacher for children with disabilities. My own experiences in advocating for my son, Kristopher, served as the motivation behind this research topic. For many, many years I wondered if we were alone. I wondered if anyone else encountered the same difficulties in obtaining a free and appropriate public education for their own children. I wondered if others who worked in the school system had the same difficulties. I wondered if anyone else worried about the ramifications of advocating against their employer. I wondered if anyone else had remained silent, until now.

To this end, three research questions were developed to guide the focus of this inquiry:

- 1) What are the experiences of school district employees who challenge their own districts in the interest of their children with disabilities?
- 2) What barriers do these parents/district employees feel they encounter in advocating within their own districts?
- 3) How do these parents and district employees perceive their involvement in advocating for their own children in relation to their job security?

Three co-researchers were identified using purposive, critical case sampling to provide the thick, rich, and in-depth analysis required of a heuristic, case study design. As described in Chapter Three, the data collection process began with a pre-interview questionnaire designed to gather necessary background information without consuming time during the interview process. Upon receipt of signed Informed Consent forms, each co-researcher participated in three separate recorded interview sessions and provided documents such as IEPs, psychological reports, emails, or other documentation associated with the experience in advocating for their children with disabilities during the school years. They were also provided spiral notebooks and asked to keep a journal upon completion of the signed consent forms. Co-researchers were asked to document their thinking in response to our interviews and any experiences they may have remembered in between. The opportunity to use the voice recording function on their cell phones was offered as an alternative to the journal notebook. Two co-researchers said they preferred the journal and used it. The other asked to use the voice recorder on her phone, but never used it for documentation. She was also provided the journal in the event she found it more advantageous for her needs. Data were also collected from my own researcher reflexive journal and interview notes which I maintained throughout the course of the study.

Each co-researcher and her child selected pseudonyms in order to protect their identities. Upon entry into the study, all three co-researchers were currently employees within school districts in the southeast United States. All three still had children who received special education services inside those same districts, therefore maintaining their confidentiality was of utmost importance due to the nature of this study and the relation to the research questions.

Heuristic inquiry begins with the researcher and the internal desire to know and understand meaning. In my case, I have experienced many situations regarding Kristopher's

access to FAPE. I have experienced frustrations over lost IEPs. I have struggled obtaining testing and classroom accommodations. And I have been on the verge of asking for due process, all while wondering if I was the only school district employee struggling with the system when it came to the rights of my child under IDEA. Therefore I sought out others who served that same dual role as a parent of a child with a disability and an educator. I wanted to hear and tell their stories. In order to do so, I developed a depiction of each co-researcher in accordance with the heuristic creative synthesis. Using a narrative format so as to *keep them alive* through the power of their own voices, I used my co-researchers own words.

I begin this chapter by introducing each co-researcher using demographic data and information provided in the pre-interview questionnaires (see Table 2). Due to the depth of information obtained during data collection, their stories are told in relation to the three research questions associated with this inquiry regarding experiences, barriers, and perceptions of job security in advocating for their children. The purpose of this organization is designed to provide the reader a systematic approach to following the findings which address the research questions. Embedded within this structure addressing the research questions are individual themes which emerged from the co-researcher's collections of interviews, documents, and journals, both theirs and mine, upon completion of the immersion, illumination, and explication phases of the heuristic method.

The written case depictions also include my reactions as I interacted with the data and took notes regarding the unique features within each interview and the numerous pieces of documentation provided. Following the depictions of all three co-researchers is the culminating depiction which brings together themes which are common, yet not immediately identifiable across the individual depictions. A return to the data following completion of all individual

depictions for further phases of immersion and rest allowed me to identify unique commonalities in our stories. These themes indicate relationships among the experiences of my co-researchers and I, the barriers we have encountered in advocating for our children within the school districts where we worked, and the perceptions of job security in relation to our advocacy. This process of revisiting the data on numerous occasions, individually and among the group, and allowing subconscious thoughts to rise up into consciousness ties the six phases of the heuristic process together into a cohesive synthesis.

Table 2

Demographic Information of Each Co-researcher and Student with a Disability

	Ruby & Chuck	Judith & Barry	Kate & Eric
Age	42	42	33
Current Position	Regular Education Teacher	Para-professional	Special Education Teacher
Years in Education	9	8	5
Eligibility Area of Child	Autism Spectrum Disorder	Specific Learning Disability	Speech Impairment
Previous Eligibility Area of Child	Language Impairment Developmental Delay		Language Impairment Developmental Delay
Current Grade of Child	10 th	9 th	5 th

Each co-researcher’s case is unveiled in narrative form with excerpts from our interviews, the collection of documents, and the journals. In order to assist with the readability

from the interview transcriptions, repetitive words and self-corrections made by the co-researchers have been replaced with ellipses. Longer quotations are presented in block format, while shorter quotations are separated with quotation marks. Quotation marks within the dialogue separate the conversations used by the co-researchers to describe discussions and experiences with school district employees.

Ruby and Chuck: Their Fight to be Heard

Life has taken an interesting turn for Ruby, a mother of a 17-year old young man. “I never had dreamed in my wildest dreams that I would go into education to be a teacher.” Initially, Ruby went to college to become a journalist. Writing was her passion, or so she thought. Her hopes and dreams to aspire to become a newspaper writer or even go into television broadcasting were put on hold when she received some news which eventually changed the course of her life. Chuck was diagnosed with Autism Spectrum Disorder. To Ruby, his diagnosis meant she would have to work closely with Chuck, making sure he was learning academically and growing socially as well as emotionally. To do so meant diverting from the direction in which she was heading; to completely alter her life plans and work toward becoming an educator.

I’m like, I’m going to be a writer. My whole life, you know, but be a writer and going to be a writer. And when I was younger my cousins or my uncle would joke about, oh you want to be a teacher. I don’t want to be a teacher. Why would I want to be teacher?

Ruby quickly discovered why she would want to be a teacher. For the same reason as I became a teacher, “because I could help him” she confidently expressed.

I had known Ruby for more than two years prior to her interviews. I had known Chuck for equally as long. Ruby and I met in a school. She was a regular education teacher and I was a

special education teacher. I met Chuck when Ruby brought him into school on teacher work days. He was always such a polite young man, well-mannered and loving of his mother. Ruby spoke of him often. Her passion for his needs was always evident, as perhaps was mine. As our friendship grew, Ruby and I quickly learned we had much more in common than most educators. We both had a child with a disability. We both were in other fields prior to entering education; ironically we both previously aspired to become journalists. And we both had a similar passion in advocating for our boys. But our lives were forever altered by the needs of those boys.

Early on we both recognized the calling to change careers. “I knew at that point that I needed to do it,” insisted Ruby. With a journalism degree already in hand, Ruby went back to school to become a teacher. But first she seized an early opportunity to work in Chuck’s school as an aide while she returned to the classroom herself.

Well at first when I thought about going into it..., because I could help him, because I could be more present, because I could learn more. But then..., this is what I need to do so that I can advocate for him.

It was the idea that working on the inside would lead to making sure Chuck got what he needed for his education. Or at least that was her intent. What transpired in the years following tested Ruby’s resolve in advocating for her son’s needs. Her experiences throughout the years have been both positive and not so positive. “It has been difficult at best at times and then other times not as difficult and not really needing to do as much.”

Chuck received his first IEP under IDEA Part C, as he was identified in a different state for early educational intervention through speech and occupational therapy. Shortly thereafter, at the age of three, Chuck was diagnosed with Attention-Deficit/Hyperactivity Disorder and a mild form of Autism Spectrum Disorder at four years old. Chuck’s impending need for special

education assistance in the school setting was evident in his first psychological report, where difficulties with receptive and expressive language, intellectual functioning, adaptive behaviors, sensory regulation, and social interactions were identified. Later assessments indicated performance deficits in fine motor skills, with a relative strength in his verbal skills. He was placed in an early childhood preschool class to better address his academic, social, and communication needs.

Upon completion of preschool, Chuck's IEP team determined he should advance to kindergarten in a regular education environment with the assistance of an individual aide, a special education inclusion teacher, and continued speech and occupational therapy services. While in kindergarten Chuck struggled with peer interactions, sensitivity to loud noises, and transitioning between activities. His writing skills were noted as below expectations, though further psychological measures indicated he was gaining in other academic areas. Even though Chuck received special education services while being educated in a regular education classroom in kindergarten, his later placements were not always as such, and the decisions were not always easy.

When he was having more trouble in first grade and I..., felt like we needed to give him more time to see how a gen ed setting would work out for him. I had to advocate in terms of..., have people..., back me up as far as..., having a neutral person in a meeting..., to say..., he doesn't need to go self-contained.

Ruby quickly found herself needing to know more. She needed to know and understand the disability which confronted Chuck. She also needed to know and understand Chuck's underlying needs and the accommodations which best addressed those needs.

Some of the things..., that I have to advocate for as a parent for him when I think about it are things that a lot of people take for granted, like really small things. In aftercare, you know..., if you don't have him have a snack first and then do his homework..., you're going to have a problem. Or if he doesn't get some downtime before you tell him he has to do his homework. Whereas other kids will just..., they'll just do it.

Developing such an intuitive nature to her parenting, Ruby was able to capitalize on her insights and share with educators what worked and what did not. At times her knowledge was received well when she had to advocate for Chuck. At other times it was not. "I wasn't in education at the time and my voice was not really listened to." So she supplemented her mother's intuition with knowledge of the laws and Chuck's disability. She learned what it meant to be a child with autism and she learned what IDEA stood for and how it outlined protections for children with disabilities in educational settings.

She even entered the school system as an aide when Chuck was in first grade, hoping to learn more and do more in the best interest of her son. It was at that point when she decided a career in journalism was not for her, and she went back to school to become a teacher.

But the road to attain more knowledge as both a parent and educator established a path not easily traveled. As Chuck progressed through the school systems in three different states, Ruby found herself experiencing the highs and lows of being a parent of a child of a disability inside the school system while also working as an educator. On three different occasions, once during elementary school, once during middle school, and once at the beginning of high school, Ruby became frustrated with the academic settings for Chuck. Each of those times she used her options for school choice and moved Chuck into a different placement. She even experienced what she called a defining moment in her advocacy for Chuck, feeling a sense of

accomplishment and confidence. “For a long time it really felt like that was just the way it was supposed to be, until the first negative experience.”

The remaining depiction outlines those experiences in relation to themes which support the three research questions regarding the experiences, barriers, and perceptions of job security while advocating from the inside and the outside.

Experiences in challenging school districts. “I would have to say the most positive experience was early childhood through..., elementary.” Ruby and Chuck’s experiences surround both the positives and negatives, with each resulting in its own implications. As I immersed myself in the data from their story, I began to make connections as seen in Figure 1 and visualize how each component interacted with the others. I refined the themes each time I visited the interview audio file and transcripts until I no longer made changes and developed my own consensus of my interpretations of the data. I shared my outline and my thinking with my peer reviewers who agreed my interpretations and themes were not a surprise and appeared free of bias. The following depiction presents Ruby and Chuck’s experiences in accordance with the themes which support my three research questions.

Positive experiences. Chuck’s early years in elementary school were not too turbulent according to Ruby. She had just become an aide and admits she was still learning to understand autism and its characteristics, “I didn’t know as much.” Therefore she had to seek outside assistance when it came to an IEP meeting during first grade to discuss moving Chuck from the regular education environment, where he had been with his one-on-one aide since kindergarten, into a more restrictive, self-contained setting.

When he was having more trouble in first grade and..., I felt..., we needed to give him more time to see how a gen ed setting would work out for him. I had to advocate in

terms of like, have people..., back me up as far as like having a neutral person in a meeting..., to say like he doesn't need to go self-contained.

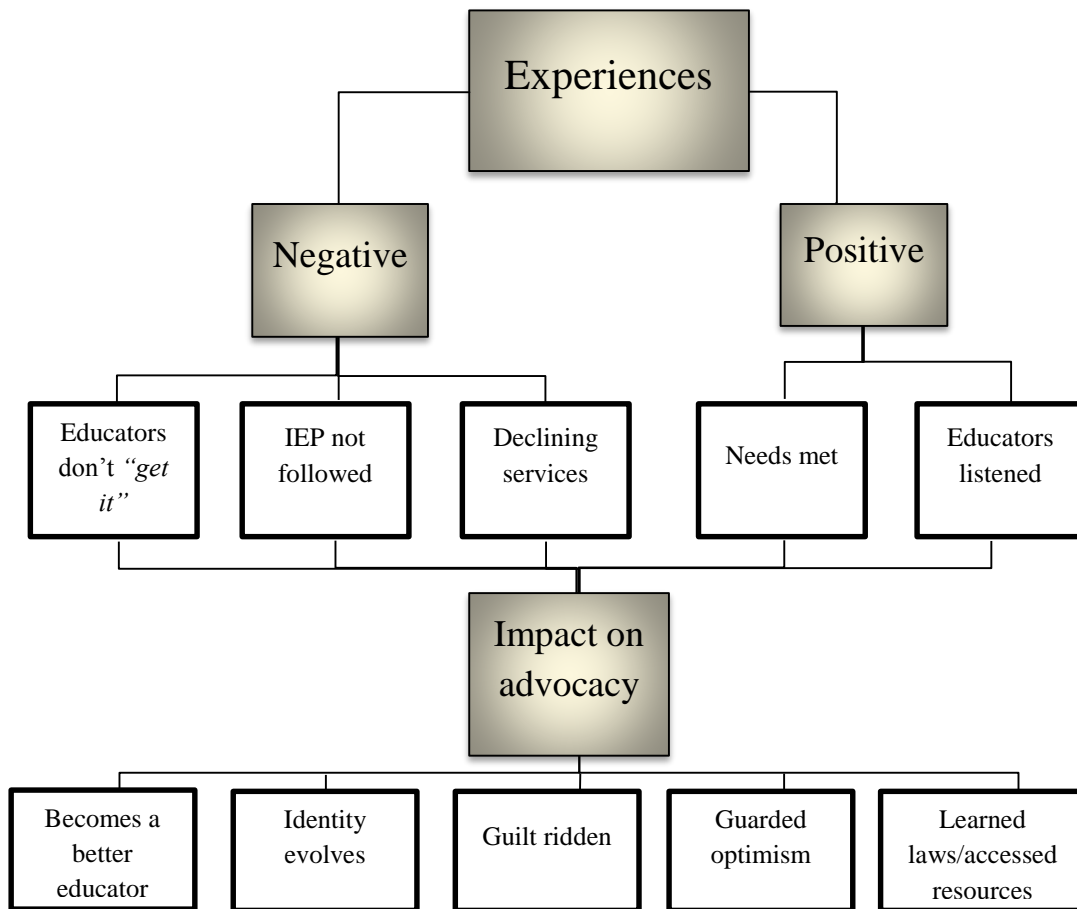


Figure 1. Ruby's experiences in challenging the schools and districts where she worked and the impact on her advocacy.

Ruby enlisted the help of a neutral advocate to help her convey the message that Chuck did not need to go into a self-contained classroom. At that time she was beginning to grasp the purposes of least restrictive environment and advocate for those rights afforded to Chuck. "That was a very simple thing. And then second-grade was a very good year." Ruby continued to

speaking of positive experiences during Chuck's years in elementary school. She did eventually agree to place Chuck in a self-contained setting for the beginning of his third grade year.

However, Ruby later found that decision to be far from the best. Midway through the year, Ruby insisted Chuck be removed from that self-contained classroom and placed back into a regular education environment. It was not an easy IEP meeting, but it was one which was met with positive results. "When they signed off on it, it was easy because I had built that case like I had said and I had outlined it." Ruby had readied herself prior to the meeting, outlining her plan in advance of the meeting, as seen in the documentation she provided, and planning to voice a wide range of concerns regarding Chuck's self-contained classroom and his need to be placed back into his least restrictive environment.

Regardless - I am his Mother, I know him best. I'm not going to "give up on him" because he has a label and an IEP. Extensive research has shown that children with IEP's and specifically children with ability levels similar to Chuck - come out more successful in their futures if they are mainstreamed and not in a restrictive environment. (Ruby's own typed notes prior to her meeting, 1/04/2006)

She left the IEP team little choice insisting that "it is OBVIOUS that he is not in the least restrictive environment."

I said you know this is the option, this is what we're doing and so they gave him that placement and he got the aide. And then two weeks later that teacher was walked out of the school for abuse of a nonverbal child.

As a result, the IEP team agreed to place Chuck back into a regular education classroom for the remainder of his third grade year and part of fourth grade. It was at that point when Ruby

began to hear from other parents of children who were also in the self-contained classroom about an all special education private school, designed for children with needs like Chuck.

The state that we were living in had something where if the district would agree to an alternate placement in a private setting, the district paid for that private setting, and that placement was the best thing that we ever got.

So Ruby asked for another IEP meeting. This time she prepared herself with what she described as a brief, completely outlining her concerns regarding how Chuck's needs could best be addressed in the all special education private school.

The district after that really rough patch [self-contained teacher being removed] had just agreed to sign up paperwork for him to go to a private setting. And in that case I..., prepared a very big thing to where I thought I was going to have to advocate profusely, and I didn't have to as much as I thought I was going to, because they agreed. And so I was prepared and I did a lot of research on all these things, but then..., we just were given that placement. So, which was pretty much like gold, not to ever be found again. So other experiences are within that private setting in that state in [state name], that was beautiful.

Ruby was clearly pleased with the treatment she received during the meeting and with the district's decision agreeing to a non-public school. Chuck's private placement came with all expenses, including bus transportation, paid for by the school district. Throughout the three separate interviews, Ruby referred back to this scenario as perhaps her defining moment, but also for comparison when she discussed difficult experiences later in Chuck's middle and high school settings.

I would have to say the..., best, I don't know that I can compare but, one of the other things that was just so wonderful was having that private setting, that was so therapeutic and was beautifully laid out, paid for, and the transportation was provided because it was a district placement. And so that setting was as a parent, I knew was the best setting.

When I asked her about what made the private placement setting so beneficial, she quickly identified specifics of accommodations and related services which were starkly different from what was provided to Chuck in his later years.

It was an all ESE setting and it was for the particular grade that he was in, it was one special ed teacher with an aide sometimes two. A very cross categorical setting which was a term in [state name] we used a lot, of a lot of different mix of kids but therapeutic in the sense that we had a social worker, we had an OT [occupational therapist], we had a speech person we had an incredible principal who was highly, highly knowledgeable and professional and teachers that were completely immersed in special education practices. So those teachers knew practices backwards and forwards.

Ruby went on to further explain how the all special education setting provided what she felt best addressed Chuck's needs.

What made it so beautiful was that even though the kids were older, there was the recognition that even though these kids are older and yes they're on a regular diploma track, they still need these things. They still need the same level of support socially and cognitively and maturity wise to get through it. If that makes sense?

Educators listened. Even though Ruby had to advocate for that placement into a private school following the situation where Chuck's teacher was removed from the classroom under allegations of abuse, Ruby continued to speak highly of her overall experience in that northern

state. Within her multiple interview sessions she continually talked about her voice being heard and educators who listened to what she said regarding Chuck and how that commitment to meeting Chuck's needs while treating the parent as a team member made all the difference in how she perceived the positive experiences.

I was equal. And so they listened to what I said about..., Chuck and there was never a moment where I questioned their judgment on anything because I knew that it was just, it was perfect. It was all at his level of need.

Ruby freely admitted that despite some difficulty of having to advocate for various placements for Chuck throughout elementary, it was just something she needed to do. "If you don't advocate for them, then they're not going to get what they need." She considers her experience during the time up north as fairly positive because of the overall treatment of Chuck as a student, and Ruby as a parent.

The most positive thing I think was..., elementary, and people that listened, and people that did what they were supposed to do. And then also there was..., a sense of understanding that all kids need different things and that they don't all need the same placement, and that the parent is an equal team member. I got that probably 75% of the time I was there.

Also of importance to Ruby was the feeling that she was not Chuck's only advocate. She felt she had an ally on the inside. One who she felt was open to suggestions and concerns regarding Chuck's classroom environments. At that time a mother's intuition told Ruby she needed to make her voice heard to those who would listen and seek a change in placement to the all special education private school.

The principal listened to me, but her hands were kind of tied. She was a first-year principal... at this school. And she didn't have the best reputation for whatever reason, but she listened to me. I sat in a meeting and I said something is wrong.

Having a voice and having someone who would listen became a vital piece of the process for Ruby. She and her husband made the difficult decision to move to a state in the central eastern section of the United States. In a new location, she found herself placing Chuck in a similar school, one which only worked with children with special needs at the steep price of \$10,000 a year in tuition. Unlike her experience up north, Ruby had to advocate when she felt no one was listening, let alone meeting Chuck's needs. To make matters even more challenging, Ruby was working in the same school as a teacher at the time. The situation became increasingly difficult, leaving Ruby no choice. She elected to remove Chuck from the all special education private school and place him in a faith-based Catholic school which served only 50 students. She also managed to find a position there working as a teacher and found the setting to be more like she had hoped; one which allowed her to be a parent first and worry less. "I probably just did as much as normal parent would there, because I had a really good..., leadership. The principal was completely on board and like she listened to me."

It was this particular setting where Ruby felt a solid connection to those in charge of Chuck's education. She was able to take a back seat, let the teachers do their jobs, while she did hers. I asked her to talk about any experiences where she felt the school had Chuck's best interest at heart. She referred to the small Catholic school, as opposed to the other public and private school, where Chuck attended.

I feel like they for the most part, especially the principal, that she always had his best interest at heart. And I think that I can say that confidently because on a private school

level..., they're making all sorts of accommodations and even modifications on a private level that other schools couldn't. And so they were constantly..., understanding him [Chuck] and they always wanted him to do his best.

Chuck spent part of his middle school years in that Catholic school, before he and Ruby moved farther south. Her decision was based on access to family and knowing there was opportunity for state level funding for alternate private placements for Chuck. For the most part, when Ruby spoke of the middle and high school years, she spoke of frustrations. But in attempting to identify areas which she considered positive experiences, she spoke again about those who would listen.

And then coming into [state name], I would say that..., we had some positive moments at [school name]. We had a very good science and math teacher that were phenomenal.

And we had an assistant principal I believe of curriculum who supported me and listened to me.

Chuck's needs met. That same support was particularly void in high school according to Ruby. Just six months into Chuck's ninth grade year, she found herself exercising her option of school choice yet again and moved Chuck to a charter school. Once again her choice to change Chuck's school placement was met with a sense of satisfaction as a parent. "I would say that at [school name] where we're at now, I can say that we've had some positive experiences this year." When I asked what was making it so positive so far this year, she instantly responded and reverted back to what appeared so many times during our discussions, "Well honestly, I think it's..., the changes and he has a completely different team of teachers that seem to be more understanding of his needs."

Ruby's desire for others to understand Chuck's needs was something I noticed as well when she discussed his schools up north. In looking back at my researcher reflexive notes, I noticed how the differences in services caught my eye as I examined Chuck's IEPs. At the time my mind was attracted by services which were not easily afforded to children in the two districts where I have worked.

As I scanned through the documents, I noticed how intense the level of services provided for Chuck up north. I was amazed, just flat amazed. Ruby discussed how pleased she was with Chuck's services on how the district approached his educational needs. Just on this quick search, I could quickly see the support in what she was saying. I still need to read all these documents for understanding, but the differences were evident on a quick read. (October 4, 2013)

As a special education department head at my school, I have seen numerous IEPs for children from other states. As an educator, I have had to condense the goals to fit our district format and wondered why so many children come from out of state with occupational, physical, or speech therapy on their IEPs, when children in my state have to display a significant need in order to receive these services. In Chuck's case, his IEP addressed occupational therapy, speech therapy, sensory and academic needs, as well as time with a social worker for his difficulty with social relations. In spending time scanning the documents Ruby provided, it became evident how she could be so pleased with the amount of support Chuck was given in school. He was given access to multiple resources to address his needs, which as Ruby explained, made it challenging going forward in another state.

I can't say for sure how middle school and high school would've been in [state]. I assume that it would've been beautiful because..., I can't compare. Because when I left

there, I didn't leave there with a bad experience, I left there with a beautiful experience that cannot be touched. And so..., going to different states since then, I always think well in [state up north] it wouldn't have been this way, but I just don't, I don't know that that's necessarily true. And it's just been very, very, it's been difficult at best.

Negative experiences which create conflict. Chuck's needs, having access to those who understood his needs and Ruby's yearning for others to listen to her as a parent of a student with a disability were important factors in the stories of their positive experiences. Yet much of her discussions on Chuck's educational experiences concentrated on the not-so positive experiences, centering on themes of declining levels of service, IEPs not being followed, and educators who as Ruby stated, "Just don't get it." Despite difficult experiences she preferred to let the positive experiences be her guide each and every year.

A school year can start off wonderful and you're like, yay, you know they understand, and it's all going to be done. And then by the third week of school it's like, who..., are these people? It's like the meeting never happened. And so it's been difficult to where I've had to search for different placements and had considered three different placements in one school year. You know and..., it's been a struggle.

In particular, Ruby spoke of a time during Chuck's third grade year and she had to advocate when she felt his IEP was not being followed and his services were not being delivered. She was working in the same school as an aide and found herself beginning to learn what should and should not be happening regarding his minutes for related social work services. Her battle came after she successfully advocated for Chuck to be removed from his self-contained setting.

One of the other things that I had to advocate for, which is one of those things where I was like, this should be a no-brainer. The year that I had to remove him from a self-

contained setting. In [state up north] the kids had on their IEP, minutes, especially kids like my son had minutes with the social worker. Like 30 minutes a week or 60 minutes a week, 30 minutes of it being group, 30 minutes of it being individual. So this was a related service that was provided almost all the time for kids like mine. I said..., “What’s going on?” And she [school social worker] was honest with me. And I said, “I’m sorry but..., he needs, his service should’ve been delivered.” And so this happened after I pulled him from that room, so I was in the mindset of you know what, I’m not letting this go. So I said, “They are going to provide those minutes that he missed.” It was on his IEP. I calculated and she was honest with me how many times. And I said, “They didn’t provide the service.” I took it to the district..., the area or not even area ‘cause it was just one district, to the director of special education and he said, “Well, we don’t need to provide that, you know school’s over..., for the year and..., it didn’t affect his education.” I said, “You don’t know that it didn’t affect his education,” and he had been pulled from a classroom. It was so important that he was getting those minutes because he was in the gen ed setting. He had transitioned into a huge difference of a setting, like this should have been provided, and he wouldn’t..., budge on it. And so..., I first contacted my advocate and she went to a meeting with me and he wouldn’t budge. And he agreed..., “We’ll provide X number of minutes,” and I said, “No, that’s not going to work for me.” And so I called..., the [state] Board of Education. The process there was then we went to mediation, which was the step before due process. And so the mediator came out and we had a meeting and then we reached an agreement that they would provide the minutes. So towards the end of the summer, the social worker that he would

have for his new school year, for it would've been fourth-grade that year, started seeing him over the summer to make up those minutes that he never got.

Declining services. Further struggles began to ensue shortly after Chuck departed from his elementary settings. As Ruby described it, the expectations began to increase while the level of support began to decrease from what was provided in Chuck's elementary settings.

I would say the biggest difference, the biggest struggle has been when elementary school ended. Because once the transition goes from elementary to middle school to high school, things completely change because of diploma requirements, because teachers are different, personalities are different, the level of support and care is different. And then I feel like as a parent, that what's expected of my kid is that he's expected to be and behave like everyone else because he's in middle school and high school. But he still has a disability and so he still needed that, those same accommodations that he was getting and those accommodations don't go away just because he's in middle school and high school. I remember when he was going into the middle school and high school years, and I remember this very vividly thinking, "How can I keep him in elementary school forever?" "How can I?" I remember when I was student teaching and thinking to myself if I could keep him in this school forever, could they just keep teaching him at his level and keep him in elementary school forever, because I felt like that was the most safe place for him to be. Not just socially, but academically..., maybe they could just teach him there, because it was so scary to me because the mentality is so completely different.

Ruby spoke of shifting her focus away from placement and classroom settings to addressing what she felt was a decline in the type of services provided for Chuck.

I would say my most, a lot of my advocating you know began..., the more intense aggressive advocating, probably began in middle school and high school. Even in private settings where I never thought I would have to do that. That's probably been my biggest challenge and my..., where a lot of my fear and anxiety..., has come in over the years, because I knew that would be the hardest. So I think that, just a lot of it was..., about accommodations. And then..., also the because it was the higher grade level of not understanding that just because he's in high school..., or middle school, because he spends his last year in middle school here does not mean he doesn't still need these things. Like he still needs..., these things..., he still needed sensory breaks and different things like that. So there when, being middle school and high school the expectation that kids don't need OT, kids don't speech, and because they can't go out of their curriculum, and I, me as a parent understanding that, but also understanding that my kid's not going to access the curriculum unless he has these things, and so..., that was a losing battle.

Ruby related much of the change in mentality from elementary to middle school to high school to a perceived mindset among the teachers, that the students are getting older and should no longer require intensive supports.

In middle school and high school the teachers are completely different. I don't mean to make it..., only about teachers but, it's a mindset because the kids are older and they forget that these are still kids with cognitive deficits. And we can joke like that because they're young adults. They [educators] don't get it and so then when he [Chuck] would get upset, I mean he's not accessing his education so [thought dropped off]. Middle school was not as bad and when we went into the high school thing, the high school was just, it was complete lack of accommodations that were on the IEP.

Ruby elaborated further on her perception of the secondary level mentality when I asked her to discuss her thoughts regarding the difference between the experiences where she thought the school had Chuck's best interest at heart and the more challenging experiences.

I think that part of it is because you get into the upper grades the expectations change as far as..., well, they're in the upper grades and they're on a gen ed path, so they have to be doing all these things, so they shouldn't need all these accommodations. And so I think that that's..., a lot of the stress, which on the relationships right there is that my level of expectation is he still needs all these accommodations, yet your expectation is well, he's in high school he shouldn't need this. And then I think that it's also mindset, like some of it was..., that mindset of like you know, it's high school you shouldn't have to do this for them. And then some of it was just complete..., close minded as far as..., what the student should be receiving if that makes sense.

Even from a teacher perspective Ruby realized the differences in the manner which educators approach the students between the elementary and the secondary levels. She used her understanding of those differences to validate her desire to protect Chuck from the difficulties she anticipated.

I remember sitting at when he was in elementary school thinking, "Can I, how can I not make him ever go to middle school or high school?" Because there is. We [elementary school teachers] have a certain level of understanding of the kids, and then we feel like nobody else is going to get it. Even my gen ed kids that I knew..., that had needs that weren't identified. And the ones that were..., I wanted them to just..., stay with me forever, because I'm like, no one's ever going to get it. No one's ever going to get it, because there's just a different level of understanding so, or lack of understanding.

IEPs not followed. Ruby continued to express frustration with the mentality she perceived from secondary school educators, stating that students who are on a standard diploma should still be given what is afforded to them by law, because if it is on the IEP, then the student is still in need of those services.

Things that are on a federal document on an IEP, not being delivered because people don't have or take the same amount of time to read an IEP, or they don't know. I don't know what was the reason is, I really don't. I don't want to speculate, I could. But, it's amazing to me that so many things go left undone, when there's a federal document sitting there, same federal document that he's [Chuck] had since he was..., three years old, is still following him. He's never been without it and all the sudden all the things that he needs are just gone, but he still needs those things and so. I mean day-to-day things like..., help with writing down assignments and..., extended time and verbal responses and an extra set of textbooks and those are things that I have had to fight tooth and nail for in more than one setting, and it's, I can't wrap my head around it because it seems like when it's on an IEP..., people assume that things are peachy and it's not being done and then well, the kid's not doing well. They're not turning in their homework, they're failing and they're not, this isn't the right setting for them, but they're not receiving accommodations and so. It's like..., how do we help them be successful? Well first we need to look at actually delivering the things that they're supposed to have and so. It's been just very, very difficult.

Difficulty with IEPs not being followed was clearly a source of discontent for Ruby when speaking of the negative experiences she has had with educators in schools, especially those within her current state at the time of these interviews.

I think that, as far as my negative experiences here have been a lot of..., things not being provided that were to me a no-brainer because they were on an IEP... And they just weren't included. They just were never being done. And so, that was..., a big part of negativity and negative experiences.

Chuck's introduction to high school, according to Ruby, was particularly difficult because "it was a complete lack of accommodations that were on the IEP." The IEP Ruby provided me which was in effect during Chuck's entry into high school indicated he had an extensive list of 16 accommodations which were to be afforded in his classrooms.

Accommodations such as more time for completing assignments, assistance with note taking, shortened assignments, provide notes/outline/study guide, cueing and prompting, and visual cues/schedule to name a few. But Ruby maintained many of these accommodations were not delivered in the classroom as they should have been.

Such as extended time, guided notes, extra textbooks, copies of notes, the teacher's notes, assistance..., making sure the planner has the homework in it. You know all of those things, dictation, giving verbal responses..., just all..., those things, so. I was given a lot of, the extended time is built-in. But if you've given the whole class 10 days, and you felt that was the extended time, my kid is having more than 10 days if you've given the whole class 10 days because that's his accommodation. That just things were not being provided.

Educators don't "get it". Ruby's concern with the decline in the level of services toward the beginning of Chuck's high school career became the topic of conversation when she requested a meeting to review Chuck's IEP. Submitted during the meeting was a teacher planning note outlining Chuck's difficulty in this class, which was not identified on the planning

note. Out of 17 written sentences, not one sentence conveyed any positive information. The note is filled with only negative information pertaining to what Chuck does wrong. Not a single sentence addressed what he can do. The following is an excerpt from that planning note, typed as it is seen, including the incorrect grammar, misspelled and underlined words.

I keep the student's in packets that cover the units. I have given Chuck probable 4 of these packets. He keeps telling me that he is studying it at home. I have told him to leave one here to work on and one at home to study. Each day he leaves with the packet and I never see it again. I posted the lesson on line with the power point. He just keeps writing the information on papers and shoves them in a much unorganized book bag, and even the notes are never seem again.

Regarding the in class paper work – I have returned to him each assignment that he did not get a grade on. These assignments were turned in very incomplete. I have explained the procedure and gave him as much time as needed to do them. (I never see them again). Quizzes are very difficult for him and it was very challenging to even fill out a scantron. In the end I did have to take the scantron and fill it out.

Communication with other students is very combative and he will jump into any conversation that is sitting close and gets his feelings hurt when he tries to add his comments. (Teacher planning note from high school IEP meeting 9/27/2012)

It is interesting to note that within the IEP which was in effect at the time of this teacher planning note was an accommodation which allowed Chuck to write on his tests, rather than bubble in answers on answer sheet.

Ruby's sentiment throughout our interviews that many educators "don't get it" was not limited to discussions about high school. Her feelings regarding what teachers did not know

regarding children with disabilities dated back to first grade when she decided she needed to join forces and become an educator. At that time Chuck was in his first grade regular education classroom. He was receiving special education support from a resource teacher, who Ruby did not feel understood Chuck and how to work with his needs. “She didn’t know how to deal with Chuck. And she thought he should go self-contained.”

I just knew that at that point I was like, there are so many kids that..., as a gen ed teacher they don’t always get it. Or then there are..., special ed teachers where I’m like, you’re not getting it..., you’re not understanding my kid and..., so I’m going to do this to help my kid. So that’s when I started [as an aide], and I just knew that was what I’m supposed to do.

Along with the changing level of services and strong sentiments that IEPs were not being followed, Ruby spoke of an inherent struggle with various teachers and educators throughout the years.

It’s always been like “what did they do wrong?” It’s number one because it’s been done to my kid. He’s had things that have happened. Number two is expected because I always feel like no matter how many years go by..., do people truly get it. I know they’ve got it so far this year, but were going to the second quarter, but are they going to get it in the second quarter? You’re always on the edge..., you’re always..., not necessarily walking on egg shells when you’ve got a good placement. But you’re always on the edge..., waiting for that phone call, or waiting for that email. And..., is someone going to call me and tell me my kid was rude because he was hungry and didn’t express himself?

Considering her constant worry whether Chuck's teachers would truly understand his disability and his needs, I asked Ruby how these repeated experiences made her feel. Her answer made me think of how I felt the many times Kristopher and I experienced roadblocks in his education.

Angry, helpless, frustrated, irritated just like make you feel..., okay, well let's just give up and go private. Let's just, because you feel like is anyone going to get it. Is anyone going to get that I'm not asking for..., something that's out of this world. I'm asking you to provide the accommodations that are on the IEP. Like why are we having this conversation? So it was like beating my head against a brick wall basically.

Impact of experiences on advocacy. From the very beginning Ruby recognized the importance of advocating for Chuck. As mentioned previously in this case, she had to do so to encourage his elementary school not to put him in a self-contained class in first grade. She later advocated for his removal, once the decision was made to place him in a more restrictive environment, and even went on to push for an alternate private placement, paid for by the district. Ruby's successes for Chuck's FAPE resulted in overall positive experiences in elementary school. The nature of those experiences began to change when she found herself advocating for affordances in middle and high school which were not so *cut and dry*. Regardless, she continued advocating for Chuck. In doing so, she developed a sense of identity, not just as Chuck's mom, but as a mom and an educator. Ruby's experiences in working to ensure he received a meaningful education had an impact on her advocacy, leading to a sense of guarded optimism and feelings of guilt, while also forcing her to learn the laws and access available resources so she could continue to fight for Chuck.

When my interview questions turned away from the explanation of the experiences and toward advocacy as a parent, I wanted Ruby to articulate why advocating was, and still is, so important for her.

I feel like if you would have asked me that question..., 16 years ago, then I would answer differently than I would answer it right now. Because 16 years ago I would say, well because they're your kid and they..., might need things, you know you have a special kid whatever. But now I can say that I feel..., if I don't advocate for him, just simple advocating, that he won't get anything. Because I feel like..., nothing's ever easy. It's never just..., well this is the law they're entitled to this, so this is what they're going to be given. I feel..., if you don't advocate for them..., they're not even to get what they're entitled to.

Learned laws and accessed resources. In order for Chuck to get what he was entitled to, Ruby took it upon herself to learn the laws and understand the framework for IDEA. She found mastering the legal language to be more beneficial than the knowledge she had acquired working inside the schools.

I needed to know the laws when I was advocating for him, which is what I..., did. When I had my first difficult IEP meeting, what I did is, I said, "Okay well I need to learn all the laws which surround special education," and then I learned the laws. And then..., as a teacher, as an educator, whichever position I was in at the time, it didn't really have to do with my district, it really had to do with me knowing what was okay and what was not okay. And then..., knowing..., I guess a little bit about the district as far as..., they tend to do this or they tend to do that. And I probably had a little bit more knowledge of that

because I was in the education system, but that didn't necessarily help me. I feel like it was..., me knowing what the laws were that helped me the most.

Much like Trainor (2010) identified *The Strategist* as a parent who uses knowledge of disability laws to advocate for change, Ruby used it to advocate for Chuck's LRE in first grade and prevent his premature placement into the self-contained setting.

This was my first situation where I wasn't quite sure of all..., IDEA and what exactly it was about. He was having some difficulties in first grade and they wanted him to be in self-contained, and at that time I said it wasn't appropriate for him and they weren't really giving him a chance. And so I then..., if I wouldn't have known about IDEA and if I wouldn't have known about least restrictive environment and all those things, then I wouldn't have known to tell them..., this is not what's appropriate for him and he has that..., right. I mean I used it backwards and forwards. I used it as far as..., LRE for least restrictive environment. I used it for free and appropriate education, getting him what he was entitled to and then the things that were on his IEP were not being provided and me knowing IDEA is what..., helped me be the best advocate for him. And then me being in the school system..., it didn't help me, I mean it didn't really help me be a better advocate for him, because if anything, it was almost worse..., just because..., well that's a whole other story. But like I knowing the school district didn't really help me that much... There..., wasn't anybody there that I could call and be like, "Hey I work here you know so can you hook me up here?" Because it was really all about..., they just needed to do what was supposed to be done.

Ruby learned at that point her newly acquired insider knowledge from working inside the school system was not the asset for which she had hoped. Instead she had to learn what to say and how to say it as a result of the laws which protect students with disabilities.

I had, had several meetings up to that point. And so and I had started really understanding the terms of appropriate and not saying what's best, saying what's appropriate. And so up to that point, I had to learn that FAPE was my friend and I had to say that, and I had to say appropriate, appropriate, appropriate. And so I kind of a built a case.

Once Ruby learned the laws she turned to other venues of support in her advocacy efforts for Chuck, accessing resources and people she had met along the way. Up north she accessed a not-for-profit organization which provided an advocate when Ruby needed it.

And then I also..., joined this site called Café Mom, which was..., a group of all moms of kids that have autism. And..., that is all online so I've..., met a few of the moms in person but..., that was a support system that I found to help me like get a better [thought dropped off]. I guess sometimes to help me take the emotion out of things and to get to where it was not about only my emotions. I had to learn to take emotion out of it when I would go to the meetings, like take the emotion out of it and go, "it's business." And so that helped me to do that because I had people that I could talk to and say well have you been through this..., so that's something that just really consumes when you have an IEP meeting coming up you go online and you're..., typing to these different people about..., this is what I'm thinking..., working to talk about an IEP meeting has anybody gone through this..., and things like that so. And then I've, not Autism Speaks but just Autism

Society, sometimes I'll use their resources center for autism and related disabilities in [current state]. And then in [state name], Easter Seals.

Following the family's move to another state, Ruby had to turn to another source of assistance when it came to finding ways to advocate for Chuck once he began middle school. Fueled by what she felt was a lack of understanding for Chuck's needs at an all special education school, Ruby resorted to the world-wide web to expand her network and seek further guidance.

So when we got to [state], it was all my online friends. I belonged to an online support group of kids with autism, moms with kids with autism, and those were the people that I would always turn to. So nobody in person, but just always online talking to different people and different parents that I knew. And now..., being that I met some educators in [state] that I would always, a friend of mine that was a professor at a university there. I would turn to her, and she understood even though she was from the same area but. And then I moved. When I came to [current state] it was just the same online people until I established friendships and trust to where I could turn to people..., that I knew. That I could bounce ideas off of. That was about it. I mean I tried to talk with Chuck's dad about things but he's not educated in that area so it was really basically me networking with other, most of the time moms or teachers.

Guarded optimism. But no matter how much Ruby learned or how much support she managed to access from outside agencies, advocating for the right to a meaningful education for her own child had implications, even when everything was going well for Chuck. She described the emotional toll she felt when Chuck's IEP was not being followed or he did not receive his classroom accommodations. But I wanted to know how she felt during the positive experiences. Her answer surprised me. "Very guarded, almost like, is this really happening?" After she

discussed the constraints of Chuck's middle school all special education setting, she returned to explaining why she met positive experiences with such guarded optimism.

I think that I approached those positive experiences..., like I was..., cautiously optimistic because I was waiting for the other shoe to drop, because when you've had so many negative experiences you're just waiting for the phone to ring. And so, I approach them in the point of like, ok I'm going to take this success and I'm going to be glad about it and I'm going to keep in mind that..., we still have..., these other areas that we need to be working on. So it's..., hard, it's very hard to focus on positive things because you're so used to things not being positive.

But even when some of the experiences in advocating for Chuck resulted in positive outcomes, Ruby continued to deal with contradictory feelings.

You do feel hopeful and you feel good and you feel like you know you can relate to people, they can relate to you. But then you're..., kind of cautiously optimistic, like will it stay this way because you've always got those bad experiences in the back of your head.

In particular, Ruby specifically spoke about having to advocate for Chuck's private school placement for fourth grade. Even though she had completely prepared herself for what she believed would be a difficult meeting by learning the laws and the school language, she found herself questioning the outcome, despite a meeting which went in her favor and ended with the district agreeing to the change of placement for Chuck.

Once the first negative experience happened..., I was cautiously optimistic to where I was like, "Well, how is this going to go? Is this really going to be okay?" But for a long time..., I didn't really know any different, like I always thought it would be good.

When..., I was able to get him into the private school that I wanted to in [state], which was a very good thing I was actually kind of ticked because I had spent all this time and..., had prepared..., almost..., a brief like an attorney would, prepared to argue that it was going to be a challenge to get them to sign off and say this is his placement so. I was very prepared for that and so I was actually kind of..., irritated because I was prepared to fight. I was like, I've had to advocate, I'm going to fight on this one, I'm going to win. It was almost like I wanted that..., victory. And so when they gave it to me so easily I was like, what the heck is this all about because this never happens. So I was nervous until the paperwork was signed and done and he was at the school and I was waiting for something to happen.

Guilt ridden. Advocating for Chuck has certainly come with both highs and lows for Ruby. She has experienced both the positives and the negatives. Through it all, she has learned a lot about the law, about Chuck's disability, and about what should and should not be happening regarding Chuck's education in the classroom. She has learned to advocate for what she believed was in Chuck's best interest. Yet amid the turbulence she has endured, she carries with her a sense of guilt, that she has not done enough.

I think that as a parent I often focus on what, how I haven't done enough. And I feel like what more could I have done. I spend so much time questioning people and fighting for what he needs, that I almost feel like I didn't sit with him and do enough math. I didn't sit with him and do reading comprehension. I didn't make him do this. I didn't make him do that. I didn't check his Edline. I didn't sign his planner. But I did all that other stuff. You can't always do both I mean, you just can't, and I beat myself up about that every day. But I know in the back of my mind like, I'm doing the best that I can to get

him on the bus and back from school and in a stable mindset after being in school all day, because he's not the same so.

She even described how her advocacy and the resulting experiences have developed a sense of unusual worry.

As a parent in the back of my head and when I lay down that night, it's not out of my head that it could all change. And it's paranoia and it's the way that my life is on a daily basis. You know of worrying. Like is someone not going to get it, is someone going to resign, is there going to be new teacher, you know what's going to happen 'cause it's all too good right now. And so I don't like that, but that's the way it's become.

Identity evolves as an advocate. What has evolved from all the advocating, worrying, and struggling to make sure Chuck received what he needed, is someone who learned to embrace a larger role. She is the parent of a child with a disability, she is a teacher for children with disabilities, and she has become an advocate for children with disabilities. Far from the woman who once wished to write stories for the news, her advocacy started with nothing but intuition. "I had a gut instinct" [referring to the teacher in third grade who was later removed from the classroom for allegations of abuse].

As a parent of a child with a disability, especially one like..., autism, I feel..., you sometimes get a sixth sense and you're given this..., thing as a gift to say, ok something's not quite right. So I knew something wasn't quite right.

But the intuitive nature of being a parent of a child with a disability led Ruby to gain a sense of confidence that she could make a difference in Chuck's life. Therefore she gained a stronger sense of parental efficacy, believing her successes as an advocate could impact future decision making in Chuck's education.

In my mind..., I've done this, I've got this..., I'm go to do this and I'm there to win this battle and..., we are going to go on and..., things are going to be okay. But then another way it's almost hindered me at some points because I hold people to that to the same level, of me expecting that they're going to do what I want them to do. And so I feel like well this is the appropriate placement, I'm the parent, I'm part of the team, like they should listen to me in this aspect and if I don't get that same, you know agreement or willingness to do what I feel that they should do, then it can get, you know, I have a certain level of certain standard of expectations, so it's kind of been a little bit of both. But I would say more of the good side because having that achievement kind of set me up for believing that I could.

And not only has Ruby found advocating for Chuck a necessity, she found it to be her calling, using her wealth of knowledge of the laws and the inner workings of a school district to advocate for her own students as well.

I think that having advocated for Chuck..., I needed to know all the laws and all those things and I needed to know..., what was possible..., what was reasonable. And so, I think that it's affected me as advocating for my students as a teacher because I feel like I have more knowledge and I'm able to do that. And I also feel like I'm just more likely to do it naturally. It's just part of who I am.

Aside from advocating within the walls of the schools where she teaches, Ruby also finds herself advocating for anyone who may have a child with a disability. She admits she easily jumps into conversations in public places, like the doctor's office, and tries to help whenever she hears a discussion revolving around children, particularly those with unique needs.

I want to say, well what happened...? Here, I need to talk to you. Let me help you. You know what, I want to do things like that, and so, that's how..., getting involved in those online support groups really helped me to fuel some of my passion, because I was able to go online and say to these people..., when they're having different problems, like I could type out everything that I knew and feel..., I was advocating, feeling like I was making a difference. And I realize..., that's how I'm fulfilled.

Her desire to make a difference and help others is even noticeable to Chuck. Ruby called it perhaps her most defining moment, when she had a conversation with a friend about the woman's grand-daughter who was having trouble in school. She began making suggestions when Chuck joined the conversation stating, "Yeah, if that doesn't work out, you just talk to my mom, she's an advocate." Ruby had never expected Chuck would see her any different than just his mom, "funny he perceives me that way." It would be easy to see why Chuck sees his mom as that, an advocate. Her final statement to me during our last interview defined exactly who this parent of a child with a disability has become.

I just, want to change the world and the way that they perceive the needs of our children being, the needs of our children have not changed. All of these different curriculums and standards and all those things have changed. But our children's needs have not changed. And their needs are I feel like being pushed to the side to make way for new things. And I understand the need..., for those things. However our kids are going to need what they've always needed and maybe some more to reach those higher standards. And I think that we forgotten that.

Therefore it would be no surprise that Ruby plans to exit the school system upon Chuck's graduation. She aspires to take all her experiences of advocating for Chuck while working inside

the school system to help other parents who may not have such access to the same insider knowledge, which has been a source of information, and a barrier unlike no other.

Becoming a better educator. Adding to her identity as an advocate is the development of a better educator. Ruby's passion goes above and beyond the norm of just being a parent of a child with a disability. She uses it to propel herself to become a better educator as well.

My role as a teacher is to educate within the boundaries of the state that I work for. But, and my role is, for me personally I feel like something that I..., don't take it as a job. To me it's my life..., it's my passion, it's what I do. And it's just..., what I do. But when I go into every school year..., seeking out those kids that may have disabilities for them to be in my classroom because I feel like that's where my niche is. And then I also feel..., that's where I thrive. And then I also feel..., nothing against other teachers because I love all the teachers that I teach with, but then I also feel like as a parent..., of a child with special needs I feel like, ok well I know..., what it's like, so I feel..., I'm going to be able to make a difference in their life. And so it's always been my goal as an educator to make a difference. And so I guess I feel like well okay..., I'm going to make a difference so I want these kids to be here, because I want to make a difference, it's kind of like a personal project.

Ruby says her awareness of unique needs allows her to do things different than other teachers would "because I'm used to it, and it's just a natural thing." She knows special education practices backwards and forwards as a result of living in special education for the sake of her son. She believes it is only a given that she would use it while teaching.

Oh my gosh, it's just so natural. I mean I use it in so many different ways..., and sometimes I have to remind myself to use it, but even..., if I know a kid is not going to

write down his homework because..., the processing and the multi-step of looking at the board and then looking at his planner and writing it down..., I know from being a parent and from knowing special ed practices that that kid's going to need that help. So I may go over and remind them or I may write it down for them occasionally. And then just using different forms of communication..., saying something verbally and then writing it down, writing something down and then saying it verbally..., repeating directions, even though that's general in fifth-grade, but repeating directions..., in proximity to that person instead of from across the room. I think for me it's just a natural thing. And then..., recognizing that some students may need to..., answer questions orally instead of written. I just use it in a lot of different ways.

Barriers to advocating as a parent and as an educator. Understanding the needs of children as both a parent and an educator characterizes Ruby as an advocate for children with disabilities. The many positive and negative experiences she has encountered come as a benefit to Chuck and many other children who need someone to speak for them. But the road to advocating has not always been easy.

This second portion of Ruby's depiction focuses on the barriers she has encountered in advocating for Chuck while working within the same schools or school systems. Many of these barriers are evident in the narrative of her negative experiences in advocating as a parent. Ruby also discusses barriers which impact her two-fold role as an educator. Figure 2 provides a visual layout of the many boundaries which have restricted Ruby in her quest to establish Chuck's right to receive a meaningful education.

Ruby's knowledge versus educator's lack of knowledge. Perhaps what stood out to me as I immersed myself in Ruby's interviews and the documents she provided me was the level of

knowledge she developed regarding Chuck’s disabilities, needs, and the accommodations which could help make him successful in a school setting. However, in listening to Ruby talk about her experiences, it became apparent that difficulties with the school system arose when she encountered educators who did not hold that same level of understanding of student disabilities, needs, and accommodations. The discrepancy between the two sides appeared to create an environment for conflict.

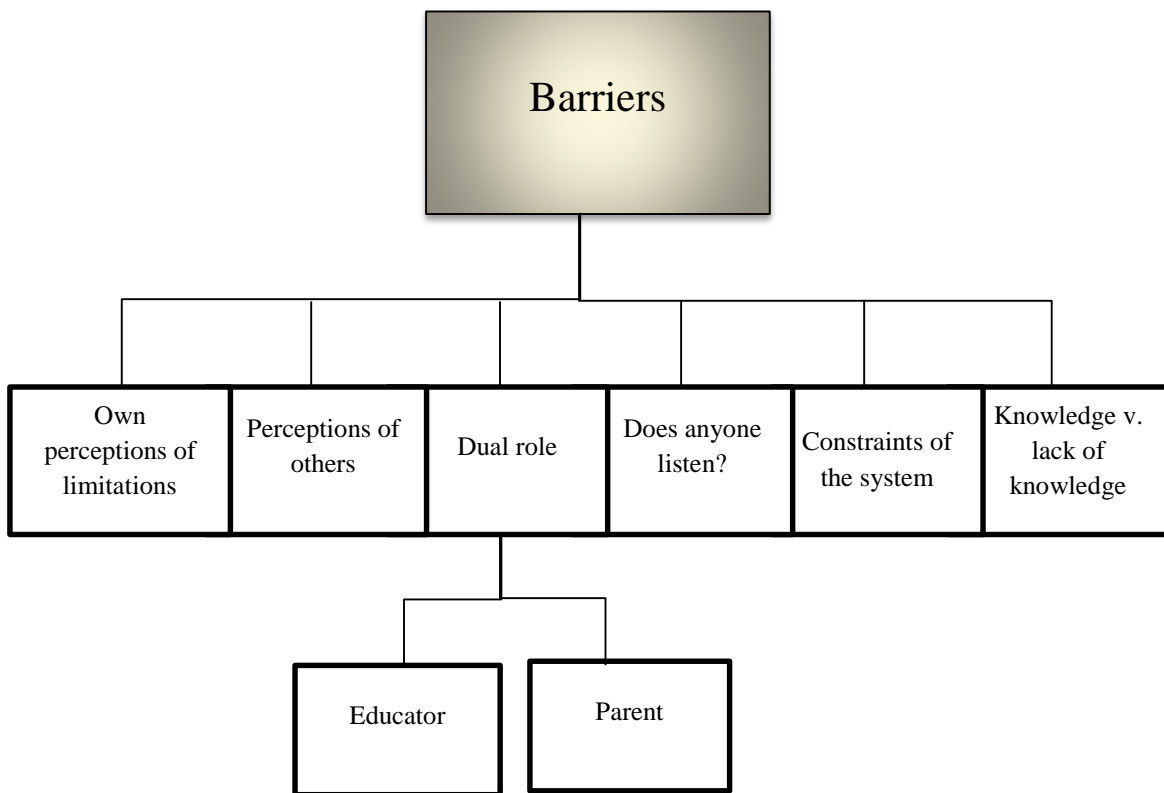


Figure 2. Barriers Ruby encountered in advocating for Chuck.

Me having to advocate being like, “Ok this is what he needs and he needs this because of his disability and this is what I need you to do.” And so those are really small things that I think that a lot of people take for granted, but for me it’s..., an automatic pop up in my head. You know, it’s like a pop-up window. I’m just like, “oh I got to do this,” because I

know the way things like that can affect him and so. And most of the time..., things like that they don't always get it.

Ruby felt when she moved out of the state where Chuck initially started school, she ran into difficulty at the private, all special education school because the personnel there did not understand Chuck's disability. She felt like his disability was an outlier, and children with Autism Spectrum Disorder were not widely served. "They had never come across kids that had parents that knew about those things or that came to their school saying this is a need that my kid has." As a result, she had to advocate for Chuck's needs when she never expected she would need to do so at such a school.

I had to advocate for him because his disability is so different. When you grouped together a lot of kids that have disabilities and his is the one that's the outlier then he's the one that's wrong. And he's the one that's looked at as the problem. And his disability being so different socially than all the other kids where, it's like well he won't do this, and he won't do that, and he won't do this, and he won't do that. It was never about, what can we do to help him be successful. It's..., he's not turning in his homework, he gets a detention, he's not wearing his belt he gets a detention. He doesn't have his shirt ..., tucked in, he gets a detention. You know, he's not on task, he gets the detention, so it was all punitive. And when I tried to create a more positive experience for him as an individual that was just not, it was just not received well at all. For me, as a parent I'm like, \$10,000 all special education school? Why are we having this conversation? It was..., unbelievable to me. And then for me making it so much harder was that I have very high standards, being from [previous state] and going to [second state] I feel like my standards were so much different in kind of a snob in that way, to

where my expectations and my standards were so much higher, to where I'm like, why do they not get it? Going into a place where me expecting that everybody knows in a special education world what OT is, and what a sensory break is, and what a sensory room is and all these things to where they didn't know what all that meant. And so..., I had to advocate on a completely different level for things that people didn't even know existed. So, that was..., difficult.

Ruby attributed the lack of knowledge to a variety of issues pertaining to personnel and the lack of appropriate training.

They served a broad spectrum of children with disabilities, but they didn't have as many with autism. And so I feel like that's part of it and then I feel like leadership and lack of education and not a lot of the teachers there had special education backgrounds or even certification. So because it was a private school and it was a different state where things were just so completely different that there was a lack of knowledge.

The discrepancy between what Ruby knew regarding Chuck's disability and needs as opposed to what his teachers knew continued into Chuck's middle school setting in his current state. Ruby found the incongruity particularly frustrating as a barrier which limited Chuck's access to an appropriate education.

But a lack of understanding..., that..., kids that are in middle school and high school do not fit the same mold just because they're there. So it was almost daily conversations with related personnel that he..., got disrespectful and he was this and he was that, and just the understanding that..., he's upset, and gets upset..., this is the way he sounds and nobody understood. It was a complete label as a bad, disrespectful kid and not understanding a disability category. His needs aren't being met, so he's going to get

upset, and when he gets upset this is the way it's going to manifest. And if you don't address it, then it's going to get worse. And it doesn't you know, just that lack of understanding or wanting to understand. And so it was..., very difficult and then teachers saying things to him that he didn't understand and then that would upset him.

Even when sitting in her role as an educator, Ruby struggled with knowing how to address her students' needs when she found it to be difficult to get the same level of support for Chuck's needs.

Sometimes they are things that have been provided. And then sometimes they are things that I do and then I say, well gosh this is really easy for me to do for my kids, like giving them extra days to complete homework assignments, and I do it and I think that I do it knowing they need it. And then I think to myself, well it's so easy for me to do this, why don't teachers do this? So I don't do it with the hopes that it would be provided but I do it knowing that these kids need it and then thinking you know this is exactly what my son needs. To me it's somewhat like, it's a very natural process for me. It's just how I was made I guess. It's just natural.

Constraints of the system. Not only did the differences in the level of knowledge between Ruby and certain educators present difficulties, so did the constraints of the system. On several occasions throughout the interviews Ruby spoke of hearing the words “we can't, we won't, we don't.” Her first encounter with such restrictive thinking occurred when she prepared to move to her current state and developed concerns whether Chuck would be provided a one-on-one aide.

They don't give one-on-one aides in [current state] and I was like well they do it in [state up north]..., so I'm thinking like this is what he needs..., I'm going to push for it if this is what he needs.

In the end, Ruby did not insist on the one-on-one aide, knowing from her online support group that such a request would fall on deaf ears. Despite deciding not to continue pursuing this issue with the district, Ruby was surprised when she registered Chuck for high school and was met with another round of "we don't do that" from the school principal.

When he left middle school we had talked about what his classes would look like for high school, and that it would be resource for science and for math and for you know language arts. And it was, "Well we don't have that here. And we just don't, you know, we can't." Well I don't remember his [school principal] exact words, but you know, "We don't have that, and I don't think any school in the county has that. And that's just, I don't know why they put that on the IEP in middle school because we just don't..., have that, and he'll be okay. We'll just put him in this class and we'll give him you know, we put them in regular class and what we do here is we put them in the regular class and give them a lot of support." And that's not what happened. There was no support at all.

The circumstances at Chuck's enrollment set the stage for a long, arduous beginning to his high school career. Chuck experienced numerous difficulties in his classes, which were not the resources classes as the middle school intended when the team developed his IEP to transition him into high school. For Ruby, the struggles multiplied. Chuck was increasingly having difficulty with peer relations. He was doing poorly academically. And he was beginning to not like school. As she said, there was no one to understand his disability and how it interfered with social interactions.

That's when I knew that I needed to do something different which would be..., either a private setting or a charter or magnet where his needs would be met based on the fact of what kind of school it was.

Does anyone listen? And for the third time since he started school as a child with an IEP, Ruby removed Chuck from his high school in the middle of his ninth grade year and placed him elsewhere. This time she enrolled him in a charter school specifically designed to address the needs of children with disabilities. I knew Ruby and during these trying days. I remembered how stressed she was whenever she would receive calls and emails. Periodically she would seek my advice on what to do. But I never embraced the opportunity to ask her how the circumstances in the high school setting made her feel, until we got together for these interviews. She answered with conviction in her voice, "It makes me feel angry, it makes me feel like I want things to change and like people don't listen."

When Ruby spoke of the positive experiences, she spoke of individuals along the way who listened to her as a parent and listened to Chuck's needs. When educators turned a deaf ear, those experiences turned as well.

Why does nobody care about him as much as I do? Why can't they see his potential? Why do I have to fight so hard, you know why is it this hard for my kid? Why, not feeling..., sorry for myself or sorry for him, but feeling why do I have to fight a system so hard? Like why is it so hard for him to get an education? Why won't people listen to me?

Dual role of parent and educator. Fighting the system has been a challenge for Ruby, particularly since she has filled two roles inside the school systems where she's worked. The

complications associated with parenting a child with a disability and teaching children with and without disabilities became apparent when discussing the barriers Ruby has struggled with.

There's no separation for me..., I live where I work, I work where I live..., it's all related. And so I think that for me it is more emotional because I see..., kids that go through struggles like my own son does. And they are not getting their needs met. Or if they are getting their needs met..., well, why is this happening over here but it's not happening for my kid? Or..., I don't really think that's quite right but what can I do about it?

Even though Ruby has learned to advocate for her son, she has used her own experiences to advocate for the students she teaches as well. As she explained, her dual role has afforded her with knowledge of the laws and how those laws interact within school systems.

When I have students who have..., some sort of special need, I'm always advocating for them. Probably in a way that a lot of teachers do, but for me it's probably different because I advocate for them from the side of knowing what the laws are, and knowing what can and can't be done. So I always go to battle for them in that way. I always..., as a teacher, in a meeting for any child, I'm always thinking of..., what the child is eligible for, what is appropriate for them and things like that. So that's how I use my advocacy skills as a teacher.

At this point in my interview, I began to think back to my literature review and how teachers according to Fiedler (2002) are more likely to advocate for their students if they themselves have experienced similar challenges. Hence, I inquired further, wanting to know whether Ruby thought she advocated in a similar manner as a teacher compared to when she has advocated as a parent.

I feel like I try to. But then I also feel like sometimes that there is only so much I can do. I think that I do advocate in a similar way, because it's what I'm used to and I'm passionate about it. But then I also sometimes feel..., my hands are tied..., I can only do so much because it's that, you know, being afraid of crossing that line.

I questioned further as to what she meant, "You know being fired. Or if I say too much or call people out or whatever, just that, you know." Ruby continued to describe the difficulty of sitting at the IEP table serving the role of a teacher, but yet feeling the struggles of the parent, sitting just on the other side.

It's very emotional. It feels like..., it's my own kid. I would definitely say I'm more emotional because I was thinking about an incident where I was at an IEP meeting for students of my own where I felt like they were completely, it was like they were my own kids and I was faced with a lot of we can't, we don't, we can't, we don't. And I knew that they could and they should. And it was very emotional for me because..., I'm that parent. So it goes both ways so like it can be emotional for me as a parent because I'm a teacher, and it can be emotional for me as a teacher because I'm a parent. And I don't think that I would be as emotional if I just had one of those roles.

Regardless of advocating as a teacher or as a parent, Ruby pressed for the understanding that parents, who are also educators, should be allowed to be a parent first when advocating inside the school system. "It goes back to the basic principles of remembering that that school district employee is a parent first and if that was your kid, what would you do?"

Perceptions of others. Within the interviews Ruby appeared concerned about what colleagues would do and how they may perceive her advocacy efforts within the very same school systems where they all worked. She described herself as being considered the "Scarlet

letter parent” by administrators when she advocated for Chuck’s removal from the public school setting and into a private school during his fourth grade year.

Just speaking from an educator standpoint and not just..., administration wise in the way that you are perceived as..., an employee. I think that when you’re working in education and you..., have your peers..., that you work with. I think that it’s really, something that is not often thought of happening is that, sometimes your fellow teachers may start to view you as, “Well they’re just being a pissed off parent.” And..., may kind of be like well, “Why are you so mad at the teacher?” Because we get defensive of each other as teachers. If I’m in a doctor’s office and I hear people start talking about teachers..., I get defensive because I defend teachers. Generally. But I think that sometimes when you’re a teacher and you’re talking about your kid’s teacher, sometimes you..., know your fellow colleagues might be..., well you know, they might start to become a little bit judgmental, if that makes sense. And so I think that that’s a part of my role as a teacher and a parent. That hasn’t really happened directly besides..., administration wise. You know, but it’s definitely something that kind of lingers in the background that you know that people are thinking..., they might look at you or they might be like why is it a big deal? When you’re networking with your colleagues and they’re not colleagues that are in the ESE area, or they’re not parents of special needs children..., you’re a completely different breed. It’s like a..., bird of a whole other color..., it’s just not even [thought dropped off]. That’s just something that I find interesting. Because they just, nobody really knows what you’ve been through and what you are going through and what your child really needs and what they’re entitled to unless they really walk..., that walk, and they’ve been there through it. So there are some that are going to be more willing to

listen than others. There's some that are going to be more willing to learn and then there's got to be others that are to be like, "well why don't you just?", "is it that bad?"..., "why can't the teacher just do this?"..., "why is it such a big deal?" And they don't always understand and sometimes your fellow educators may be quick to judge because if they're not in the same role as we are, they don't get it.

Own perceptions which limit her advocacy. It became clear in Ruby's interviews that she perceives a limit to how far she can go with her advocacy for Chuck and other students with needs like him. Those perceptions forced her to withhold her advocating.

I feel like there's more boundaries here. I feel like there's tighter borders. I feel like when I was in [state in the north], and I do have to be fair in saying that..., when I was in [state in the north] he was in elementary school. And I want to say that because I do feel..., things become different as we've talked about in middle school and high school. I think that when I was in [state in the north] I was not a full-time teacher yet. I was employed in the district as an aide at the time, and then a sub and I was married, and I feel like I didn't know the educational system as well as far as the gen ed system and all of those things. I knew my special ed stuff backwards and forwards. But I don't feel like I knew, I just..., don't feel like there were as many boundaries..., I felt completely comfortable doing those things. And I don't know if it's because I never felt those constraints..., I never felt like these were people I'm going to have to be sitting in meetings with, or if it's because I just wasn't scared and I was fearless. But then coming here, it's just so different. I feel like here..., it's very much like, "Oh no we don't do that", "we don't do that in [current state]", "[current state] doesn't do that." Whereas in [state in the north]..., everything was always on the table, everything was always open

for discussion. I still somehow feel..., I would not have the feeling of constraint, restraint like I do here. It's just a feeling that I have because I feel..., there's more sense of professionalism of, not saying that we're not professional here, but I can't explain it. It's like they have separated their roles of parent and parent and educator or parent and employee.

Specifically, Ruby discussed feeling limited with a complaint at Chuck's high school, describing the emotions at the IEP table as awkward. "I didn't want to make a name for myself, knowing that these are people..., I was going to be sitting in meetings with."

Perception of job security in relation to advocacy. Ruby's perception of the barriers presented by her dual role within the school system became what she believed a limiting factor in her involvement of advocating for Chuck in relation to her job security. Within the interviews she spoke of her fears, how she may be judged, and the internal conflict she endures throughout the everyday occurrences in her roles as a parent and a teacher. Despite it all, she gave an indication of what lies in the shadows for someone who fights the system from within. Figure 3 represents the two themes which emerged from Ruby's case pertaining to her advocacy as a parent and a teacher and her perception of job security while serving in both of those roles.

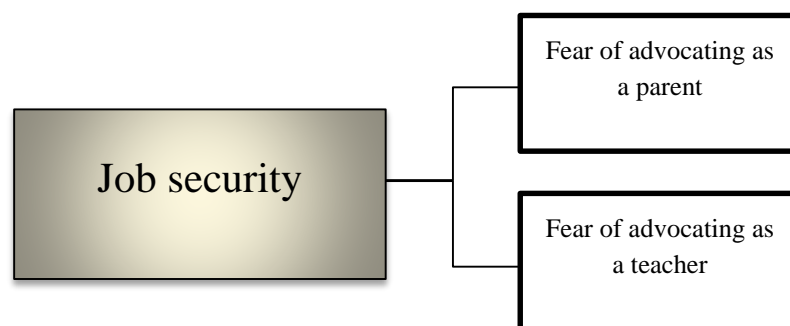


Figure 3. Ruby's perception of job security in relation to advocacy.

Fear of advocating as a parent. The idea of fighting for the rights of children with disabilities inside the system where she works is a fear which Ruby carried with her on a regular basis. She understands there is an expected level of professionalism for employees who represent their school districts. But when it comes to fighting for the rights she believes her child is due, she feels there is a limit. “You always feel a cap,” she said when speaking of advocating as a parent.

When you’re inside the district you always feel..., there’s a line you don’t cross. And it’s an unspoken thing, it’s an..., it’s just an automatic expectation that you set for yourself and that you know that the others are expecting of you. And nobody will say it, and nobody will say..., “You can’t talk to anyone in the district that way because you’re an employee and you could get fired.” No one’s ever going to say it, well they might. They wouldn’t say it in [state in the north]. I’ve heard it said in [current state]. No one’s ever going to say it but it’s expected. And then you go home and then you start analyzing everything that you said and everything that they said, and then it’s like, “Did I say this okay? Did I say this okay? Are they going to think I was being disrespectful? Are they going to think I was being rude? Am I going to lose my job?” It’s a fear. It is a constant, constant fear.

Ruby worked in two different educational roles during her years advocating as a parent for Chuck. For her, the fear about her job security was always there, though admittedly to a lesser degree when she worked as an aide while Chuck was in elementary school. “I had the advocate, and because I was only an aide at that time.” However, those fears intensified as the years progressed and her duties as an educator increased.

I think that as an educator more of my fears of being fired probably came as he got older in the middle school and high school settings because, you're challenging people on things like accommodations that he's not receiving. Whereas before in elementary school it's..., minutes. And I had proof of that, and it was more..., concrete, and here it's just different.

I probed Ruby to elaborate further on her fears by asking her to put into context the issue of job security and her concerns associated with pressing educators to consider Chuck's disability and his academic needs.

That I would get fired. I mean as a district employee, that I would get fired because I was pushing, but I was pushing for things that were appropriate, things that he was entitled to, but I was afraid that somebody would go to my boss and..., that actually somewhat kind of happened to me.

Ruby went on to discuss how that fear of advocating for her child while also working as a district employee materialized when she least expected it. It was at the beginning of Chuck's first year in high school. According to Ruby, there was a mistake in the paperwork which left Chuck without his IEP assigned specialized bus transportation for several weeks. Unable to get him to school due to her own teaching schedule, Ruby complained to the district special education and transportation offices. "All I did was open the parent link magazine thing that they give all the parents and find the number for transportation and call it." What she got was an unexpected call to her principal's office.

So my principal basically told me to stop calling transportation. And that is completely inappropriate. She shouldn't have been in that position, I shouldn't have been in that

position, none of us should have been in that position, and I didn't do anything wrong.

And even if I had, it shouldn't have been brought to my boss, but that's what happens.

If it were not for her perceived fear of losing her job as a result of advocating for her son and other students in need, Ruby feels things may have been completely different.

Now if I didn't work for the district I would've pushed to get things done and I wouldn't have been afraid I was to lose my job. I also feel..., on the other side of the table that those people know she's only going to go so far because she knows that if she goes further and tries to go to due process or something like that, she's got to get fired, so we can push her so far. So..., they're on the other side of the table being like, well we can push her to right here because she's not going to go any further. If she was a parent that we knew she was going to be just a parent and not a district employee, uh, we should probably do things right you know maybe. I think that there is that, there's an understanding of that. It's an unspoken understanding and no one will probably ever talk about it, but it is there.

Fear of advocating as a teacher. But the fear does not only come with being a parent. It comes with being an educator as well, particularly when sitting at the IEP table where feelings for the concerns of the parent conflict with district expectations and protocols. Ruby outlined how she feels the toll of such circumstances, and at times finds herself at odds with living in the multiple roles.

It's very emotional. It feels like..., it's my own kid, and like..., somebody's telling me no. It's just, it's very emotional..., it's a feeling like wishing I was on the other side for a moment as the parent so that I could fight in a different way. And feeling..., "Oh I wish I

could tell this parent something.” So it’s a very emotional thing and a very, a feeling of
..., “What can I do? What can I do without getting into much trouble?”

Yet no matter her feelings, she feels restricted. That restriction is related to her
perception of job security and whether advocating as an educator has its limitations as well when
you are working from within the system.

But I do feel like there is a cap. And so I don’t feel..., I can completely advocate for my
children [students]. I feel..., I will always try, but knowing in the back of my mind that
there probably will be that cap there.

That fear has even followed Ruby into the classroom as she attempts to take into
consideration the needs of all her students, identified disabilities or not, and how to advocate for
them regarding classroom placements, accommodations, and decisions which may impact the
overall learning environment for her students.

I can say that I felt like sometimes because I’m a parent, sometimes in those educator
meetings I feel..., I don’t want to be quiet and I feel..., then I could get fired, because
I’m very passionate. But I’m speaking the truth. It’s not like I’m telling lies.

Summary of Ruby and Chuck’s Fight Within

For Ruby and Chuck, gaining equal access to education has not been a given. The two of
them have been united in their efforts from the moment Chuck entered school. He learned what
it meant to be a child with autism, and she learned how to be his voice when no one was
listening. For Ruby this meant changing careers for the sake of her son. In doing so, she has
taken on a system while fearing repercussions.

The experiences of advocating for your own child inside a school district can be
challenging for any parent. But for Ruby, her battles particularly ensued when she felt no one

heard her concerns; when no one seemed to understand Chuck's disability; when teachers did not address his needs or abide by the accommodations set forth by IEP teams; when she felt she could only advocate so far without losing her job.

She entered education to help her son, but found she could advocate so far. Her insider knowledge became a *double-edged sword* when educators would respond with "we can't, we don't, we won't," especially when she knew they could and they should. She armed herself with the language of the law, but still encountered constraints of the system in advocating for not only Chuck, but also the children she touched. Her dual role became a barrier for this parent and educator. She found herself troubled while sitting at the IEP table. As a parent, she wanted what was best for Chuck, but worried what her fellow educators would say or think. As an educator, she wanted what was best for her students, but worried about crossing a line. That line became a central fear and even became a reality when she was called to face her superior because she advocated under her right as a parent. Throughout it all, she stayed resilient and true to her cause.

There were times where I didn't feel like I had to push hard. I felt..., things were just kind of going smoothly. Especially in [state name]. And then there were times where I felt like I had to push harder than I absolutely should've had to as a parent to get what he needs. And then there were times where I was like, "How much harder can I push?" You know, like "Why aren't they budging?"

Long from the moment when she became an educator hoping to cure the ills which plagued the academic pursuit of her son, Ruby's fight for Chuck transformed the woman she has become. Chuck now refers to her as an advocate, someone who gives voice and defends the

rights of others. She now sees the results of her persistence and perseverance, “because I fought and I’ve never given up.”

Ruby’s story of advocating for her son spoke to me, nearly each and every inch. I noted the connection in my researcher reflexive journal following our second interview session:

In a world where I feel alone and isolated trying to advocate for my son, it is incredibly reassuring someone else is working just as hard, while also trying to make sure such injustices don’t happen for the students we teach. I am NOT alone! I knew this person prior to my study, but have never felt such a connection to our passion and purpose until I had the opportunity to discuss these very questions. (10/23/2013)

For Ruby, her passion, her purpose, and her commitment beyond the needs of herself are evident in the outcomes for her son. “He’s received I mean so many benefits. I think that he’s received a voice. To be heard.”

Judith and Barry: Their Fight to get it Right

Understanding the educational system from a parent perspective is one thing; understanding the legal language and nuances of IDEA is another. The fight to secure the rights of 15-year old Barry, which began with the intent to understand the law, has since transformed into one mother’s mission to educate herself within the law. Meet Judith, a 42-year old mother who works as an assistant in the special education department at an elementary school. As a nine-year veteran within her school district, Judith is taking her *fight within* to a unique level. “I would like to be an education attorney, but not for schools, not for school districts, not for states, but for the kids.”

Judith entered education like Ruby, like me, and after she confirmed what she had suspected for quite a while; her son had specific learning disabilities and needed an IEP.

“Believe it or not, it was someone who worked for another agency under our school district that said to me, ‘you might want to get a job at the school district so that you understand the in’s and out’s’.” New to the world of special education and laws associated with it, Judith heeded that piece of advice and left behind a job as a staffing specialist for a home healthcare agency to become a one-on-one aide for a child with Autism Spectrum Disorder. “I went in it... because my thing was I needed to know what these kids were entitled to. What the norm was? What do they normally get?”

Meet Barry, a freshman in high school who was identified with Specific Learning Disabilities at the age of eight. According to his mother, Barry’s academic struggles began immediately.

We knew something was different when he was in kindergarten. Because upon entering kindergarten he knew all the letters, all the sounds they made, but he couldn’t piece them together. They said, “Oh it will come, he’s young, it’ll come.” May [end of school year] comes around in kindergarten, it didn’t come. Gets to first grade, still can’t read, not a word, can barely write his name on paper. And the whole time I’m saying, well..., do we need to do anything extra at home, blah, blah, blah? No. Still couldn’t read and they pushed him on to second-grade. I said that’s it, something is not right, because verbally he can talk to you and he can tell you things that he’s seen on TV or that he’s heard, but couldn’t read, couldn’t write, couldn’t spell.

Judith did not stop questioning her son’s academic performance. Her pursuit for answers changed the trajectory of her entire life; from a mom working to help her son who could not read and write, to a mom seeking to help others, all because of what it took to make sure Barry could read and write.

Judith provided numerous documents allowing me to understand the full progression of Barry's educational experience. She showed me a three-ring binder she has kept since Barry was in second grade, complete with parent conference forms and informal assessments prior to his entry into special education, followed by: the evaluation which identified Barry with elevated levels of anxiety and processing deficits in relation to the areas of long-term retrieval, processing speed, and cognitive fluency; every IEP which ensued after he was found eligible for Specific Learning Disabilities; and parent and teacher planning notes associated with those IEPs. This extensive collection of documentation allowed me to analyze Barry's academic progression by viewing his present levels of performance, progress on his goals and objectives, scores on statewide standardized assessments, and concerns noted within the parent and teacher planning notes for IEP meetings. My reactions to analyzing these documents were captured in my researcher reflexive journal. Judith also provided me with her own journal, which I asked her to use as we journeyed through the interview phase and capture her own thoughts and feelings regarding her experiences in advocating for Barry. These components facilitated my understanding of her experiences in ensuring Barry's rights as afforded under IDEA, the barriers she encountered within those experiences, and the perception she maintained of her job security as a school district employee advocating from within. The remaining depiction exemplifies themes associated with the three research questions.

Experiences in challenging school districts. My first question to each co-researcher asked them to describe their experiences in raising a child with a disability and advocating for their needs. When I began with this question for Judith, she laughed and responded with her own question, "You have that much time?" Judith's experience in advocating for Barry began in

the years prior to his initial IEP, when she noticed he was not learning to read at the same rate as his peers. Barry noticed as well.

I remember, he was sitting at the kitchen table, trying to do math homework, I was getting dinner ready, I look over and he's crying his eyes out, banging his hands on his head, and I went over and I grabbed his hands and I turned his chair around and I said, "Look at me, what is the matter?" And he said, "Why am I retarded?" And I said, "Buddy you are not retarded, you just learn differently." To which he said, "It's not fair, it's too hard, school is too hard, they don't help me, I'm not getting any help." And I said, "We'll fix it, we'll get the help. If I have to take you outside of school, if I have to put you in a different school, we'll get you the help, but you are not retarded." And I don't think to this day that he really gets that yes, you're different, yes you learn different, but you're just as bright as these other kids.

What transpired following that conversation between a mother and her son changed the course of life for Judith and Barry. She sought help, from Barry's elementary school, and when turned away, she did not give up. Her experiences to make sure Barry could learn to read and write were both positive and negative. Within those experiences were a collection of themes which epitomized the good times, and the not-so good times for Judith and Barry as they advocated for getting it right. Figure 4 provides a visual description of the positive and negative experiences in Judith's advocating for Barry and the impact on this parent and educator as a result of the good times and the bad.

Negative experiences began immediately. Unlike Ruby and Chuck, the experiences for Judith and Barry began on a far different note. Judith noticed Barry was struggling in school.

His parent-teacher conference forms provided by Judith indicated below level performance in reading as early as first grade. She asked what could be done to help.

And the whole time I'm saying, "Well what we do, do we need to do anything extra at home? Blah, blah, blah." No. Still couldn't read and they pushed him on to second-grade. I said that's it, something is not right.

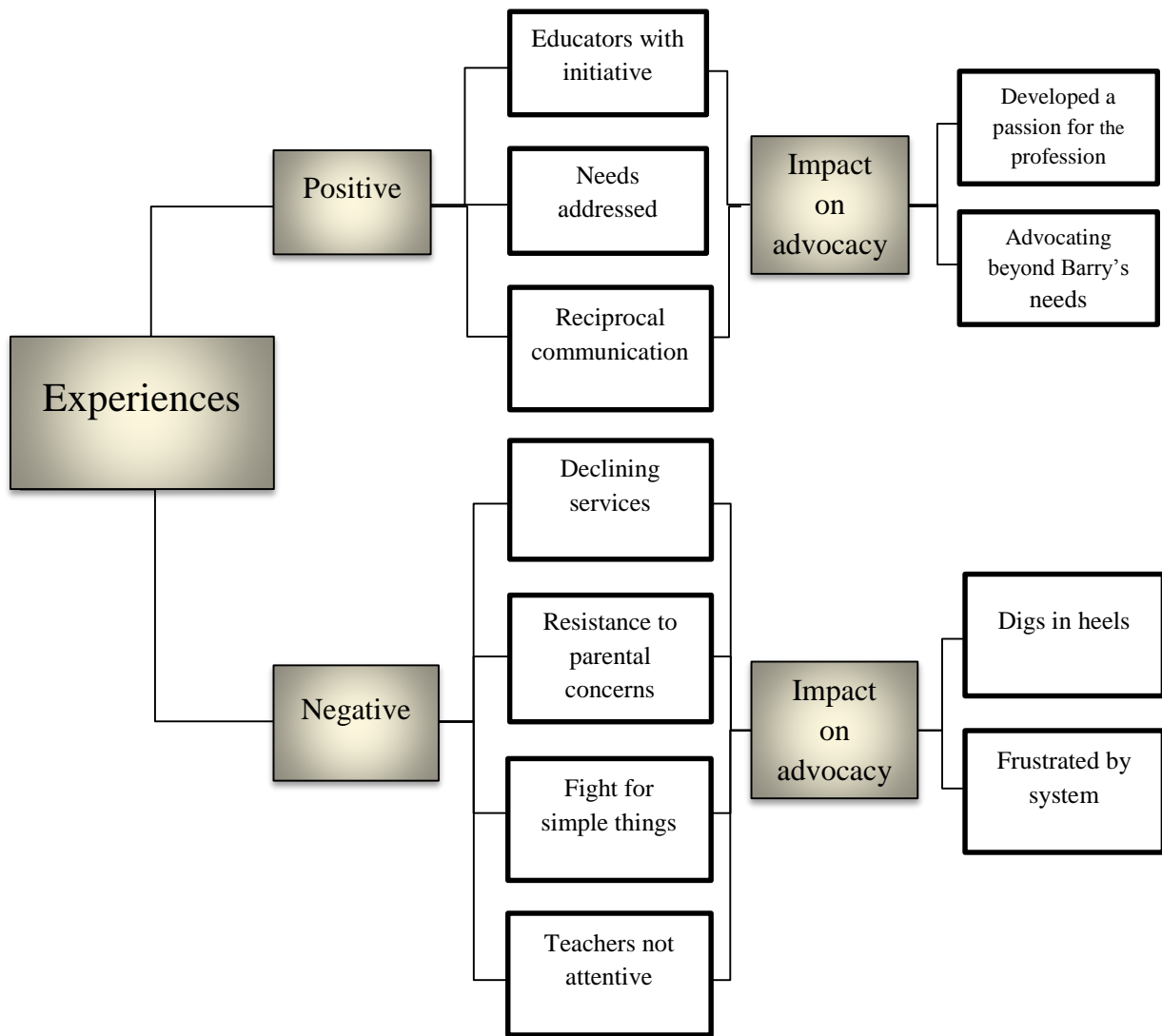


Figure 4. Judith's experiences in challenging the district where she worked and the impact on her advocacy.

She took Barry to have a psychological evaluation conducted outside the school system, despite her formal written request for the school district to evaluate Barry.

So I did not know that if you ask the school to test your child that they have X amount of days to do so. I did not know that. I asked, they said, “We do not test for learning disabilities until third grade and they have been retained.” That is what I was told. So I spent \$1650 to have my child tested outside the school district by someone who was certified through the school district.

The evaluation did not reveal anything Judith did not already suspect; Barry was a smart young man, with an IQ of 113, but had discrepancies between his IQ and his long term retrieval, processing speed, and cognitive fluency. His Broad Reading score on the Woodcock-Johnson III Tests of Achievement indicated an overall weakness in Barry’s reading achievement, confirming what the school district would not; he was eligible for an IEP under Specific Learning Disabilities.

Amid the collection of Judith’s portrayals of her negative experiences emerged themes of: declining services from elementary to middle to high school; resistance to parental concerns despite her knowledge of Barry’s needs; Judith’s need to fight for simple things; and teachers not being attentive to a child who did not easily advocate for himself.

Declining services. After an initial rocky start, Barry’s entrance to special education services was described by Judith as “the best.” For a child who was significantly behind in his reading performance, Barry eventually caught up, meeting district benchmarks in reading and even meeting proficiency on the statewide standardized assessment in both reading and math as seen within the documentation on his IEPs. But the payoff in special education services during

elementary school quickly diminished in middle school, as noted in Judith's journal, and continues into high school.

You know it's sad that...your/our kids really start to make great progress by fifth grade.

It all gets shot to [expletive] the second they hit middle school and no one gives two shakes about what their IEP says or even comes close to following it. Same goes for high school.

By the time Barry reached eighth grade, his statewide standardized assessment scores had fallen two levels, to basic in both reading and math. The decline was a concern to Judith.

You get to middle school and it falls apart. I don't know if it's because of the multiple teachers, that how big the campus is, how many kids they have, I don't know what it is about middle school, but gradually it starts to fall apart.

It was not just the decline in Barry's performance on the statewide assessments which caught Judith's attention; it was the decline in the approach to students with disabilities and educators not being aware of which students had an IEP.

When he takes a test and the tests come back that he failed it, and the teacher writes on the test, you may need tutoring. No, why didn't you catch this when he was in the class, sitting doing nothing? Because he's not going to tell you that he needs that help. You know he has learning disabilities, you know he has an IEP, you should be looking for that, you should be observant of that, you should know I've got 22 kids, I've got two with IEP's and one with a 504. Those three kids I need to make physical contact with every day at some point in my 55 minutes to make sure they're getting what we are going over. They don't.

Aside from teachers at the secondary level not being as attentive to student needs, Judith also found herself struggling with the mentality toward students in middle and high school and the expectations from teachers.

I've heard them say in middle school to these kids, well you need to grow up you're not in elementary school anymore. To which my child responded to a teacher, "Excuse me miss, but three months ago I was." So these kids are still 10, 11, and 12 years old, but you're constantly telling them that they need to grow up. All of the sudden you get the kid come eighth-grade who's noncompliant, who doesn't want to do what you ask. You told him for the last three years that he was a grown person. That doesn't work, they're still kids. I don't care if he's 16 and didn't turn in his science homework for a week and you watched him do it in class and you say to me, well he should know to turn it in. No, he needs that reminder. Well, he's in 10th grade. And, your point is what? He's still a child. He doesn't have the right to vote, he doesn't have the right to drink, he's still a child, he lives of my house, I pay his bills, he's still a kid. So he needs that. And he may need it when he gets to college from mom. Mom may be calling him and saying hey dude, got any assignments going on that you need to catch up on, because your grades aren't looking all that great right now. Oh yeah, oh you got some stuff you need to turn in, well you might want to do that so put it in the front of your book bag so you know to turn it in. You know it may be mom when he gets to that point. But right now it's them and they just kind of overlook these kids.

For Judith, the decline in the treatment of students in special education did not only surround academics. It transcended other pieces of the educational puzzle as well, such as who

was responsible for what and why diminishing communication with the parent in the post-elementary school years was difficult.

I've had them increase my son's services for a week and a half before his IEP meeting and not tell mom, not say anything, and then go to the meeting and have them say, "Oh by the way he's in a co-taught math class," when before he was in a regular math class. I'm like that's an increase in services, that's inclusion, you have to let me know ahead of time. Oops. Sorry. "Well you know how it is, sometimes there's miscommunication because..., his math teacher felt like it would be the best for him to go to this, so he went to the guidance counselor. And the guidance counselor didn't really understand that he had an IEP." And my response was, "You've got to be kidding me, all of you are working together to serve these children. But nobody knows anything? You're telling me the guidance counselor doesn't know which kids have an IEP? They're her kids, she's their guidance counselor. She's responsible for guiding them to the classes they need to take. How's she supposed to do that if she doesn't know that they have an IEP? "Well you know Judith, sometimes these kids get lost in the whole shuffle because there's so many kids that we don't realize which kids, sometimes the guidance counselors don't realize which kids have an IEP and which kids don't."

The decline in the attentiveness to the IEP process has also frustrated Judith. She keeps any and all documents related to Barry's education and stores it in that three-ring binder. She also knows the law after years of learning everything she could. So when Barry's annual IEP review comes up each year, she knows what to expect. One of those pieces is a draft copy of the present level narrative which is expected by the district to be sent home for the parent to review prior to the meeting, especially when the parent is requesting it.

I said to them, please send me home a copy present level narrative. Present level, which means present, today, in the now, in this school year. I got one that said Barry is an eighth grader at [school name] middle school. No he's not, he's a ninth grader at [school name] high school, so let's try it again. That one never even showed up. My kid didn't bring it home. It didn't show up in the mail, I don't know where it went. The gremlins must have ate it, but it didn't show up.

According to Judith, this happened on more than one occasion through middle school and into high school. There are also stark differences in the information within the present level narratives from second through tenth grade. The descriptions of Barry were more detailed in his elementary narratives than middle and high school. In this district where Barry goes to school and Judith works, special education teachers are assigned as case managers for students they may never see in any class. In Barry's case according to Judith, none of his middle and high school IEPs was written by anyone who serviced him in class. At the time of these interviews with Judith, Barry's case manager was the teacher in a self-contained class for students with intellectual disabilities. A class Barry never set foot in and a teacher he never met until the development of his IEP.

Resistance to parental concerns. Judith also found a level of resistance to her concerns for Barry's educational needs in middle and high school; something she never indicated when outlining experiences in elementary school.

I've had the lovely experience of when he started middle school, his very first IEP, actually hearing from the middle school team say to me when I requested he be evaluated by occupational therapy because you still couldn't read his writing, "Well, we could do that, but he could probably write better if he just slowed down and took his time." And I

said, “Okay, no he really needs this.” “Well, you know, we have a lot of kids that have higher priorities that have higher needs that really, that can’t even hold a pencil.” And I said, “Yeah I get that.” “And you know how it is, you work for the district. You see how it is that sometimes it takes a long time for these kids to get services that they need.” The kid was never evaluated by OT. Let’s just say this. I had a friend who was an occupational therapist who came to the school that I worked at, showed me a trick with a rubber band to keep the pencil properly in his hand and that’s what we used. So we taught him on our own how to hold a pencil the right way.

Resistance to Judith’s concerns for Barry’s needs went beyond the physical aspect of performing in class. She was also concerned about his declining academic performance on the state reading test. Barry had been placed in an intensive reading class due to his below proficient reading performance. But he did not have a reading goal on his IEP. Instead he had a writing goal, even though he had passed the state writing exam. For Judith, who was familiar with typical special education practices pertaining to IEP goals, addressing Barry’s area of weakness seemed like a given, but not for the IEP team at the high school.

I went to his IEP meeting, the first one was five hours. The second one was four for the same thing. He had a writing goal but had passed the writing portion of the [name of state test]. But didn’t pass the reading portion and is in resource English I and has an intensive reading class, but has no reading goal. Okay, so if he has no reading goal you’re telling me he can read. If you’re telling me he can read, then why does he need intensive reading and why is he in a resource English one class that has 12 kids in it? He’s in those classes because he can’t read well enough to pass the [name of state test]. That’s lovely then he needs a reading goal and if his reading goal is nothing else but to

pass the [name of state test], he needs reading goal. “No.” Yes, and I don’t think they understood for the life of them that I was not going to give in like the normal parent would. And I did say to them after spending four hours discussing, I said, “I’m not signing this, this is garbage, this isn’t even close to what my kid needs. You need to get somebody in here to mediate between the ESE team, the teachers, and myself because all I’m doing is getting angry and this is not going to work the way it is. I spent three years fighting at the middle school for every little tweak. I’m not doing that another four years. I can’t. It will suck the life out of me if I have to do this for four more years. So let’s get it together as a group and figure out what we need to do.”

Fight for simple things. The battles have been both big and small for Judith. She’s had to fight for services, accommodations, IEP goals, and things she did not expect to have to advocate in order for Barry to receive.

It’s been tough having to fight for the simplest thing, as far as I mean, one time we had a discussion with a particular teacher about the type of pencil that he used, because he liked a particular pencil. And she didn’t want those kinds of pencils in her class, mechanical pencils. So it was, he just wrote neater, it was more clear. We bought a special grip that went on the end and she said, “But he’s just going to sit there and click it and play with it and it’s going to annoy me.” So we literally had to like talk to the principal and say look, if we can’t do this amicably then we’ll have him evaluated by OT and we’ll just have it put in his IEP if we have to.

She has even found herself having to make sure educators knew that Barry had an IEP, despite typical district procedures that regular education teachers are made aware of which students have an IEP through codes on student rosters, as well as the expectation that special

education teachers provide a student IEP to each of the child's teachers in middle and high school.

I've gotten to that point where I got tired of hearing, "Well I didn't know your son had an IEP." Okay well that won't be a problem ever again because every year I give it to every teacher. Here my child has an IEP, my phone number and my email are on there, if you need anything call me, if you have any questions call me, I'll be glad to fill you in. And they look at you like, what? Oh thank you and they take it from you, and you know the whole time you're going, they have no clue, they have no clue.

Judith has also found herself fighting the middle school to provide the proper special education supports Barry needed in math, even though the school provided the type of service one year and did not provide it the next. Never mind that Barry's demonstrated success in that least restrictive environment.

They didn't have a co-taught pre-algebra one class, at all. So I went to them over the summer and actually sat with the AP of curriculum and said, "Look, you guys were adamant in seventh grade when you put him in a co-taught resource math class, unbeknownst to mom for a month. You were adamant that this is what he needed and yes it worked out fine, he got an A in that class all year long. So now it's in his IEP that he is to be in a grade level appropriate co-taught math class, you have to make that happen, he has to have two teachers in the room." To which I got from ESE specialist, "Well we don't do that, when it gets to the higher classes they don't co-teach, it's just regular and he has to be able to sustain." No. You were adamant that it be co-taught [in previous school year]. It worked for him, so now you have to make it a co-taught math class,

otherwise come day one when he walks in that math class if there's not two teachers in there, you're violating his federal rights from day one. So how do we fix that?

Within the interviews, Judith spoke about making sure Barry's IEP was right, and she candidly explained why. "I've always tried to tell them, listen when things are going bad we have to approach it with the attitude of it has to be fixed. It has to be fixed and it has to be right, because it's Barry's future." In particular Judith explained how in Barry's most recent IEP meeting she had to push the high school teachers to provide Barry's homework on yellow paper. The contrast on the yellow paper made it easier for him to see the print. According to her, the IEP team was unwilling to provide the accommodation until the assistant principal got involved and offered to buy the yellow paper. This self-described mom on a mission explained in her journal why continuing to fight for what may seem like simple things to others is so important for her. "First because he's my son and I never ever want him to say to me again, 'Mom, why am I retarded?' with tears in his eyes. And because I'm a mother, so it's my job to fight for my kid."

Teachers not attentive. The importance of proper special education services was valuable to Judith when considering her son's future. But what also appeared to bother her within the interviews was inattention to Barry, particularly inside the classroom, where the instruction and support for his needs began. Judith described Barry as the quiet student who would not typically advocate for his needs. Barry's initial psychological evaluation indicated elevated levels of anxiety. He did not speak much when he was young and his lack of speaking carried into the classroom, leaving him hidden from view in larger secondary level classes where students with more noticeable behaviors garnered teacher attention.

My biggest concern for him is the fact that because he's, as ridiculous as this sounds, because he's well behaved and can sit in a classroom and even when he doesn't understand what's going on in the room, he can sit there quietly. So he gets overlooked. They're constantly overlooking that, hey wait a minute he's got that deer in the headlights glazed look on his face, maybe I need to wander over there and make sure that he understands what I just explained. But you get the opposite. You get [from the teacher], well he sits in class and he's very quiet. Well that should be concerning to you that he's just sitting and being quiet. Have you gone to check on him? Have you checked his work? I think that's my biggest thing is that, because he can sit in class and just, if he doesn't understand something he can just sit, so they miss it, they just overlook it, they don't get it.

Within her conversation with me Judith wrestled with how to get teachers to pay attention to her son's needs in and among the larger classroom settings where she claimed he was lost in the monotony of daily instruction.

And as long as nobody's checking, the teacher may be more than happy to let your child sit. I used to think like with Barry, because he could sit and he was well behaved and he was quiet, that they would just let him sit there and do nothing, because he didn't misbehave. And I actually said to them the one meeting, "So if my kids started rearranging the furniture in the classroom, chucking chairs, and flipping desks you'd get him more help? But because my kid can sit and behave, he's overlooked and you just do nothing. How is that fair for him? So do I need to go home and tell him okay when you go to school tomorrow start flinging chairs?" Because I can't think of anything else to get them to do what you need to have done.

Even though Judith began thinking in desperate proportions, she longed for a place to release the frustrations which accumulated over time. Her children and their education were vitally important, and the experiences Barry encountered in his middle and high school years, despite his high average potential, took a toll.

Oh my gosh, I wanted to go outside and scream. I wanted to shake somebody and say listen to me! I don't care that the district says, I don't care, I don't care! I don't care about the other 125 kids in your room, I don't care that your dog died last night, I don't care that you get to that point, I don't care that your car broke down on the way to work, I don't care that you've had a rough school year and you have six classes full of the worst behaved kids on campus. I don't care! I don't care about any of that. What I care about is my kid that's sitting in your room not getting an education. That's what I care about. I don't care that you don't get a planning period and now you have an additional..., period that you have to teach. As cruel as that sounds, being in the system, and you know how stressful it can be, and you know how tough it can be because you see it firsthand, you see the kids that act up and the teachers trying to teach and you have the kid that's quiet in the corner and the teacher's trying to, you see all of that. But as a parent that shouldn't matter to you. What should matter to you is, what are you doing with my kid? You're doing nothing because he's performing and he's doing nothing. He's sitting in your class and doing nothing. And you're okay with that. Why are you okay with that? I get that there are some kids that you just will never be able to teach to, whether it's they don't want to learn, they don't want to put forth the effort, they don't care, they're going to drop out, they know they're going to drop out because they're going to go do this or do that, or they just don't have the ability to understand what you're doing. But when you

have a kid that's sitting there that you know can do it and you just let them sit there and you do nothing, that's when I get aggravated.

Impact of the negative experiences on advocacy. Judith's aggravations with the decline in Barry's services, the resistance she experienced from school personnel to address her concerns for Barry's needs, the degree to which she said she had to fight for accommodations and IEP goals, and the ease at which she felt teacher's overlooked a young man who historically struggled to advocate for himself not only caused her undue frustration, it caused her to dig in her heels even more and question Barry's future in a public education setting. She documented her turmoil in her journal: "Sometimes I have wondered if he'd be better off home schooled or taking the [name of scholarship] and going to a private school with less kids and more individualized attention."

Frustrated by system. Judith recognizes the lack of individualized attention for Barry is not just isolated to teachers. She realizes the teachers are also constrained by systemic barriers which exist within her district. Of particular concern to her is the number of students placed in enlarged co-teaching situations with both a regular education teacher and a special education teacher, leaving the students to get lost in the system. "These kids are still getting overlooked. It's still missing, they're still not getting what they could out of education because of the way it's set up." Judith feels the scenario still leaves children with no more of an advantage than being in a classroom with only a single teacher and no special education support.

How the district goes about those co-taught classes, I don't think that's what he needs. He does need that additional teacher. He does need that additional help. But to put 33 kids in that class is ridiculous. Nobody's getting the help. The whole point of co-teaching is that these kids have two teachers available that they can go to, to help them.

One teacher's teaching, one teacher's walking around the room. There's 33 kids.

There's no way all of those kids are getting that extra attention that they need. It can't be.

There's too many kids in there.

In relation to students with disabilities being assigned to large classes, Barry's experience has given Judith a different perspective. Barry did have a smaller class for eighth grade pre-algebra and his experience was far different than the over-sized class which awaited him in his first year in high school. With two teachers assigned to lower the teacher-pupil ratio, Barry shined, giving power to Judith's argument for school personnel to set him up for success by placing him in a smaller classroom with co-teachers.

Instead of trying to tell me what your policies are, listen to me as a parent when I tell you this doesn't work for him. This isn't working. It's not what he needs. We have to do something else. Listen to me, listen to him, listen to him tell you the math curriculum is going way too fast, I [Barry] can't keep up. Give me the same math curriculum throughout the year at a slower pace I'll [Barry] blow your mind, because I'll get a higher test score than everybody else.

With two teachers in a smaller class slowing down the pre-algebra curriculum to a pace appropriate for the students, Barry did so well Judith says he scored higher than any other student on the end of the course exam, setting the curve for the entire district. Yet upon entering high school, Barry was back in a large setting for Algebra I. Judith had to argue for a special education teacher to be assigned to the class to provide support along with the regular education teacher. Otherwise, Barry's IEP was not being followed. But the larger setting, void of adjusted pacing, left Barry struggling and his grades declining. Barry told his mom he needed more help.

Judith says the teacher claimed she was unable to slow down the pace and that Barry just needed to keep up. That scenario infuriated Judith.

Sometimes I just, you just want to get a group of moms together and just stand outside and scream at the top of your lungs, you've got to be kidding me. Do I really have to go through this? And..., you find out the longer you're in the system, that it's not just you, that you have friends that go through it too. But you don't know that when you first start, you really don't. And the more frustrated I get, the thing that frustrates me the most is, if I know all of this and I know who to call and what to ask for and now I know, no..., adjusted pacing means, if my kid doesn't get it in a week, then you're supposed to keep teaching it to him until he does get it. No matter what the district says, because my child's document is a federal document. And federal laws trump district. So give it to him and if I know all of this, how is it for the parent that was like me X amount of years ago that has no clue, that has no clue?

As I read through every one of Barry's IEPs and other documents, I too found myself getting frustrated. With nine years of experience in special education since my career change, I had seen numerous IEPs. As a specialist in charge of the special education department at my school, I had been trained in identifying student strengths and weaknesses, and targeting those areas for improvement. I had the luxury of analyzing Barry's IEPs from start to finish. I documented my impressions of what I saw in my researcher reflexive journal.

Then when he does have his IEP meeting for his first high school IEP, I got incredibly angry reading it. Constant talk about not focusing or turning in his assignments. Seriously?! Again, just like Chuck in case #1, these difficulties are documented many years back. Here again is a child with organization problems. He completes his

homework, but forgets to turn it in. Well, heck, he's had difficulty with this dating years back. So why not provide him supports to help with this, rather than repeatedly badger him throughout many years? In other words, what the heck are they going to do about it? Seems like nothing, because it's gone on for years with no visible signs of support in those areas. I am extremely frustrated reading this, and I can only imagine how his mom feels. (12/27/2013)

Digs in heels. As a result of all her frustrations, Judith has found herself digging in her heels, less willing to let her position as a special education assistant in the district prevent her from making sure educators addressed Barry's needs. Insisting she could earn more money working at the local McDonalds, Judith came to the point of balancing the purpose of keeping her job with being an advocate for Barry.

It gets to the point where several years in a row of not getting what they need, I find myself at that impasse where I'm just not going to accept, "Well you know how it is you work for the district." I can't do that. My kid's got four years of school left and then he's off to college. He needs what he needs and he's going to get it. And if I have to fight you every step of the way I'm going to.

Yet having an avenue to voice her concerns is complicated. There is a chain of command in place, a hierarchy of district personnel who respond to parental concerns. But this has not been an easy answer for Judith because of her position as an employee within the school district.

I know they tell you, you can call at any time anyone in the district and they will explain. Bull! They will give you a technical explanation, or district policy is ma'am blah, blah, blah, blah, blah. I don't care what district policy says. I work for the district, I know what district policy is. But I'm telling you this isn't working for my child. "Well ma'am

maybe you need to call the school's guidance." I've already been through everybody at the school. Do you not understand what I'm trying to say? So it's like you get frustrated, you get mad, you hang up the phone, and you look at people that you work with and go, really, is it really this complicated, does it really have to be this hard? Who are these people? Do we need to have a mass, like these are all parents that work for the district, you are all teachers. They're not going to push you, you don't push them. Right now shake hands, everybody play nice. And if the mom says the child needs extra help in a subject, okay you have them for 55 minutes. When they tell you it takes them more than 55 minutes to do their homework at night for your class, maybe that's an indication that the kid really does need more help.

Positive experiences. For Judith and Barry, their journey through the special education program was just beginning, and so too was their *fight within*. Barry's entrance into special education was a little troublesome for Judith at first. She formally asked the school to evaluate Barry for his reading and writing difficulties, but she says they declined. Barry eventually received his first IEP in November of his second grade year and Judith changed careers and went to work as a one-on-one aide in a middle school. Judith did not talk much about that point in time, other than she moved to an elementary school position and decided to move Barry to the same school where she was employed for the beginning of his third grade year. For the two of them, it became the best decision she made for Barry's education and the beginning of a string of positive experiences.

The best one was moving him from the elementary school that he was at that refused to test him, to the elementary school where I was doing my job. Two weeks after him being there, the VE teacher came down to me and she said, "Look, we start next week, we start

pulling our resource kids.” Because at the time they pulled them for reading, writing, math. I said okay and she said, “I cannot pull Barry because his IEP says he’s not to be outside the gen ed [regular education] classroom for more than 21% of the time.” So I said, “Okay well he can’t read, he can’t write, he can’t spell. What am I supposed to do?” And she said, “We have a meeting and we change this so that we can pull him out of the classroom so that he does get the services that he needs.” I said okay, can we do it right now? She said, “Absolutely, give me 30 minutes.” I said that was the best because she knew that he needed more than what he would’ve got if she served him in the classroom. She came and found me. She told me she went above what she had to do because she really could’ve just left him sit there, because that’s what his IEP said. But she knew that that wasn’t going to work for him. We had that meeting, signed off on it, right from the get-go he was getting the services that he needed.

Educators who recognized Barry’s need and acted on it built the foundation for happier days for Judith, as well as those who maintained open lines of communication, no matter the circumstance. Perhaps among the positive experiences emerged the most important theme for Judith, that of particular educators who used their initiative to go above and beyond, proving their willingness to build a future for Barry.

Educators with initiative. Throughout our interviews she spoke highly of the elementary school special education teacher who made the decisions to change Barry’s services, for the better. As a result, Barry went from reading more than a year below the expected level in second grade as noted in his initial IEP, to reading on level by fourth grade, just two years later, all because a special educator realized Barry needed a more intensive service delivery in order to close his reading gap.

So we did all of that and low and behold it worked. The following year, same VE teacher, “Listen he needs resource math, he is really not getting this [understanding the content]. He’s not going to be able to keep up with these kids in fourth grade. So not only is he going to get resource math, but when he goes back to class, because his resource math is only 40 minutes, they’re still in math block. So he’s going to get it twice. Even though he’s not supposed to, he’s going to get it twice, because he has to go back to class.” I said, “Great perfect, where do I sign? Because what you did worked for him. You are worried about him, my kid. Not about anything else.”

The intense effort to improve Barry’s reading and math performance paid off. He had met proficiency on the statewide standardized assessment by the time he left fifth grade. He no longer needed special education support for reading and he was placed on a consultative status to make sure he maintained his growth in math.

Had she not said something he probably would have sat up there in class and they would had to go serve him in class and he wouldn’t have made the gains that he made. He would’ve just sat there. But to make that big of a gain. And she knew, I mean just by seeing him a couple times in class, looking at his IEP reading his psych, she knew that he needed to be pulled [into a resource class]. And she came right to me to make sure that it could be done. So that was the biggest positive that he’s had.

Not only did Barry’s reading level rise to grade level expectations, so did his confidence. Before leaving fifth grade he reached a milestone in his mind. Judith said her older son was always a straight “A” student and always on the honor roll. Barry aspired to receive the same recognition, but school did not come as easy. And for one moment in time, Barry not only met

his goal, he reached the principal's honor roll, earning straight "A's" the only time his brother did not. It was a moment for both Barry and his special education teacher to savor.

And the VE teacher he had at the time came over and she literally..., picked him up and she said, "I told you, you could. I told you, you could. This is all you. You worked for it. You did it. Nobody else did."

It was moments like these which Judith cherished, while wishing there were more. And there were more. And even though Judith said they were few and far between after elementary school, there were moments when certain teachers took that extra step. Judith even described a moment while she and her boys were out for dinner and Barry's middle school intensive reading teacher approached her. With an arm around Barry and nothing but words of respect for this hard working young man, she explained to Judith where Barry was struggling in her class.

Because she took initiative to come over and say, "Hey mom he's a good kid I really like him, he's trying, but he's not doing this and I really need him to do this. Not just because the other kids in my room do it, but because I want to know that he's reading, that he's understanding the book that he's reading. And if something's confusing, he can write that down. He can say this is the chapter I'm on, I read this, but this part doesn't make sense to me. And when I look at that I can go, oh well here Barry didn't get this."

Needs addressed. Addressing Barry's needs was the recipe behind further positive experiences for a young man who, according to Judith, had big dreams. Barry aspired to either build the space shuttle or be on the space shuttle, with plans of attending an Ivy League school. His mother said he developed a love for science at a time when other subjects, particularly reading and writing, were hard. Regardless of the difficulties, Judith spoke more about how Barry's needs were addressed in elementary school, more so than in middle and high school. "In

elementary school I have no complaints. They went above and beyond letting me know as a parent what my kid was getting. What he needed.” Addressing Barry’s academic difficulty was exactly what he needed, and it happened in the hands of an elementary school teacher who continued to make adjustments in Barry’s services to better address his needs. In doing so, Barry learned alternative methods to learn how to multiply and divide multi-digit numbers using a lattice and a t-chart. For a child who struggled memorizing the standard mathematical processes, Judith was amazed. Barry explained to her how he learned it. “And he said, ‘because [special education teacher] told..., [regular education teacher] I didn’t get it the other way, so she taught it to me this way’.”

Barry’s sixth grade math teacher took a similar approach after Barry came home from school on the first day crying. Barry was placed in an advanced math class due to his proficient performance on the state math assessment. However, he struggled with memorizing his multiplication tables, making it difficult for him to quickly and efficiently solve multi-step problems.

I sent her an email and I said, “Look he can’t remember his times tables. Not for the lack of trying, but he just cannot, that’s one of those things that he’s never going to be able to retain.” I got back, “Okay no problem, I’ll take care of it.” That day he came home with his math rip-out notebook, and said, “Look at what the teacher did for me.” And you open it up and on the inside there was his times tables. She glued them in there. Times tables chart. She said that he doesn’t have to think about it, he can just do.

Barry had a similar math teacher in eighth grade. This time he was in a small resource class for pre-algebra with two teachers, a special education teacher and a regular education

teacher. The curriculum pace in that class was slower than the typical regular education setting. It was here where Barry excelled, proving his potential with the right type of support.

He needs that [curriculum pace] slowed down, gone back over, and when it's done that way, my kid can shine. Proof in the pudding is last year, when he had pre-algebra and he got a 96 on the final, blew the curve for everybody else. Why, because he was in a co-taught resource class that only had 15 kids in it with two teachers. And they slowed everything down. They were never on timeline. She said there is no such thing in this room. And she taught to the kids. Every single kid in that resource class passed that exam. Kids in the other classes didn't pass. All 15 of these kids passed that exam and are in algebra one honors at the high school.

Slowing down the pace was of particular concern for Judith. At the time of our interviews, Barry was struggling to keep pace in a large group regular education setting with two teachers. He complained the pace was too fast. Yet she had proof Barry could perform, and perform exceptionally well when teachers addressed his, and other student's needs, to slow down the delivery of instruction.

You'll find there are few and far in between, but there are teachers that say, it doesn't matter what the district says, it doesn't matter about the district timeline, federal law says these kids are entitled to this, so..., I'm doing it. And proof is in the pudding when these kids excel versus the kids that didn't get it. So you taught at such a fast pace that nobody got it, but you slowed it down for 15 resource kids and they all passed it? That tells me that either A you're going too fast for even the gen ed kids, and or B it works for these kids with learning disabilities, you have to slow it down.

Ironically, Barry was not scheduled to be in that small resource class with two teachers. Judith had to insist on it the summer prior. It was written in Barry's IEP at the end of the school year and he had proved his least restrictive environment existed when he was taught by both a special education and a regular education teacher. Judith convinced the school it was what Barry needed and Barry proved her right.

Reciprocal communication. Also working in Barry's favor when everything was going well was two-way communication between Judith and Barry's teachers. This, she felt, was the link which kept all the pieces working for Barry.

I feel like a lot of the times it's one-way communication and when things work and they're in sync, it's because it's two-way. It's not just the parent saying this is what my kid needs... You actually have that teacher that sending you an email or calling you saying hey, look, I noticed that Barry's not doing such and such and I really need him to do this in order for him to understand the next set of stuff that were going to.

Keeping those lines of communication open were vital for Judith. Organization is one of Barry's weaknesses, and so is remembering to turn in homework, even though Judith says he always completed it. It's documented in his IEPs dating back to sixth grade, when he began changing classes in middle school. But hearing from the teachers was not the only piece of communication Judith expected. She held the same expectations for herself and for Barry. "When things are going good, I want to recognize that. I want to be able to say, hey thank you, thank you for helping me, thank you for letting me know."

On one occasion in middle school, Judith received a phone call from one of Barry's teachers. Barry was upset and crying about being "puny" and the comments other students were

making about him. The teacher stayed with him until Judith arrived. Judith made sure that moment did not go unrecognized.

Three days later when my son finally decided to go back to school, the first thing he did in the morning was, he took her a thank you card and he took her a box of chocolates and he said thank you for caring enough to listen to me. And I'm like that's important. You have to let them know, listen, I know you're doing the best you can with my kid with what he's got to work with. But when you're not even trying to do any of that, that's when I lose my mind.

Impact of positive experiences on advocacy. Just as the negative experiences had an impact on Judith's reaction to the events which unfolded, so did the positive experiences. She entered education to learn more about what her son needed. New to the field of special education, she asked anyone and everyone who could answer her many questions. "I wanted to know, I needed to know the in's and out's..., the more I found out the more I dug a little further." Making a career change into education came as a benefit to Barry and especially Judith. She quickly learned she had a passion for special education. She fell in love with the kids. Her passion was so devout that she began to help other parents understand what they needed to know about their child's rights. More importantly, her advocacy extended to Barry, as he learned what his IEP meant, and what he was entitled to as a student with a disability.

Developed a passion for the profession. As an assistant in the special education department at her elementary school, Judith was not as directly connected to students as if she were a teacher. Prior to her current position, she worked as a para-professional for children with autism and intellectual disabilities, positions many people find more challenging than they prefer.

I love the kids. You do it for the kids, you don't do it for the money. If you're in it for the money then don't ever teach because you're going to be broke all the time. Get a different profession. If you want a job that you truly love, and you truly love these kids, and you want to see just that one spark from that one kid, if you get that from one kid once a year, it was a brilliant year. Forget what my evaluation said, forget all of that. If I can get that one kid, just that one spark, and you can see it when the light bulb comes on, then that's good.

Clearly impacted by the kids she has worked with, I asked Judith to explain how her advocacy for Barry has influenced the manner in which she worked with the children who have touched her heart. Her answer indicated how her experience with Barry has impacted her on the job as well.

I think it just makes you more aware of the kids that you're with and the kids that you work with, what their needs are. And that you want to meet those needs because you want that parent to know their kid is getting what they need. You don't want to be on the other end of that, because you've been on the other end of that. You want to be that person that is making sure this is what their IEP says, this is what we're going to do. And if we have to do it in a roundabout way so that we're in compliance with whatever the district says, then we need to figure out a way to do it, because it's what they need.

The word "need" came up frequently within our discussions about her experiences in advocating for Barry, and it transcended how Judith approached the students she worked with as well.

So that's why we do what we do. We don't do it for monetary gain. We do it for the kids. Our own [child] got us into it, pushed us sort of in that direction. But we continue to do it just because we want them to get what they deserve.

Advocating beyond Barry's needs. In order to help the children get what they deserve, Judith extended her advocacy beyond Barry's needs in order to help other parents. After all, she did not understand the language of special education nor the services Barry should have received when he was initially found eligible for an IEP. She had to learn, and learn a lot. So she wanted to lessen the impact on other parents.

Some parents are like, I have no idea. I know he gets extra help, that's all I could tell you. That drives me nuts. That makes me crazy. He's your kid, go find somebody, ask somebody, ask your pediatrician. Ask him who to talk to. Call some people on the phone. Call the district on the phone and say hey, I have some questions, where are there people that I can talk to that are going to give me answers. You have to go find, go, shoo. You have to physically do, you can't expect an entity to tell you every single in and out that's going to cause them to have more work. They're not going to do it. So you have to find other avenues, other parents, other groups.

But the restrictions of the position placed Judith in a quandary. She wanted to provide parents of students in special education with the information they needed. Her own experience told her there is too much to absorb in regards to the language, the services, and the nuances of the field. Knowing that the more informed a parent can be, the better the potential for positive outcomes for the students. She found being as forthcoming as she wished was not so easy.

Because if you're new, and by that I mean your kid just got diagnosed with whatever it is, you have no flipping clue what to do. I've been there. You have no idea who to ask,

who to call, nothing. And you get all of this information thrown at you that this is what we're doing. This is, you know, like they'll say, we're going to work with them with reading mastery and decoding and you leave there going, well okay, yeah, that was great but I don't even know what that is. So is that the right thing for my kid? I don't know. The teacher said it is. So you learn to say, excuse me what is that? Because I have no idea what you're talking about. You know, to begin with, I didn't work in the education system, so I was like, I have no idea what that is. So who's supposed to explain it to me? You don't know. So I've been in their shoes. And then when you get into the, okay now I'm an educator and now I know, sometimes you want to look at that parent and say, please oh please, ask this question. You can't come right out and say it, but you're looking at them and you're thinking please ask this question so I can give you the answer, because I can tell by that look on your face, but I can't until you ask me.

Once that door opened, Judith was quick to respond. She had been there. She knew what it was like to have so many questions and find someone available to provide the answers. Therefore she was unwilling to leave any parent in a lurch, especially when they too began to ask questions.

And then if you are lucky you get a parent that comes to you and says listen, who do I talk to because I don't think this is working, I don't think what we're doing is right for them, and I don't know what else to do. Then it's my job to say, especially if they come to me, I don't exactly know but let's go find out. Let's go talk to the teacher, let's go talk to our ESE specialist, let's go talk to the guidance counselor, social worker, whoever we need to talk to. I'm more than happy to take you and find somebody.

Not only did Judith find the avenues to help other parents who were struggling to find answers, she also taught one of the most important people in her life how to advocate for himself. Barry learned what it meant to be a child with a learning disability. He learned about his accommodations and how to remind his teachers when he was allowed to receive extended time. He also learned to recognize when his own advocacy fell on deaf ears as evident in Judith's journal.

He knows he has accommodations and he knows they're not being met and it frustrates him. Last school year he told the ESE Specialist, "Why do you all keep saying I need to advocate for myself, and when I do, absolutely nothing happens about it. The teachers just ignore me or say, 'Well you don't need that, so I'm not doing it'."

Barriers to advocating as a parent and as an educator. But addressing Barry's needs was the difference between the positive and negative experiences for Judith within the school district: the same school district where she worked and learned about what should and should not be happening in Barry's education. When teachers addressed his needs, Judith was pleased. When those needs went unchecked, she found herself at odds with her employer; encountering barriers she could not foresee when she decided to become an educator herself. Once she overcame her own learning curve, her insider knowledge seemed to become the bane of her existence as she struggled with her son not getting what she thought he was entitled to under IDEA. Through it all, she perceived her job as a limiting factor as she hedged at taking her concerns to a point of no return. In turn she balanced her roles as a parent first versus a sympathetic employee. And at times the unwillingness to bend, both she and the district, presented barriers which restricted Barry's full access to an appropriate education. Figure 5

represents those barriers Judith encountered as she advocated for her child with a disability inside the very same school district where she worked.

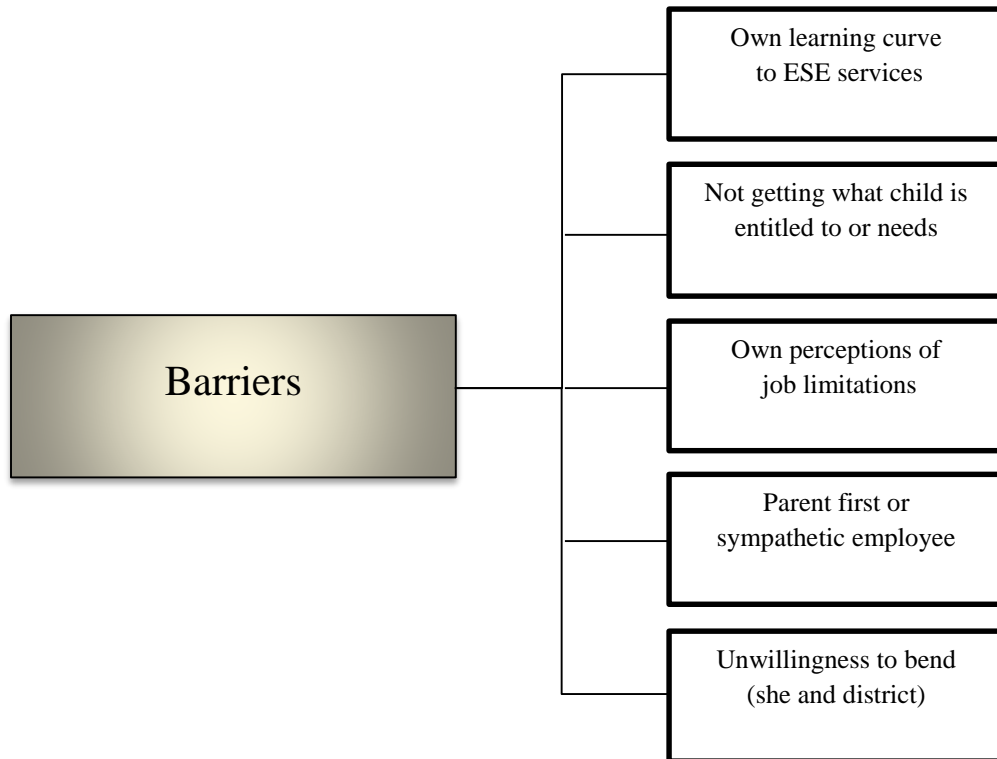


Figure 5. Barriers Judith encountered in advocating for Barry.

Judith's learning curve to special education services. Special education was a second career for Judith. The need to understand what it was all about was thrust upon her by Barry's learning struggles. Had it not been for someone she knew inside the school district, she may never have made the cross-over into the world of education, and may never have learned what outsiders could not.

Because as a parent you know absolutely diddley nothing. Even the outside psychologist, when she sat us down and went over his test results, when we left there I was like, okay yeah that's great, and I had this big great piece of paper but I still don't know what that

means. I'm like, that's lovely. She said, "He's going to qualify for an IEP which is going to get him additional help." That's great, but what is that? Who do I go to? Who do I ask?

The whole concept of Barry needing an IEP was overwhelming to Judith. She had so many questions. It was all new to her and she knew of no one else at the time that had a child in special education. So the decision was made to join the system in order to understand the system.

I went into it after because my thing was I needed to know what these kids were entitled to. What the norm was? What do they normally get? What is normally available to them, are they entitled to you know special materials, are their books different, are their rooms different, and not having had a child in that situation that he was in, that was my first instinct was okay, I got to get a job in education because I got to find out. And especially it has to be special ed, because I have to find out what these kids get. I didn't even know even getting his IEP that was great. I was like okay perfect lovely. You go to your first meeting and if you've never had an experience, you leave there feeling like, okay I don't even know what that was but they're the teacher so they must know best feeling. And you just take it for what they say it's worth, face value, and then when you get in the system and you start looking up IDEAS and FAPE and all these different things, you go oh no, no, no this isn't going to work for me. What you put on paper doesn't even come close to what my kid needs. So now how do I fix it? What's the next step? It was like okay well this is good, but this isn't. This is good, but this isn't. Okay, so who do I approach? Do I approach his teacher? Do I talk to the guidance counselor? You don't even know who to talk to.

Studying the pieces and finding direction in the special education system became a priority for Judith. Her persistence to know helped her triumph in understanding the language in IDEA. Not only did she read it, she had to break it down into understandable context.

To begin with..., it was almost like reading the procedural safeguards, it was gibberish to me. And I was like, ok I can't go about it this way because this isn't going to work for me. So literally I had to go like the very first paragraph and stop. And say okay, how does this apply to my child? Is this something that I need to be aware of that he's entitled to, for future, for now for? Go to the next paragraph and break it down and say, okay now is this appropriate? Is this something that I need to be aware of that he's going to need for his future, for college, or in the moment? Does this apply right now today? And am I going to remember six months from now what this is? That, oh wait, I read somewhere, where did I read that? So for me I literally had to get out a notepad, get out a pen, and just start writing. Okay well it says this. Okay well where do I find, it says they are entitled to accommodations? Well I know what he's getting, but is that what everybody gets, is it all the same? Well I don't know, now I got to go look it up. Now I got to go find out. Where does it say exactly what the accommodations are and how they're applied, and who gets them and who doesn't. So it's really a long process if you want to know every in and out of what your kid should be getting.

Judith's persistence and willingness to learn was driven by her intense desire for her son to become the man he wanted to be. After all, Barry had grand ambitions. He aspired to go to Harvard, Yale, or Duke. He wanted to prove that people with disabilities could be scholars. Yet it took dedication from his mother who proved her resolve as she immersed in special education practices.

I will always and forever be a mom first. I was a mom first when my son first got diagnosed, I was just a mom. So I went into this knowing I got to know, I got to know more. And not so much more, I got to know what all these programs are, I got to know..., what's EBD [Emotional/Behavioral Disorder], I got to know. You know, what's ASD [Autism Spectrum Disorder]? I got to know. Okay well you know that's autism, okay that's great, what is it? Does it vary? Are all autistic kids the same? Is there severe, mild, medium, I got to know. And it was almost like instantaneous, I got to know. I got to know what I'm dealing with here, so, in order to do that I'm just going to kind of jump in head first, you know and here we go. Okay now I'm going to be a sponge, I've got to absorb all this because, I got to know when somebody says reading mastery, I got to know what that is. To just tell me isn't enough for me. I got to know so I can help my kid.

Not getting what Barry is entitled to or needs. Throughout her research avenues, Judith became versed in the law and fluent with Barry's needs. She knew he needed certain accommodations to help him succeed in class, such as: cueing and prompting to remember previously taught information in class or turn in his homework; adjusted pacing when the curriculum moved to quickly; extended time to complete assignments; or even manipulatives to help Barry build his mathematics skills starting from a concrete level. Yet Judith struggled when she felt Barry was not receiving the very accommodations he was entitled to. "It's so tough when you know what your kid should get, you know what your kid isn't getting, and you know they know it too." Such instances became a dilemma for Judith as she juggled the needs of her son, and the need to keep her job.

I have found myself biting my tongue on more than one occasion in a meeting where I've been told, we can't adjust the pacing. District policy says we cannot adjust the pacing. That's great, but federal law says my kid is entitled to this. "Well yes ma'am we know, but it's a new math curriculum, we're trying to work towards Common Core, so we have to stay on the timeline, so we really can't do that, that's why we offer tutoring." Yeah no, this is so my kid can get what he needs when he's in the classroom. We're not talking about extra tutoring, we're talking about, he needs this to get the most out of his 55 minutes in your room. "Well, I can let you talk to our AP of curriculum and you know maybe she can explain it to you better to you why we just don't do that." And you..., want to hold back because you know they know who you are. They know you work for the district. But you feel like, gosh if I really just sat down and did what was called for in this instance, I would be directly on the phone with downtown stating, I was just told this by such and such teacher, is this true and what is your name? Because I need it to give to my attorney. Because I'm now going to sue you because my child isn't getting what they need. And according to federal law, my child is entitled to get this because he needs it. It's not a want, it's a need. He needs it to be successful.

The opportunity to be successful, according to Judith, begins with students with disabilities receiving what they are entitled to under IDEA. And when she spoke of Barry not receiving his accommodations, she spoke of how other students than just Barry were essentially not receiving what they were entitled to by law either.

So when we see all of that [meeting the needs of students she works with] and we're on the flipside and want our kids to get what they're entitled to, I think the district needs to understand we are not just a select few, there's a bunch of us, a big bunch of us. And if

it's not right for us and our kids, it's not right for anybody else and their kids either.

And..., my kid's not the only one in the room with an IEP whose accommodations aren't being met. Means everybody else in the room theirs aren't being met either.

Barry and other students not receiving what Judith felt they were entitled to by law was a source of discontent. In her journal she expressed her frustration with feeling as though she has had to fight the system which is designed to help.

I am so tired of feeling like I'm banging my head against a brick wall. I'm not asking for anything that my son isn't entitled to under the federal guidelines, so I don't get why they make us feel like we are asking for so much more.

Own perception of job limitations. As Judith encountered various barriers associated with an appropriate education for Barry, her own perceptions of being a school district employee restricted the degree to which she carried out her advocacy for Barry. Throughout our three interviews, Judith spoke much about limiting what she said and how she said it, particularly when I asked how she felt in regards to advocating inside the district knowing she was an employee.

It's sucks, because you feel like you're in a rock and a hard place. Like you know what you want for your child, you know what your child can do when they're not getting it, and you so dearly want to be able to say to the teacher, who's your direct supervisor, because that's who I need to talk to. But you're more cautious, you're more careful about going that next step, because heaven forbid, that principal now becomes your principal, that boss now becomes your boss, and is aware of, oh wait a minute I know you, you're the mom that was giving me such a hard time about such and such accommodation and the teacher wasn't giving it and you were down there every day in the guidance office

and I had to come over and we had to sit and we had to talk, oh wait, I know you. So I'm already watching you just because you're on my radar because I know you as that difficult parent. So does that mean you're going to be a difficult employee? And is there a difference?

I later probed Judith to discuss those differences. I wanted to know how she perceived the variations in the way she advocated for Barry in relation to the manner in which other parents advocate for their children in the district. Her answer demonstrated the fine line of being a parent of a child with a disability while also working as an educator within the same school district.

I've encountered the parent that will say okay, well I don't like that so and I don't like the answers that I'm getting and just pick up the phone and call the area office. Being in that position working for the school, I'm a little leery to do that because I don't want to step on toes so to speak, but I want what's best for my kid. So..., you have to weigh that and you're not as quick to the draw as they are sometimes.

Judith said the position of being both a parent and employee makes advocating a challenging task. Unlike the other co-researchers in this study, Judith is not a teacher. Yet she has worked as a special education aide and an assistant. Her salary range allows her different decision making in relation to her employment than it does for the other co-researchers. "I could work the third shift at McDonald's and make more than what I'm making." Regardless, she perceives her position in the district as a limiting factor in advocating for Barry.

I think they know that a lot of parents, this is their livelihood. This is how they pay their bills. Now it is for me, but it wasn't before. But they see that and they go, they're only going to push it so far because if they want to further their career in the district and if

they don't always want to be a teacher and they want to move to the administrative side, and they want to move to the downtown side and you know getting these different jobs, they're going to be mindful, so they're only going to push it so far.

Parent first or sympathetic employee. Concerned whether she could only advocate so far, Judith found herself thrust into the position of being pressed as a parent first or an employee, sympathetic to the demands of the job and the institutional confines experienced by school personnel.

If I wasn't the school district employee, I would've called downtown two weeks into my kid being at the middle school. Yeah it would've took me five minutes. Because I wouldn't have thought my job was in jeopardy. I wouldn't have felt like I had to be careful what I did. I would've been on the phone downtown, hey look this is what my kid is supposed to be getting, this is what he's not getting. I talk to them at the middle school and I get nothing. I get no emails back, no verbal response, nothing. Nobody can tell me anything. So you're my next step. And if I don't hear from you what I think I need to hear from you, then I really think I need to go talk to an attorney and we need to sit down at the table and say look this is how it has to be. And as a parent you also think it shouldn't be this hard, it shouldn't be this hard.

But she was an employee and she was a parent. A mother to a young man she struggled to obtain initial services for; a mother to a young man who struggled to learn to read and write; and a mother to a young man who continued to need his services and accommodations, no matter how much she felt he was overlooked inside the classroom.

I don't know if it's the way they come off or the look that you get. And like I've said, they've said, "Well you know how it is, you work for the district. Well you know, you

work in the system and you know how it can be.” And multiple times I’ve said to them, and that doesn’t matter to me when I’m in this meeting, I’m a mom. I’m a mom first. And I have to be a mom first. And I don’t care what the district norm is. And I don’t care that that’s not how you perceive it needs to work. “And well you know this is how things have been done in the district for a long time. Well you know because you work for the district.” Yeah I do, but it doesn’t work for me as a parent. That doesn’t, it’s not what my kid needs. So we have to fix that.

As someone with an understanding of Barry’s needs, Judith found her familiarity with the inner workings of the district clashed with her priority to her son. “It was just that I think it’s looked upon as we know the steps, the chain of command so to speak, and because we’re an employee we follow that.” In particular, Judith spoke of an IEP meeting at the middle school when she found out the school had changed Barry’s services without notifying her. She pressed them for an explanation and explained the laws and how the school was obligated to notify her when a more restrictive environment was chosen. In this case, the school moved Barry from a regular math class to a co-teach class with other students with disabilities. Granted, the change was for Barry’s benefit, but she knew the law and knew a parent is supposed to be informed when the school decreases the child’s time spent with non-disabled peers.

So then they were, I don’t know if the term is for lack of a better word, using the fact that I worked, still work for the district to try to sweep it under the carpet so to speak to say, well you know how it is, you’ve..., seen how hard it is to get these kids things and you know that sometimes..., we have these little snafus where this was supposed to be implemented and it wasn’t. Or this was supposed to be happening and it wasn’t. So you know how it is, sometimes we make mistakes, sometimes this stuff happens. And you

almost want to say that's fine if it's not my kid. But it's my kid, so if it's my kid and you know I work for the district you think you would be on the ball. Because you know I know what I'm talking about. So you think you would have your ducks in a row and you would say okay this is what the mother is asking for, this is what she prefers, this is what the child says, this is what the teacher says he needs, let's make sure we're all going in the same direction that he's getting everything out of every day because the parent knows this and this. And knows this person and this person that they can pick up the phone and call our area boss and say yeah I know your direct line because I work for the district, but I'm calling you as a parent. But they know that you won't do that because you're worried about your job, you're worried about your job.

Unwillingness to bend, she and the district. Judith's continued struggles within the system where she worked has placed her in somewhat of a quandary. She has found herself unwilling to bend, refusing to give an inch, specifically when the school or the district does the same. Sometimes this worked well.

They finally figured out that mom, even though mom works for the district and we tried that angle, mom cannot be pushed. Mom is not going to waiver. Mom is not going to give in to just whatever they say and mom will make phone calls. Mom will find out. Mom will bring us information and say listen, this is what is best for this child. This is my son.

As previously explained within the negative experiences, Judith felt the schools and teachers did not always listen. Therefore the relationship became tenuous. She let them know where she stood in relation to Barry's needs. She knew her son and she knew what worked best for him. So when further contentious situations arose, she did not back down. She kept her

concerns at the school level, but was not willing to bend, because in her mind, it was for Barry's benefit.

And then you get to the point where after fighting the same school for so long, they see you coming and you can see the look on their face, oh no here comes so-and-so's mom, oh good Lord what did we do now? She's going to say something about this or something about that, she's going to complain about this or complain about that.

Despite her insistence that Barry's IEP address his needs and educators follow through with the services and accommodations which are outlined, Judith admits that both sides, the parent and the school, are needed to help the student achieve to the best of his ability, and that both sides must remember the sole purpose of an individualized education plan. And finding a means to common ground may be the difference between the positive and negative experiences when parents of children with disabilities work within the same school district.

The willingness of each party, them and me, because sometimes it's me, I won't give an inch, to remember we're doing it for this kid. We're not doing it for you the district.

We're not doing it for me the parent. We need to do it for this kid. And if we do what's right for this kid, then it's positive for you, and it's positive for me, and it's positive for him. You're not always going to agree with what they want, they're not always going to agree with what you want, but you should both always agree this is what we've seen works for this child. That in itself should be the difference between having a bad experience, positive experience, it shouldn't matter..., you should be able to do that. But I think the big difference between anything positive that's happened and anything negative that's happened is, not just the communication, but them being willing to work

with you as a parent and going wait a minute, yah, they work for the district but that doesn't matter.

Perception of job security in relation to advocacy. Advocating for one's own child is no easy task when you have to push back against the very system which provides your paycheck. For Judith, her paycheck is small in relation to a teacher salary. Regardless, this now single mother of two high school-aged boys needs to still provide for her family. Losing her job, even though as she stated, she could make more money in a fast-food restaurant, is not a preferred occurrence. She has considered other long term options, but in the meantime, she continues to need her job. As we discussed her experiences in advocating for Barry within the school district, she expressed not only frustration in fighting the very same system, she voiced concerns regarding her job security. Figure 6 represents the two themes which emerged from my conversations with Judith, as well as her own journal, concerning fears of potential repercussions for her and Barry, and her perception that her position as a school district employee was being used against her.

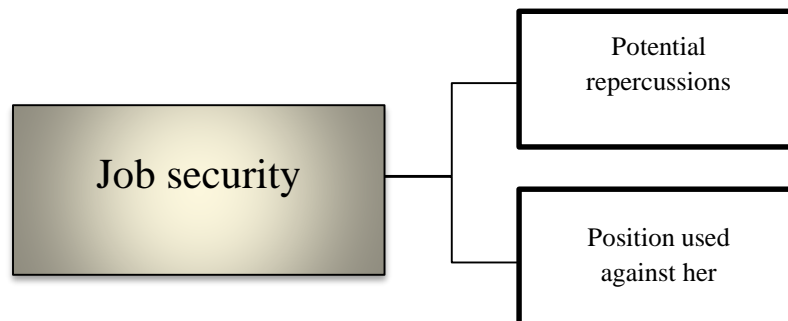


Figure 6. Judith's perception of job security in relation to advocacy.

Potential repercussions. Judith entered the school system as a means to learn more about how to access the right supports for Barry's educational needs. Knowing the reason

behind her career change, I asked Judith whether she thought her position inside the district helped, hindered, or had not effect on her advocacy. She instantly spoke of the internal struggle of being a mom first versus a district employee and how her beliefs that advocating for Barry could result in potential repercussions.

It's hindered it quite a bit, it's hindered it quite a bit. Because you learn very quickly who you should call, but you hesitate to call. Like you know, who you should call in the district when your child doesn't get such and such, and they should have been getting it all along. But you hesitate because they're going to say, well don't you work at so-and-so elementary? Or don't you work at such and such middle school? Yes I do, but I'm also this child's mom. Well, let me see when somebody can get back to you, and you know it's, you're going to have that mark, whether you intentionally want it or not. It's just going to be there, because everybody's going to know oh, she's the mom that called the district. Yeah, but she works for the district. So then you feel like if you have an off week or something that you're going to get wrote up quicker than anybody else would because you have an off week. But you also have a target on you because the district has now told your boss, hey listen your employee called me about their child. They need to be careful, especially if they want a promotion or they want to move up the ladder they need to be careful, because their name will be out there. And that's a tough one.

Judith's concern for possible job repercussions was embedded in several of her responses. On many occasions she discussed how these fears impacted the degree to which she fought for Barry and whether she used her insider knowledge to seek assistance above and beyond district level mediators.

They make you feel like if you push it, that you're in jeopardy of not getting promoted, of not getting that next interview, not being able to move up the ladder that everybody..., almost like you got a target on your back. Because they know your work for the district but they also know that you are somebody's parent. But then when these jobs come open they go, oh yeah, but it's between this parent or this employee that's also a parent and this employee that's also a parent. Both of them have special needs kids, but this one doesn't make any noise and this one is driving us crazy because she is constantly calling wanting to know why this isn't being done, that is being done, that isn't being done. So let's pick the mom that doesn't make a whole lot of noise that's an employee and we won't pick this other one. They literally make you feel like you have to choose, the district or your child.

When considering that choice, Judith also expressed a sense of inequality being a parent who also works inside the system. She attested that she feels she cannot advocate to the same degree as parents who do not work as district employees. And even if she could, the consequences may extend beyond her, leaving Barry a victim of those repercussions as well.

Because you almost feel like you're tied..., like I said, if you know what is best for your kid, you know what you want for your kid, but you feel like they know I work for the school system. So if I call and I talk to the area director, I'm going to get, well you work for us. Can't you work with us on this one? Can't you, you know, you might want to stay below the radar..., if you want to move up the chain. So you're a little more leery than most parents I think. Most parents, especially if they're really advocating for their child, and I don't think they hesitate to call the ESE specialist and complain, to call the principal and complain and say, okay you know what, you're not doing anything for me,

I'm calling the area office. And then if they don't like that..., then they're calling the office, office. And they're saying no, I need to talk to [superintendent name] because this isn't working for my kid and nobody's giving me the answers I want. And we're a lot less likely to do that. Just because we don't want to have our kid marked so to speak. That next year my kid will be at the same school, he'll be 10th grade and I don't need him walking into a class and the teacher going oh wait, wait, wait, wait. Isn't that the child, isn't his mother the one that called the area office on us? Well he can just sit right over there and he's not going to get squat from me because she did my friend who teaches here wrong. You know you almost feel like if you push too far your kid's not going to get anything.

Position used against her. Judith called the position of being both a parent and a district employee a “no-win situation” as she said she has heard on several occasions, “You know how it is, you work for the district.”

They just make you feel like if you make too much noise your name is out there and everybody is going to know that you're the mom that's bucking the system. You're the mom as advocating for your kid more, so then you're worried about your job.

But for Judith, her fears of her job position being used against her when advocating for Barry was an actual reality, just as it was for Ruby. She too was called into her principal's office after voicing her concerns above the school level when Barry was in second grade. At the time, Judith was working in an elementary school and Barry attended another elementary school. Regardless of their different locations, Judith was questioned and then warned by her employing principal.

I kind of got called in and you know when you get called into the principal's office, it's just like when you're kid, you know but now she's your boss. So you know if you get called in as she shuts the door, it's like oops..., what did I do? What boundary did I step over?

Judith went on to explain that the principal's intention was to make her aware of the need to be cautious of what she said and what she did, because she worked for the district.

At first I was like about what? She said, "You know." And I just kind of looked at her, and I said, "Oh the advocating?" To which I got, "You know." And I said okay. I said, "And as far as I'm concerned, I'm going to do what I feel is right. And if there's repercussions from that, there's repercussions from that, because that has absolutely nothing to do with the job that I'm doing, day in and day out." And she's like, "Well I just wanted you to be aware." She's like, "I'm not upset because I know you and I know how you are. But this came from someone higher up that you need to be careful what you do." And I said, "Well you can reassure them that you told me, but I'm still going to have to do what I feel is right."

As a result, Judith spoke of only job related fears in the years following that experience. Those fears were rooted in a real life situation. But she did move Barry from the school where she felt it necessary to voice her concerns on a higher level, to the school where she currently worked. That, as she discussed, became the best decision she made, as Barry became the product of a teacher who identified his needs, used her initiative, and made the necessary decisions which resulted in his learning to read and write and eventually achieve honor roll status.

Summary of Judith and Barry's Fight Within

For Judith and Barry, gaining access to special education services prompted their *fight within*. Initially denied an evaluation by Barry's elementary school, Judith went outside the school district to ask a psychologist to look into Barry's learning difficulties. What the appraisal found was a young man with weaknesses in the areas of basic reading, processing speed, cognitive fluency, and long-term retrieval. To Judith it explained why her son could not read, write, nor spell as he entered second grade. But it did not explain what types of services he would need, or the inner workings of the world of special education. Feeling at a loss in understanding the legal language and nuances of IDEA and the rights and protections afforded to Barry, Judith became a member of the same system which initially denied Barry's entrance.

What ensued following her decision to make a career change for the benefit of her son was years of ups and downs in relation to Barry's services, accommodations, and goals. And just as Ruby found out for herself, Judith discovered her position as an insider came with a *double-edged sword*.

I just think it's very hard when you're the parent and you work for the district, to walk that fine line. You don't want to rock the boat where you work, so to speak. You want your kid to get what they need and you have to be very careful how you go about both. And there are days that you want to bang your head on the wall. You want to yell at somebody downtown. But in the back of your mind you hold back, because you don't want to..., have that black star next to your name anywhere in the district. You want to be able to go and interview for jobs and whatever, and they don't even know who you are. But if they've heard your name 50,000 times, then there's going to be a problem. But it just, it shouldn't have to be this hard, and if it's this hard for us, it's twice as hard

for people that don't have contacts, that don't have friends in the system, that don't know who to talk to, that don't know who to ask. And the whole thing is just, it's too hard, it shouldn't be this hard. No, it shouldn't be this hard.

Judith and Barry both struggled with a decline in services from the elementary to secondary level, educator resistance to her concerns, and teacher inattention when Barry was struggling, leaving her fighting for things she never expected. And just like Ruby, Judith armed herself with her own education of the educational system. She read IDEA inside and out, contextualizing Barry's circumstances. She asked anyone and everyone inside the system about the types of services and instructional practices used for students with learning disabilities. Frustrated by the system of barriers, she dug in her heels when she felt Barry was not receiving all he was entitled to by law. She advocated from the inside-out, yet found her position as a district employee being used against her in order to silence her voice. Though, she did not let the warning damage her spirit or her advocacy for Barry and the numerous other students in special education, because according to her, every single one of them deserves the best.

I'm like, if people just knew these kids, it's not necessarily a disability, it's a unique gift. You have to learn how to tweak that gift so that, that kid gets everything out of their education that they should. That's what that IEP is for. We're not asking as parents for you to give our kids more, we're asking you to tweak the way you give it to them, so they get it the way that they need it to get the most out of it. That's all we're asking.

And asking for schools and educators to address the needs of students with disabilities is something Judith plans to continue to do, for Barry, and for others just like him. At the time of our interviews Judith was working as an educator by day and a law student by night, aiming to become an education law attorney upon Barry's high school graduation.

I know I'm not going to make a dime or maybe just a dime, and that's not what's important to me. It's they need a voice. And sometimes parents just don't have it in them to be that voice, to fight the big guy. I want to be that voice. I want to be able to say to the school district, to the state, to the government, I don't care, this is what the law is, black and white. And if I have to go to the Supreme Court steps and lobby to get this done, this is what needs to be done. This child isn't getting what they need and they deserve to get everything they need out of their education. They deserve it, just like everybody else.

After all, Judith's *fight within* for Barry has always been about getting it right, and getting him what he is entitled to through IDEA. So why not spread that advocacy and be that voice for many others?

Kate and Eric: Their Fight Without

Being the parent of a child with a disability carries a unique set of responsibilities. Being told you are a "bad parent" carries implications which may last beyond the diagnosis of your child. They are words which influenced years of advocating for a mom who fought to get doctors to notice and educators to take note. "I've been told more times than I care to repeat that I was/am not a good parent because I wasn't giving my son the help he needed." Kate began advocating for Eric's needs very early in his life. As dependents in a military family living abroad, Kate says she tried for years to get doctors to listen. At a little more than a year old, Eric was not walking or talking. He made sounds, but no words, and he would mimic and use expressions to communicate with his family. He also had difficulty with his behavior. "I could tell you at 13 months that something wasn't right." After years of expressing her concerns with medical personnel, Kate finally found a doctor who gave her advice beyond "he needs more

time” and that she was “worried about nothing.” Her advocacy led to a diagnosis for Eric and a decision for Kate to alter her entire life course in response to their experience.

Eric is a young man who was diagnosed at the age four with Disruptive Behavior Disorder, Developmental Disorder (language and phonological), Pervasive Developmental Disorder under the autism spectrum, and difficulties with speech. Kate says it took nearly two years for someone to attend to her concerns that something was different about Eric. He had an older sister and she developed at a faster rate. Doctors told Kate she needed to not compare and that Eric just needed more time to develop. Kate had no one else in her home to support her concerns. Her husband had been deployed in Iraq for the majority of Eric’s life at the time, and the family lived far away from relatives. She was essentially raising Eric and his sister on her own.

Kate entered education after Eric received his diagnosis and was placed in a self-contained pre-kindergarten special education class with an IEP supporting his academic, social-emotional, and communication needs. Inspired to pursue a degree in Human Services Management to help other parents like her learn to navigate and understand the types of interventions available within the human services industry, Kate instead found herself volunteering in Eric’s class, learning about activities which improved Eric’s skills. She also began learning about the types of services Eric had access to within the educational system. “He had assistance, he had paras, he had centers that he could pick and choose. He had a routine that worked for him.” According to Kate, Eric also had multiple layers of support from school personnel who provided separate services for speech, language, and independent functioning skills. “There were more available services for him. And he got what he needed.”

But the family moved when Kate's husband was assigned a new duty station. Looking for something to occupy her time during the school day while attending to her college classes at night, Kate began looking for a job.

I didn't want anything to do with the school system. No, you hear horror stories about the school system. You don't want to work for them. Yah, you can work pretty close to the same hours as your kid and you get summers off. I didn't want it. And it just happened to be that we were having problems with Eric at school, and more problems, and more problems.

Ironically, Eric's teacher recommended Kate for a position as a para-professional within the same school. For a few months, mine and Kate's paths crossed. We worked within the special education department for the remainder of that school year before I transferred to a different school. Kate stayed, completed her degree, and became a special education teacher. We did not stay in contact, but occasionally saw each other through mutual friends. I was aware she had difficulty with Eric and his social-emotional development in school, but I was not privy to the details and had never even talked to her about her struggles with him until she was recommended to me for this study by a friend.

Kate was willing to share her story with me and even requested copies of all records pertaining to Eric's special education services from his cumulative file at his elementary school. Those records included copies of Eric's IEPs from his current and previous states beginning with pre-kindergarten. Information within the IEPs aided in my understanding of the difficulties of their *fight within*, which has potentially left Eric on the verge of losing the remaining services associated with his IEP at the time of this study and Kate struggling with the idea of labels and eligibility categories as opposed needs based decision making. She also provided copies of

Eric's diagnosis from a military child and adolescent psychiatrist, which documented her extended concern with Eric's development as well as his social interactions. As requested, Kate supplied a journal of the thoughts and feelings she encountered throughout the course of our three-week interview phases. These documents helped me shape a portrait of Eric's progression through the world of special education as he moved from an eligibility of Developmental Delay, to Language Impairment and Speech Impairment, and eventually to only Speech Impairment. My own thinking in relation to the data collection process of this case was documented in my researcher reflexive journal and used within portions of Kate and Eric's depiction.

As in the previous depictions, Kate and Eric's story is presented in narrative form using a structure to address the research questions. It portrays a mother with limited, yet growing knowledge of the school system, advocating for the continued needs of her son as demonstrated by his difficulties with social relations, sensory reactions, and explosive behavior, while struggling with the long term implications of eligibility labels and the results of limited special education alternatives.

Experiences in challenging school districts. For Kate and me, our interview sessions were much more conversational than with Ruby and Judith. We met at a restaurant which was mutually convenient for each of our three interview sessions. As soon as I sat down and began preparing for our first interview, we began talking about work. Both of us being special education teachers, we had a lot in common with understanding the complexities of our jobs and quickly found ourselves *talking shop*. Before long Kate had naturally turned the discussion and began talking about Eric's experiences with his special education eligibility prior to me asking the first interview question regarding her experiences. Not only did she seem eager to share those experiences, I also found the interviewer/interviewee relationship more comfortable from

the moment we first sat down to talk than my previous co-researchers. Not that I had not developed a pleasurable interviewing relationship with Ruby and Judith, but that the comfort level with Kate and I was stronger from the beginning. I noted the difference in my reflexive journal. “Unlike my other two participants, Kate began our interview sounding passionate. I noticed she routinely switched roles between parent and educator when answering the questions. It spoke to me as someone who sees and feels those roles as one.” (1/16/14) At the time I did not understand how or why Kate combined those roles more than Ruby and Judith. But after careful analysis of all the data in relation to her case, the meaning began to unfold, uncovering a mother who felt she had been stripped of options in retaining Eric’s future special education services and therefore focused her advocacy on ensuring the same did not hold true for her students.

Kate and Eric entered the world of special education within weeks of finally receiving a diagnosis explaining Eric’s social-emotional and developmental difficulties. He was eligible in the state where he lived under the category of Developmental Delay. He was also eligible under the categories of Language Impairment and Speech Impairment. As a result, he was placed in a self-contained pre-school classroom for children with disabilities. Following his first year in that setting, the family moved and Eric continued with special education services under the same eligibility areas in his new state. Eric was placed in a regular kindergarten classroom with support for reading, writing, and math in a resource classroom as noted in his transferring IEP in his current state. As required by state law, the eligibility for Developmental Delay was removed at the end of Eric’s kindergarten year, leaving him with special education support for only his Language and Speech Impairment. By the end of third grade, the Language Impairment eligibility had been dismissed. Eric remained eligible for services related to his Speech Impairment, meaning he would maintain access to an IEP, though his IEP no longer provided

classroom accommodations to assist with his behavioral needs. According to Kate, Eric's academic skills were never a problem, his behaviors were. She felt he needed continued assistance in that area, but the categories with which he was currently eligible left him without special education support. And as explained later in this depiction, Kate may not have considered other eligibility areas if the IEP team considered them as well. Kate felt categories of Autism Spectrum Disorder (ASD) or Emotional/Behavioral Disorder (EBD) would place a label on Eric and potentially limit his future. The declining service options over the years left Kate and Eric in a quagmire. Further explanation of the details behind these experiences is contained within the remainder of Kate's story. As she outlined, her experiences in special education initially began on a positive note. However, the years which followed Eric's initial placement in special education were not always positive, particularly within the area of eligibility. Figure 7 provides a visual description of the positive and negative experiences as Kate advocated for Eric and the implications of those experiences in relation to her advocacy.

Positive experiences, but not plentiful. As with Ruby and Judith, I asked Kate about the positive experiences she encountered with Eric and his schooling. She initially shared her positive and negative experiences with me from the moment we started talking, but I wanted to know the good with the bad in an effort to pinpoint what worked as opposed to what did not. When I pressed her to discuss the positive moments which came about as a result of her position with the district, she took a long pause and replied, "I'm still thinking." Clearly her direct answer did not provide any affirmation of experiences for which she could speak highly. But what appeared to work for Kate after immersing in the data and identifying themes were moments when Eric's needs were met and when she was able to collaborate with teachers and

administrators regarding Eric’s behavioral challenges, even though those behaviors were mentioned in the present level narrative of his speech related IEP in limited form.

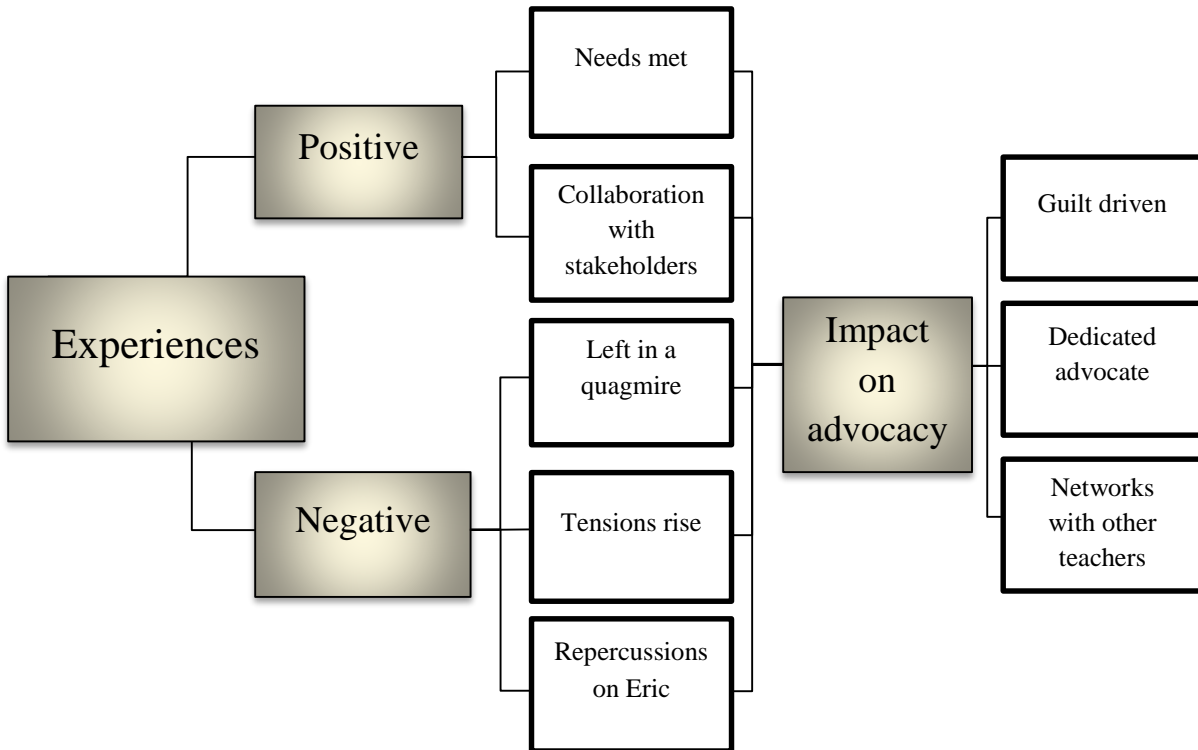


Figure 7. Kate’s experiences in challenging the districts where she worked and the impact on her advocacy.

Needs met through appropriate services. For Kate what worked the most took place when Eric was in his self-contained pre-kindergarten setting, prior to the family’s move.

In [previous state] he was in a, basically like we have here, an EELP [Early Exceptional Learning Program] unit. And if you looked at what we have right now it would be comparable to EELP plus. You had a diverse group. It wasn’t your communication kids that have some independent skills. It was the adaptive skills. It was the kids who need more proximity, because he would just do stuff that was totally not safe. He needed to have picture schedules. He needed to know what was next. He needed to know what, he

still does, he needs to know what's expected of him. And unfortunately he's going to do exactly that and not a minute more.

Kate and Eric's introduction to special education services was one of their more memorable positive experiences. For Kate, her positive view came as a result of the multitude of options and services provided on Eric's behalf at that time.

In the department of education it was very welcoming. If I had a question they answered it. And yah, we do that here. We do. We answer every question we can for parents. But I think for me at that time there were more available services for him. And he got what he needed. Whereas if we were to do that at say third-grade, which is where we get a lot of our kids coming into the ESE population, I don't know what it would've been like, I didn't experience it there. They got him the services and he had every flipping service known to man that was appropriate, appropriate [stated with emphasis] for him.

I wanted her to explain in further detail what types of services were provided so I could garner an understanding of what she determined appropriate. Her answer amazed me. "He had speech, he had language, two different people." It only surprised me because the school district where she and I once worked did not provide two different people for speech and language services. Instead students with those eligibilities were seen by a single speech and language therapist who worked with both impairments.

Two different people because they had two different therapists. They just had. They split the caseload. It was one of those things that if you had so many minutes for this, say 30 minutes for speech, 30 minutes for language, you got 30 minutes for speech and you got 30 minutes for language.

Not only did those services address Eric's speech and language deficits, it also addressed social aspects of his identified disability.

He had one-on-one services where somebody would come in and work with him. Well, because he needed to learn inhibitory commands. So how do you teach inhibitory commands other than no and stop? Well you can show them pictures so you're building the background knowledge, so they did that, and I did it at home. So he learned if I ever come across this setting, stop, okay I know, don't touch, don't talk to the stranger I saw the pictures, I did the activity yay me. And it was like 10 minutes a week and every kid in the basically EELP therapeutic, would get it and they move on to the next class, and they get it, and it was 10 minutes. It's not expecting a teacher to throw that in there and really make sure that this kid got it and that kid got it and that kid got it.

Kate found this level of services to be very beneficial in Eric's development as the school district in the previous state even addressed Eric's difficulty in understanding elements of speech which would keep him safe, something which was not covered in his current state.

In [previous state] I had great experiences because he got what he needed. I mean there are things that weren't even on the IEP. And they got services because they understood, well like inhibitory commands. I mean like that's the big one that sticks out to me because it's common sense. If we want them to know we've got to teach them. You know don't assume a kid knows how to blow his nose, teach him how to blow his nose.

However, those were the most extensive services Eric would experience. Following his move to his new state, he maintained academic resource support for reading, writing, and math. The staffing committee met toward the end of Eric's kindergarten year and removed his eligibility for Developmental Delay as required by law. Even though the present level narrative

stated that Eric “requires some assistance” in the area of social and emotional behavior because “he can become disruptive” and “oppositional”, the IEP team based continued special education services only on academic and speech/language evaluations. From that point on, as Kate explained, the positive experiences diminished because the results of that eligibility meeting left her in a difficult situation to maintain future support for a young man who continued to struggle with behavioral control in the regular education classroom. And being new to education, she also did not know enough to ask the IEP team to seek other areas of eligibility.

Collaboration with stakeholders. Understanding that Eric was beginning to lose access to special education support in the classroom, Kate quickly realized she was not going to accomplish obtaining continued behavioral support through the paperwork [IEP] side. Eric was struggling to appropriately express his frustrations while in the classroom setting and it was becoming a concern. Therefore she took on a new approach in accessing assistance for Eric. She began advocating for his needs further through constant collaboration with teachers and/or administrators who would listen.

I’ve been able to build good relationships with some of his teachers. You realize, it’s some, to where they understand. And I’ve always encouraged them, please go talk to this teacher, let them know and ask them..., well what about this, what worked? And so sometimes some, some, very some small, small, tiny some, they’ll listen.

Kate has been able to use her communication with Eric’s teachers to provide them ideas they could apply in their own classrooms to meet his social-emotional needs.

I’ve had some good teachers that want to know, and will apply what I help them with.

I’ve had teachers that say you know we’re having a problem with this and I was wondering what you think. And they kind of get my buy-in. Well you know I was

thinking that maybe this might help Eric. And it's something that they can provide in the classroom, oh let me do that at home. I mean there's been some really good regular ed teachers that have offered ideas and have been willing to absorb whatever I have to offer. So in a professional learning committee we've got that going on, we can collaborate, we can move forward.

Her desire to maintain a positive collaborative relationship with Eric's teachers was vital in Kate's mind for his success. She needed the teachers to feel free to contact her when Eric was struggling and all else failed.

When he was in third grade, the teacher had my cell phone number, had my husband's cell phone number, if you ever have a problem please call me, I will do what I have to do. Because with Eric I know if we can get there early, we can diffuse the situation, we can solve the problem, we address the antecedent and we can move on. And I would be called and I would leave work. Because I'm sorry, my kid is more important than my students. He's my baby. And I would go and I mean, end of semester, I'm sitting there and helping him finish his work in his class while..., everybody else is doing their thing, and he's doing his work. Some teachers realize that they do and they do and they do and they don't reach him. Let me call the big guns in. And I've gone in, [husband name] gone in, and we've done what we've had to do.

Kate explained that she was never hesitant in letting Eric's teachers know right away that she could be called on to help.

So if we use the tools available call me if you're having a big problem, write home if there is a problem, let me know if you have any concerns, it's been successful. Because I care and I'm one of those engaged parents, how many are, how many aren't.

In particular, Kate said her position as a teacher in the district was beneficial at times, as it simplified collaboration opportunities even after she no longer worked in his same elementary school.

You know there's that side of everything where, oh that mom..., teaches in the district, don't piss her off. Whether it's true or not, because I've never been the angry confrontational type because you don't get anything accomplished when you're ugly to the teacher. You know vinegar doesn't work, honey does. So I've always had that for him. Oh yeah his mom works here and that helps. I've always been lucky enough with the few teachers that when I say, well this is my contact information you let me know if you have a problem, I will take care of it.

Kate's understanding of Eric's needs was evident in her approach to communicating with his teachers. Eric displayed difficulty in his peer relationships. Kate knew how to eliminate the causes of those struggles and she knew the teachers needed to know as well.

I know Eric. So I advocate what I know is successful for him. Please don't expect him to walk where you want him in line. Listen to him if he tells you he can't be near somebody. You know if he has a bad relationship with that person then let's work around it. So I mean it's all backdoor conversations helping him be successful. What am I going to do when he gets to middle school?

Middle school was a concern that plagued Kate throughout our interviews. She knew what she was doing would help Eric since he currently had no access to services under his IEP for his behavior. But she found her home-school partnership was the answer in a system where she felt she had no other options.

How can I work for the teacher to get Eric to where he needs to go? What do you want him to do? Tell me and we will work on it at home. And the problem is..., I don't know middle school, so we're going to have a bit of a problem adjusting to that one.

Negative experiences with nowhere to turn. Perhaps what beleaguered Kate were the experiences which overshadowed her hard fought battle to get a doctor to realize the significance of Eric's social-emotional development. She advocated for her son when no one else noticed. Her fight resulted in early intervention services through IDEA Part C. Eric had been diagnosed as having Pervasive Developmental Disorder, which was under the autism spectrum umbrella. His access to early intervention services ended when he was no longer eligible for the Developmental Delay program. By definition, children are eligible under Developmental Delay from ages three through nine, or ages three through five, depending on the state eligibility requirements. For Eric, the state he was living in ended the eligibility at the end of the child's fifth year. The problem was Eric could have been found eligible for further special education services due to his medical diagnosis. Yet, according to documents pertaining to the eligibility meeting, other areas of eligibility were never pursued. And if they were, Kate may not have been willing to accept the implications of those eligibility labels. She says she was not in favor of Autism Spectrum Disorder (ASD) or Emotional/Behavioral Disorders (EBD).

Okay he is eligible for ASD. He's also eligible for social-emotional because his ASD results in behaviors that are non-typical in a standard classroom. You have kids [talking to me], would you want them labeled EBD? Especially after being in an EBD classroom?

However, Kate did not have a voice at the meeting which resulted in the removal of Developmental Delay eligibility. She was not able to attend because she was working as a paraprofessional and her class was on a field trip that day.

I told them I have to go on a field [trip], I have to, you know what I mean. What were they going to say? I said let's reschedule it. "No, staffing is coming, we'll just have it and you can always have a..., review, a rewrite."

Documentation on the Prior Parent Notification for the IEP meeting, May 21, 2009, notates that, "Parent will not attend – wishes for meeting to proceed without her." Kate says she was told Eric was being successful in a regular education classroom, so the staffing committee left him eligible only for services under both a Language and Speech Impairment. The staffing committee did not pursue other areas of eligibility, and at the time, Kate was not knowledgeable enough to ask them to consider other areas. "I was told he would have access to VE [varying exceptionality] services under Language Impairment." Such services would have allowed him access to classroom accommodations to assist him with his behavior, as long as he remained eligible with having a Language Impairment. As it turned out, Eric lost that eligibility at the end of his third grade year, essentially losing access to certain classroom accommodations linked directly to his disability, including more time for completing assignments, proximity control, reminders of rules, cueing and prompting, and access to supports which were put in place to help with his behaviors.

However, Kate repeatedly referred to a statement she said was made following the eligibility meeting which stripped Eric of services to support his behavioral needs, "We can always give him a 504, don't worry, we can always give him a 504." Kate has waited for that plan under Section 504 of the Rehabilitation Act for five years. It had not yet happened by the

time of our interviews or completion of this study. Her dislike for the person responsible for developing a 504 Plan was evident throughout our interviews. She also carried distaste for the manner in which Eric lost services associated with his IEP during his elementary school years. It left Kate in a quagmire, with no support for Eric's behavior in his classes. Consequently, tensions elevated between Kate and certain individuals at Eric's school, leaving Eric the one suffering the consequences.

Left in a quagmire. For Kate, Eric's classroom behavior and diminishing access to special education services to accommodate his social-emotional needs was a concern. Throughout our interviews she spoke of Eric's difficulty with his explosive behavior and hitting other students.

I can tell you that all of this is still the case. I mean he still has disruptive behavior, the whole gamut, it's still the case. [Kate's first school] will support that. They've got lot of data since kindergarten. He's been there for almost 6 years. This is his sixth, did they do the paper? He's never been suspended. He's ..., had in school suspension.

Eric's IEP in his pre-kindergarten setting addressed his social-emotional areas of concern. His behavior was noted then as displaying tantrums, presenting as oppositional, and being physically aggressive toward other students. Eric's IEP following his kindergarten year continued to discuss difficulty with disruptive and oppositional behavior and a need for assistance with peers and adults. That IEP was written after Eric's eligibility for services under Developmental Delay was dismissed, leaving him currently eligible for both a Speech and Language Impairment only. It was also the one meeting concerning Eric's education where Kate was not present. She says she was told by the school psychologist the meeting date could not be changed and that she could ask for a revision to the IEP if she did not approve. This was also the

same year where Kate said she had “meeting after meeting after meeting on how to help Eric.” In the end, Eric no longer had assistance from a special education teacher to help improve his behavioral challenges. He still had access to classroom and testing accommodations through the Language Impairment eligibility, but no IEP mandated behavior supports.

And none of that has gone away. None of that. It’s still all the same problems. We’ve gone up to the assistant principal’s office and spent the day there, several times. We’ve gotten kicked off the bus, we’ve almost gotten kicked out of [after-school care], a lot of times.

Perhaps what was most difficult for Kate to comprehend at the time was the difference in the two service delivery models between the two states where she lived. According to Kate, her previous state provided much more than her current one.

So I came in and I based everything on my experience in [previous state], which was a great experience. And then I come here and it’s like, oh well we do things different in [county name], or..., it’s a little different here in [current state]. I gotcha, let’s see what we can do.

Being new to education and working as a para-professional for only a few months prior to Eric’s meeting which dismissed him from services under Developmental Delay, Kate did not know nor understand the complexities of IDEA. She also did not know enough at the time to ask the IEP team to examine other eligibility options.

Yeah well I read the law after he got in the district. Because remember, that first year here in [county name] I was a para. So when he lost his eligibility for DD [Developmental Delay] I was a para. I didn’t go to school to be a teacher. None of my classes covered it. And my electives that I did take in education because [principal]

encouraged me to become a teacher, were not in special needs. They were on those core, like you know, here's the pedagogy of teaching. I need that, that's a common thing. Not, here's special education law, I didn't take that, that's not even an elective course.

Knowing the eligibility predicament created by Eric's dismissal, I asked Kate what she thought after she had finally learned enough and read IDEA. Her response, "Ah [expletive], I'm screwed," was not surprising considering the circumstances.

Well because at first he was eligible under Language Impaired, so Language Impaired comes with accommodations, small group setting, extended time, what else did he have, he had a bunch of stuff we'll have to look on his IEP, which I requested. So he had all of these accommodations, he'll be covered Kate, he'll be covered. But he grew out of it.

Okay, when you took it away, the eligibility for DD, I told you I wanted a 504, because I didn't want him to be ASD, because I knew that wasn't going to get him anywhere. And I knew that it was going to screw him up future wise. I didn't want you to put EBD on him, even though I knew that that was a problem. I mean he hits kids. I've had cops called on him. I'm not unaware. But it's so infrequent and it's so sporadic, like the cause for this time will not be the cause for next time, because we had a conversation, we worked out the strategy, we figured it out, we're good. So now it's come to the point where, what I do? I keep him SI/LI [Speech Impairment/Language Impairment], he still gets the accommodations he needs and modifications, we're good. Not as good as we need to be, because he really needs to be on a computer for writing, or have an Alpha Smart, something to help him get his thoughts out, not pencil and paper. But let's get him a 504. All right Kate, [guidance counselor] says. Oh well, we'll bring the

paperwork in and will get it done. I gave her four copies in that school year that I was a first year teacher [Eric's first grade year].

Instead, for the next five years Kate waited for the 504 Plan, and waited, and waited. She says she kept hearing the school was still working on it. A 504 Plan would have provided him classroom and testing accommodations to support his behavioral needs and could have been incorporated into his IEP as the school district allowed 504 Plan accommodations to be included on IEPs for the Speech Impairment program. Feeling like she was at a dead end in obtaining further supports for Eric, Kate decided to stop waiting on personnel at the elementary school to enact the 504 Plan.

As soon as he gets to middle school, I'll contact the middle school and get something done because his guidance counselor at his school isn't going to do it. That means that because he lost his LI [Language Impairment], he doesn't have any accommodations for fifth-grade testing for [state test].

Eric lost his availability to such accommodations when he no longer met criteria for receiving Language Impairment services. Kate explained in her journal the frustration she developed when a second eligibility was dropped from Eric's IEP.

Because eventually he developed appropriate language skills (for his age) and poor eligibility changed to only SI...behaviors continued and most are due to being understood or not I should say. He becomes frustrated and physically reacts...shuts down, yells at person, tantrums, destruction...but he doesn't have appropriate documentation [through the IEP]. (1/24/2014)

Having an IEP only related to the Speech Impairment, Eric was not entitled to those accommodations. Even though he had a medical diagnosis for Pervasive Developmental

Disorder and Disruptive Behavior Disorder, neither the school nor Kate pursued other areas of eligibility under IDEA to support his related needs. Despite the existing dilemma, Kate knew the quagmire still presented Eric with protections from years of documented reference to troubling behavior.

It's a day by day thing. Even in the most frustrating of situations there is always some sort of silver lining, at least I hope. Eric still has eligibility. This year will probably be the end of that one, because I'm not going to have him leave fifth-grade, well maybe I will and just let him be on consult. No matter how frustrating the IEP process is, it has always had the potential to look out for my son. Because of federal law. I've always had a leg to stand on. And I've always had the paper trail to prove, duh, we have a problem.

And as indicated within her positive experiences, Kate had to access the teachers outside of the IEP meeting room and inside the classrooms when she needed to advocate for Eric's needs. However, advocating for Eric with his teachers did not always end with positive results.

Tensions rise. When collaboration did not work, tensions with Kate and school personnel began to rise. Kate found herself in difficult parent-teacher conferences beginning in Eric's first grade year and shortly after he began losing eligibility.

I've had parent-teacher conferences where we go into talk and it's supposed to be just me and the teacher. And I walk in and there's [guidance counselor] advocating for the teacher's perspective. And it had nothing to do with Eric. I've felt like it's confrontational, I've had those meetings.

Kate went on to further explain the difficult conversation she encountered at one particular parent-teacher conference.

This wasn't a helpful conversation. Well he's doing this and he's not doing that.

Basically it was a blame situation. Okay, okay, I understand, this is what's happening.

He is not complying, he's hiding underneath the table. He doesn't want to talk to other

people. He has a problem talking to other people when it comes to peer-peer situations.

He doesn't like doing centers. No [expletive]. What are we going to do to fix this? No,

well let's go just to keep going. Eric doesn't do this, Eric does that. When he shouldn't

do that, he has a hard time walking in line. Let's pick one thing and work on it. But that

wasn't the meeting. So I left frustrated, and I left a lot of meetings frustrated. If you

need my help I'll be there. But if you're not telling me you want help, and instead you're

beating my son down, and you're making this look like a bad situation, which by the way

that first year I requested him be moved to a different teacher, because it was a bad

situation. But at the time first grade wasn't all that pretty with teacher choices.

By the time Eric reached third grade his frustrations in school began to mount. Kate noticed he even had trouble when the class sat as a group on the carpet. Knowing her son best, she related his difficulty with his sensory needs. But advocating for those needs was not an easy task.

You know how many parent-teacher conferences I had over carpet? It had to have been

over a dozen, over carpet. He just doesn't want to sit on the carpet, he doesn't engage

with us, all he does is move around, it's like he's unhappy. No [expletive] he's unhappy.

Did you give him something to sit on top of? He'll sit from the carpet if you'll give him

a chair, give him a pillow. He doesn't like the feel of it. Or he doesn't want to sit

crisscross applesauce, because by the time we got to third grade, he just didn't want to sit

the way everyone was supposed to. He's taking up too much space. Umm there's a

whole lot of leg on your calf. Let him sit with his knees bent. You know going up. There's less skin touching the ground.

Despite the tension, Kate shared that she preferred to navigate meetings with Eric's teachers in a productive manner, "Vinegar doesn't work. Honey does." But there were moments when she found herself calling in reinforcements, her husband who was in the military. "And whenever it came to [principal], I let [husband] deal with him." Referring to her husband as the confrontational one, Kate explained why it took this type of action to get school personnel to understand Eric and the causes behind his behavior.

[Principal] backed down and listened to Eric because he wanted to expel Eric. And we're like no, did you not look at his past history, talk to his teachers? They know. Yes he hit another student, but you know it's not as big of a deal as you're thinking. It wasn't with aggression. It was fight or flight. I need to do something, pow. So [principal] dropped it, twice.

Kate also found that tensions with one of Eric's teachers elevated as a result of her own willingness to take charge in calming Eric when others were unsuccessful. "If you have a problem, send him across the hallway." Though, that means of advocacy became a detriment. Kate and Eric's classroom doors were feet away from each other. She offered suggestions. But when those suggestions were not utilized, the walk across the hall became a problem.

And you don't piss the person off that you're working with because then it just makes the situation to where it's against Eric. I'm mad at the mom, let me take it out on the kid, and I will never have that happen. I've had it happen before, first grade. You know that was [first grade teacher]..., evil toward him because I was cracking down on her and it just made it worse for Eric. He'd come home crying.

Instead, Kate says she had multiple parent-teacher conferences that year. She understood Eric's behaviors were difficult in a regular education classroom at times. She wanted his teachers to understand what antecedents caused him to react negatively and she wanted them to know she was always available to help him de-escalate if he was too frustrated to listen to others. Her approach did not result in particularly positive interactions that year, but she did refer to times when her advocacy efforts were met by individuals willing to listen. Those practices of communication and collaboration developed the positive experiences Kate already shared.

Impact of experiences on advocacy. For Kate, the beginning of her negative experiences with the school system began after the family moved to a new location. Even though her only positive exposure to the institutional nature of the system was during Eric's pre-school year, she was pleased with the level of services provided to support all of his academic, social-emotional, and communication needs. "I based everything on my experience in [previous state], which was a great experience." As a result of the experiences which left Kate frustrated and feeling as if she had limited options available to accommodate Eric's continued social-emotional needs, Kate consequently channeled her energy in other directions. Driven by a level of guilt throughout Eric's educational experience and prior, Kate became a dedicated advocate inside her own classroom and out, campaigning for continuing special education services for her students and networking with other teachers to release her frustrations and find solutions to support Eric, all while he struggled with appropriately expressing his own frustrations in classroom settings.

Guilt driven. While listening to Kate discuss her passion and commitment to her students, I wondered what provided such a driving force in her advocacy. I was particularly stunned by Kate's disclosure that a doctor referred to her as a "bad parent" because she had not yet acquired a diagnosis for his delayed development. As I immersed in the data, I began to

sense feelings of guilt. Kate wrote in her own journal about feeling “beaten down as the uneducated parent of this little boy.” Four times she referred to feeling as if she failed Eric because he was facing the possibility of moving into middle school without accommodations for his behavior written into his IEP or that he had not acquired the 504 Plan as promised for many years by the school. These findings began to paint a picture of a mother haunted by her struggles in seeking appropriate services for her son, only to be scarred by the institutional barriers of both the military medical services and the school system.

Kate’s feelings of insufficiency from not knowing how to seek early intervention services for Eric led her to solve her own educational dilemma, pursuing a college degree. She noted in her journal, “I wasn’t the only person (parent) advocating for my child with frustrated and limited success. So I began my education.” (1/11/2014) Kate hoped that a degree in Human Services Management would provide her the know-how to help other parents, like her, who witnessed their children developing atypically, yet found themselves uninformed in the world of early childhood services.

Kate’s struggle with identifying appropriate services for Eric continued after he entered kindergarten in a new state. He was no longer eligible for services under the category of Developmental Delay due to his age, and the prospect of having Eric found eligible for ASD or EBD was not an option Kate wished to consider.

I feel like I failed him here. But it’s what’s eligible for him with a long-term perspective. Because yeah, he is totally eligible for ASD. And he’s totally eligible for EBD. I’ve got enough documentation legally. You’ve got enough documentation and observations at school. We can totally slap this label on him. But that label is going to hurt him and it’s not going to help him.

Understanding her options were limited, while attempting to avoid eligibility labels which Kate felt carried long-term implications, she still expressed concern whether she did enough to help her son with his education. She questioned her efforts, right or wrong, while also recognizing her accomplishment in persevering to obtain Eric's initial medical diagnosis.

I really feel like I failed with Eric. Because I can look at [sister] and know I've given her everything she needs. And I look at Eric and go, did I do what I thought was right, but it wasn't the right thing? Could I have pushed harder? Did I push too hard, because that was my problem with [teacher] the first year in first grade? I pushed too hard, so what does that teach you? Pull back. Encourage the question. You know I thought about dah, dah, dah. Anyhow the point is, I feel like I did fail Eric. I don't know if you feel that way with Kristopher, but I mean at the end of the day, a day passed and I can't get that day back. And all I can say is my greatest achievement in Eric's education is I pushed and pushed and pushed. And he went through the child case study. We got the data that supported DOE [state name]. He got the service he needs. I still have the paperwork that's still..., accurate for who he is because we're still seeing the same behaviors. It's not anything new. I've been able to go to psychologist after psychologist, and doctor after doctor, counselor after counselor, police officer only once. But I mean the point is, it's not like I've sat on my [expletive] and done nothing except to put my kid in front of the television. But I still feel like a failure, because you want the best, and nobody understands that.

Kate even indicated further feelings of guilt in her journal. Her whole, yet still young, career as an educator has been dedicated to working with children who exhibit challenging behaviors. Even though Kate's own son demonstrated behaviors which challenged his teachers,

it is something she indicated was distressing. “It’s so frustrating because I work with modifying behaviors and _____ [blank intended] I’m not reaching my own kid!”

Dedicated advocate. Driven by feelings of failure and limited alternative options which could provide further supports for Eric, Kate has channeled her energy toward helping other children. Her advocacy started with getting her degree after her children were already in school. “I was able to find comfort for myself knowing I could help others NOT be me. And it really worked. I’ve helped others find help, travel the pothole road towards help.”

Kate has carried that philosophy beyond her degree and into her classroom, again not wanting her students to experience the same pitfalls as she and Eric.

I advocate for my students’ needs and try this strategy and let’s see how it works. Let’s collect some data and let’s prove it. I’m going to show you what I’ve done and this is how it’s worked in my classroom. This is what we’ve decreased, and even one percent is success.

As a parent of a child with a disability, Kate has used her perspective to connect with parents in a way not many other educators can, especially when participating as a member of the IEP team.

And when it came to IEP meetings the parents were like, who was she and what’s she doing here? And then I explained it, that I said I’ve dealt with it in my classroom. And they’re like, oh well what kind of kids do you..., well I have these kind of kids and I’m a parent. I’ve been on that side of the table, and they’re like, oh okay. Some parents are like [expletive] you, I don’t give a [expletive]. But for the most part those parents that you can kind of tell that are going to do something for their kid, they’re grateful for it. You know because you build that connection. And we need a connection. And you’ve

probably seen it for yourself you know. It's easier for me and the fact that my kids have always had behaviors, and my kid has behaviors. My kid has problems communicating his needs, wants, and feelings. All of my ESE kids, same problem, so I understand.

Kate also understands the inner workings of the school system. She pointed to instances where she had to secretly advocate for her students, sharing information with the parents she would not otherwise be allowed to discuss, especially when it came to circumstances very similar to her own. To Kate, her efforts are all about doing what is right and building a comfortable relationship with the parents of her students.

Well like when it comes to the parents, I'll tell you the common phrase. 'I didn't tell you this one, or come with me for a walk.' I mean I do it all the time, especially if I've had experiences with it. There's lots of situations where I'm like, look this has worked for me or it hasn't worked for me and we'll try that one. I've always preface it, meetings with, hi my name is so-and-so and, especially if it's a staffing meeting and I've never met this kid. I am a parent of an ESE [student], I understand, and if you have any concerns or questions, come to me and I'll help you. And for the most part they're like, ah there's somebody on the other side. And that's where we go. Because when I started I didn't have anybody on the other side of the table that understood. So it helps build a good relationship with parents. So that's good.

As an educator dedicated to ensuring the right special education services for her students in the future, Kate expressed her conflict with the constraints of the system and concerns that inclusion with limited supports was setting her students up for failure, just like Eric.

And it hurts, that's the thing. Like you state all these things because you know them and you don't just like know it because it's kind of in your environment. Like you start to

feel painful for the fact that I'm saying to this new kid, he's not new I've had them for a while, you're going to go to regular ed. And I know it's not the right place.

In order to combat those feelings of worry for her students' futures, Kate has inspired the parents of her students to conduct a little research. She has encouraged them to consider available educational options outside the school district on occasions when she felt the assigned setting was not appropriate for the child's needs.

I can advocate that one. Maybe your child isn't in the right setting. The little kiddo that's like Eric, hey you know, there's [charter school]. And this is somewhere that might be best for a fit. Look into it, here's some research, dah, dah, dah, dah.

Finding a way to communicate and advocate for her students in a positive manner is an important factor in Kate's dedication as a teacher. After all, what she does for her students is something she has wanted to experience as a parent herself.

As parents we always need good news! I haven't seen much with Eric, so I push to find something to share. Because I send home daily communication with each of my students. I often jot down progress towards a goal, an observation, something cute done/said... I don't know if it makes a difference for mom/dad/foster/grandparent/g-grandparent, but I wanted & still want to hear good things, beyond "he can play ____ or likes ____" [blanks intended] in the intro to the present level. (1/24/2014)

Networks with other teachers. Reaching out to those in the know is a supporting link in Kate's continued advocacy. Not only did she collaborate with Eric's teachers, she frequently collaborated with fellow professionals in the special education field, "because they all understand. They are fighting the same fight with no success, or limited success." Therefore

Kate has found it helpful to network with other special educators in order to get through the frustrating moments experienced while fighting the system.

So you sit there and you go, hey Keri, you know you've been here. Remember that kid we had a couple years ago? Remember whatever the situation is? [Friend name] and I go for walks, not lately, because we haven't had time. And you just have vent sessions, and then at the end of it you're like, I feel okay. But then you're still like, the problem is still there and it's never going to get better.

Knowing she has an outlet in friends, Kate has also used the networking opportunity to seek advice on how to advocate for Eric. Though she found she must disguise the scenario as not her own, but that of another student.

I talk to other ESE teachers I know and say well okay you have had this experience in your area, what did you do? You know I have this parent that, I never ever say it's me, because then you get the, well don't you know you work in [county name]. No, [county name] is very good about keeping secrets about things or changing. Everything changes and it never changes in a good direction. I mean what has changed that's been in a good direction [speaking to me]? You're still thinking. That's bad. You should be able to pop something out there, right? Because we're here for the students and the families and we're trying to help them. But nothing has changed in a good direction. So I'll say you know I have a student and they're having a problem, you know the mom is trying to do this dah, dah, dah.

Participating in online advocacy groups was something Kate also tried in order to network beyond those who worked in the same district. "You want to advocate." But her participation was short-lived, "I did for a while, but it was really depressing." The overall

experience of attempting to help a larger population of parents in need left her conflicted when she considered the time and energy while still raising two children with a husband who remained active duty military and was often away from home.

And you can't, you can't spend all of your heart and your energy, and help advocate for every little pocket, because I've still got to do lesson planning and grading and prep work for..., whatever is going on in my classroom. And I still got to be a mom.

Barriers to advocating as parent and as an educator. With negative experiences impacting Kate's advocacy for the better, several barrier related themes appeared from our discussions as well as the documents and journal she provided; themes which indicate a mother coping with the constraints of the system on her roles as a parent and an educator, and a child coping with the expectations of society. Figure 8 represents a diagram of the barriers which impacted Kate's ability to advocate as a parent and as an educator.

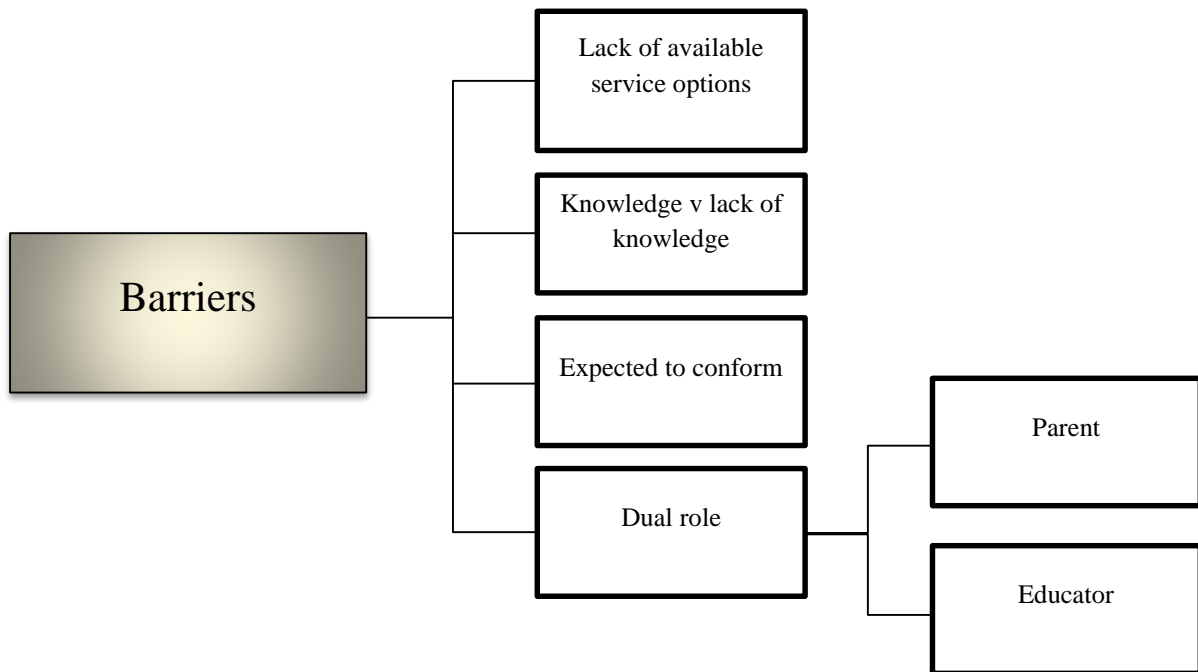


Figure 8. Barriers Kate encountered in advocating for Eric.

Lack of alternative service options. Kate and Eric's *fight within* has much to do with a lack of available service options to better accommodate Eric's social-emotional needs inside the regular education classroom. He has a medical diagnosis of Pervasive Developmental Disorder, which falls under the autism spectrum. His difficulty with change in routines, sensory responses, and social relations with peers are challenging and indicative of students who are eligible for ASD or EBD according to Kate. Yet, the idea of such eligibility is troublesome for Kate.

So at the end of the day knowing that EBD is the right thing and it could help him, I don't want to chance the fact that he's going to get mad and throw table and you're [referring to teacher] going to say no, no, no, no, no, he needs to go into the classroom that's just for them. He's done it. He's thrown chairs. He's thrown tables, because you [teachers] won't leave him alone. Well, we have to deal with the situation. He's autistic. Let him calm down. You don't..., keep poking a bear that's mad. He ran out of the classroom. Well actually he ran out of the lunch room, ran to the classroom and hid underneath a table. Leave him alone.

Eric entered kindergarten in his current state still under the eligibility of Developmental Delay. His new school provided comparable services and transferred his academic and social-emotional goals from the IEP written in his previous state. During that time, Eric had access to special education services in a pullout, resource setting for reading, writing, math, speech/language therapy, and social skills instruction. By the end of the year, it was time to remove the Developmental Delay eligibility. "Remember his release from DD, I wasn't there for that meeting." With no parental representation in the meeting to develop a plan for Eric's future in special education, the IEP team continued Eric's access to special education supports, but only under the eligibility categories of Language Impairment and Speech Impairment. Nonetheless,

those supports only included cueing and prompting in the classroom and did not include an IEP goal to address his behavior. “Well because he’s being so successful in regular ed. Uh, did we not realize that we still have to get through the future yet?” Despite the reported success with his behavior, Kate maintained that Eric’s behaviors were problematic and did not resolve with his transition from a small self-contained class with extra adult assistance in one state to an inclusive setting in their new state.

But when we left [previous state] and we came to [county name] we’re going to put Eric in a regular ed kindergarten class. He wasn’t in a regular class at all in [previous state]. At all. He had assistance. He had paras. He had centers that he could pick and choose. He had a routine that worked for him. But now we’re going to sit him in the classroom. I think at the time it was like 20 kids, 22 kids, back then, where he was just in six. So you went from, still a frustrating situation, to whoa my God, what are you doing? Well I’m dealing with the same thing with one of my students right now. And all I keep being told is, “I understand that this is not the most appropriate setting, but there’s really nowhere else to send him.”

With nowhere else to place Eric with only a Language Impairment and Speech Impairment eligibility, Kate says she was worried about his limited access to classroom supports and accommodations. “So he had all of these accommodations. He’ll be covered Kate, he’ll be covered.” The school proposed providing those supports under a 504 Plan. That was at the end of kindergarten. By the third quarter of Eric’s fifth grade year and the time of this study, he still did not have a 504 Plan, despite years of difficulty in the classroom, many visits to the principal’s office, and numerous days in in-school suspension. With limited special education

eligibility alternatives and a proposed 504 Plan which would have provided the classroom accommodations Kate believed were needed but had not materialized, Eric continued to struggle.

In his first year without classroom support from a special education teacher, Kate says she had “meeting after meeting” with the school about Eric’s troubles in his first grade class. The social-emotional section of his IEP stated, “Eric has previously shown behavioral issues that can be addressed through self-monitoring” but made no direct mention nor described the types of behaviors he was exhibiting in the classroom setting. The IEP team did add classroom accommodations for proximity control, reminders of rules, and testing accommodations in a small group setting, yet did not address the increase in behavior difficulties through a social-emotional goal. By the end of his second grade year, an accommodation to give Eric more time to complete assignments was added, as well as more testing accommodations of frequent breaks and extended time.

Classroom and testing accommodations were slowly being re-introduced to Eric’s IEP. But then came March of his third grade year. It was time for his re-evaluation. Eric’s language assessments indicated he no longer needed therapy to address his receptive and expressive language skills. But at the same time, an individual student behavior management system was added to his IEP. The social-emotional section of his IEP stated, “Eric has demonstrated behavior difficulty in both the regular education classroom and in the therapy setting.” With improved evaluation scores in the area of language, Eric was no longer eligible for the Language Impairment program. As a student with only services for his Speech Impairment, Eric’s IEP no longer outlined classroom or testing accommodations, although his behaviors were presenting a challenge for him, his teachers, and his mother. There were other options available to make up the difference, but the one Kate was willing to accept was not materializing.

A 504 that he does not have. And he's not going to have it with [guidance counselor], especially with him being in fifth-grade because we'll just let middle school deal with that, which I already knew was going to happen. I knew it was going to happen when he was in first grade, because he's got accommodations through LI.

All throughout our interviews Kate referred to Eric's limited access to support services in his current state. I asked her to compare her experiences in her current location to the previous. "He wasn't in the same program here so I really can't compare. At the same time I can because I'm the teacher in that setting, so I can. We don't have anything." As a teacher in a similar pre-school program to the one where Eric began in his previous state, Kate not only experienced the barriers of available and appropriate service options for Eric, but also for her students.

And yet me as a classroom teacher I can look at that kid with appropriate services and go yes, but this kid is worse and this kid came from [current district]. He was identified through Child Find. He was staffed in this county and he's not getting what he needs. Yet students with IEPs from different states, with less severity are staffed for programs because those states did what was right. Because we have some magical number of students that are only allowed to have those services, and I'm sorry kid but you're not that bad. Seriously in [previous state] we had services to make sure that, that kid would be safe, inhibitory 10 minutes. I think the max was two kids that she would pull. It was a she, it could be anybody. It could be a donkey for all I care. Somebody did the services, pulled one or two kids max and they learned safety, what it means to be safe.

The concept of comparable services was a large point of contention in Kate's attempt to advocate for Eric. "But my son needs a 504 Plan because I don't want ASD and I don't want EBD. That's going to screw him life wise." She has seen and experienced the limitations of

service options in her current state for both Eric and her students and she realized there are other options which could provide the right setting and supports, but those options were outside the public school system and presented their own challenges.

And now looking at him they could have put him ASD and served him regular ed and that would've given him the services. But there was nothing comparable to what he had in [previous state] or could've had in [previous state]. And here in [current state]..., how many other kids are in the same stupid situation. And I'm sorry I shouldn't have to send my kid to [charter school] so that he can get services. And let's be honest, I can't.

Because you have to be able to take your kid to [charter school] and you have to be able to pick your kid up, and I'm working.

Kate's knowledge versus other's lack of knowledge. Just as it did for both Ruby and Judith, Kate's level of knowledge about Eric stood out to me when I evaluated the data time and time again. She knew what type of events caused him to lose control, how he viewed the world around him, and how teachers could support him the best. And she also knew early on that her son needed more. But at the time she was told otherwise by professionals in the medical field.

I didn't know what I was talking about and I just needed to get my child time to develop. He's just a slow developer. You're comparing him to other kids. He's Eric, give him time. It just takes longer, slow bloomer, blah, blah. Two years of that. Like I could tell you at 13 months that something wasn't right.

When he got into school, Kate's understanding of Eric's needs told her he needed more support there as well. "So every time we have a problem in school, it's a majority of the time, it's because he's black and white and you went a little too grey for him. He needs concrete concepts." But the services to support his behavioral concerns were removed at the end of

kindergarten, leaving regular education teachers to cope with Eric's frustrations without consideration of other areas of eligibility under IDEA by both the IEP team and Kate.

He gets frustrated because everything is black and white for him. So if maybe my pencil breaks and I don't like the other pencil, because you know we're taking [state assessment], he's going to shut down. And he's going to fail. I mean that's just like the smallest minute thing. He doesn't like writing and there are other triggers in other settings.

In order to help, Kate found herself sharing what she knew about her son to those who were unfamiliar when it came to supporting children with autism. She was quick to brainstorm with teachers on methods to help Eric calm down and how to support him in the classroom with simple accommodations to avoid his outbursts.

So when you look at him and you're like okay, he doesn't like writing. Well how can we accommodate this one? Put him on the computer, he'll type. Because what are we assessing when it comes to writing? That he can do the skill. Not whether he can put..., a pencil to a piece of paper. But what gets in the way for these kids? The piece of paper and the pencil. It's not the ability to express himself.

What Kate finds frustrating is the gap between those who know and those who do not, especially when she encountered teachers who are not aware that Eric even had an IEP. So she had to inform them, explain what is on it, and outline how they can help.

The biggest problem I have in this district is..., you have all the paperwork and nobody reads it. Hey welcome new school year, we're going to put the student in your classroom and he has, hey look an asterisk by his name, he has an IEP. That means that you know this week or next week you're going to want to read his IEP before the school year starts.

How many of them really read it? So then you go to conference night and you start telling them, you know I've heard you say this over and over again about he has this problem or that problem. Did you read the IEP? Because let me bring it out and show it to you. And then they're like oh, that makes sense. It makes sense? This is my kid you're torturing in this classroom and if you ever had any question I've always provided my phone number, my cell phone number, my email, you can get ahold of me how many different ways, oh personally and professionally. But you don't see you're just torturing my kid. No wonder he hates school.

At times Kate would even have to change her method of passing on her knowledge of how to meet Eric's needs. She began to hide her level of expertise and play the uninformed role, asking questions instead supplying answers. But she proclaimed she did not like the way it made her feel.

Like the idiot. I think you know..., I've seen other cases where this situation worked. Maybe it might work for Eric. Can we do this? And then if they say, well, and then I keep pushing on it, and pushing on it, and pushing on it until unfortunately it often feels like they say, well let's put that in place and try it out, and then you know nobody read the IEP, and they didn't try it out. Because everyone looks at the goals and looks at the accommodations, but no one seems to read the narrative of who this child really is and why sitting on the carpet is a bad idea.

An obvious sticking point for Kate within our interviews was her belief that teachers do not read the present level narrative in the IEP. "Read the damn thing! And you will know Eric. I wouldn't have the problems I have, seriously." Despite whether she felt teachers would read the present level narrative to gain an understanding about her son, Kate insisted on providing

parental input at Eric's IEP meetings in hopes someone will then know more about Eric. "Type the stupid thing in there and if anybody wants to take it seriously or not, at least I know my two cents is in there."

Expected to conform. Another barrier which has plagued Kate in her efforts to advocate for Eric is the expectation that he conform in typical settings, even though his needs are vastly different and require a scaffolded learning process, more so than his peers.

I have all these conversations with him about the fact that I understand but you have to play their game. Because let's be honest, that's what it is. He's not, when he grows up, this isn't going to be Eric. He's not going to be reading a book for..., the meaning of it. So most of our conferences are about the fact that Eric does not conform to what they expect. Sitting on the carpet, following rules, standing in line, standing in order that they want. He doesn't like the person in front of him. Why do you make him stand there? If you know that getting in line for lunch this is a bad place, move him somewhere else. If he needs to go first or last, whatever. Can we adapt? But there is no adaption. It's he has to adapt. And I understand when he is 18 and he is a legal adult, sure. But we kind of have to take baby steps to get to where we need to go.

Kate has even had to advocate for Eric in places one would never imagine, within her own household. "Even with my husband. He wants Eric to be Eric, but Eric has to conform to society's expectations. So even in my own household I advocate for Eric." She has had to help others, including her husband, understand that being like everyone else takes time.

That's the thing [husband name] has been fighting me on. You know I understand he has a..., disability. But extended time, not a good thing. He needs to be like everyone else.

And I'm like, but you don't understand. We need to go from what he needs now and wean him down to where he is a normal kid.

Kate's understanding that Eric needs to conform to society's expectations in order to be successful and develop like other children around him for the sake of his future ambitions was evident in her journal, referring back to those early days when she noticed his development was not like others. "We went to parks... just about anywhere to give him time with typically developing children. Friend's houses, pool, park, school activities. You name it." (1/11/2014)

Kate's aspirations that Eric grows and learns to cope with his frustrations in a positive manner may have much to do with opportunities in the future. She had already shared that she did not want to place him with special education services under ASD or EBD. Her dilemma with labels associated with eligibility categories as opposed to needs based decision making had much to do with her belief in the long term implications of such eligibility categories. "It's going to blackball him from a lot of things, military, police department, fire department, some colleges. Is that fair? No." So she pressed on, with the understanding that conforming allowed for possibilities.

My husband is military. Every other male in my family, except for my father-in-law, military. I'm not saying the military is right for him, but..., it's his choice and it might be something because it's so rigorous and it's black and white that it might work for him enough. I don't know, but I don't want to limit him.

Kate explained to me how Eric resembles her brother, her father, and her grandfather. She touched further on her brother and that "back in the days you didn't have those services or the acknowledgment that there was a problem. He was just special." But her brother had a lot of

problems in school as well, “Until he realized it was better to conform and it broke his, in a nutshell, his spirit.”

It was of no surprise that Kate did not want the same outcome for Eric. Yes, she knew the gravity of conforming, at school and in society, if he is to have a future for himself. That, she explained, is why she has worked so hard at supporting him, whether he is at school or at home.

I look at the big picture, the long term picture, and maybe that’s a bad thing for Eric, but he’s in a regular ed classroom. He’s adapting to an environment that’s typical of life, and you know I’m trying to get him to where he needs to get to without that EBD label. And ASD, I don’t care how many people say, but it’s becoming a larger percentage of the population. They’re still employers and schools and opportunities out there that are limited.

Consequently no longer having access to special education services beyond speech therapy, Kate has taken on the responsibility of supporting Eric’s social-emotional development within the school setting. She has helped Eric solve his problems when he has become frustrated or helped him find the means to de-escalate when his emotions ran high, all with the intent he will one day learn to adapt and fit in with any disruptions.

Dual role is a double-edged sword. Amid the barriers which Kate perceives has hindered her ability to advocate for Eric, is a force with which she never expected would have to be reckoned, that of being a parent and an educator. Working as a teacher when you are a parent allows one a perspective far different than others who are not privy to the inner workings of a school system. But when you teach children with disabilities while also raising your own child with a disability provides a perspective unique to very few. For those like Kate, this dual role

comes as a *double-edged sword*. “As a parent I want what’s best for my son. And when I put on my little teacher hat, I want what’s best my kids, my student kids, they’re my babies.”

Parent first. As a parent first, Kate made herself available to Eric’s teachers, whether she worked at his school or had transferred to another. “I’m just like everybody else. This is my kid and I need to know.” Nevertheless, the *one-way ticket to mom* was something Kate felt was a detriment for Eric, even though at times it was what he needed to unwind from frustrating situations.

The problem is for me, I can’t teach at the same school my son attends. Mind you, I’ve moved to two different schools since I started at his school. That was an ugly situation, because I got, well Eric is having a problem, come and help. Uh, I’ve got my own class here, so that didn’t go well. And I understood where they were coming from, and they were trying to give me..., a courtesy. It didn’t help. It didn’t. It didn’t help him.

I asked Kate if she thought her experiences as a parent would have been different had she not been a school district employee. Her answer spoke straight to me and the mutual understanding we had developed of walking in each other’s shoes.

Because some parents can be a [expletive] and get what they want. How many IEP meetings have you had where the parent goes off on you, and you’re like, where did this come from? Because every conference we’ve had has always been good and positive and this is what we’re doing in the classroom. But when you pull up that page that says these are the services that they are going to get, and these are the accommodations and what it means, like the devil horns pop out of their ears. And anger just spews from them. And you’re like, well wait a minute.

As a parent first, educator second, Kate found herself struggling further with the types of special education services provided for her students when they moved from her therapeutic pre-school classroom and into kindergarten. They displayed characteristics that reminded her of Eric, yet she was very familiar with the limited options which would be delivered.

I know what's right for this kid. I've been there. I've got the kid at home. With [student name], he looks just like Eric. Just like Eric. I know what you're going to do. You're going to throw him in a regular ed classroom. You're not going to give him a unique needs aide, mind you he needs a one-on-one [aide].

I asked whether she had any advice for other parents of children with disabilities who also worked in the same school district. Her answer could not have been more clearly direct because she sees what other parents are able to advocate for, while she cannot, "Don't do it!"

I love my students and I love my class, but it's a hindrance, and I would love to leave and go to a different school district that I don't know, that I don't work for, and be that psychotic parent that gets what they want.

Educator too. As an educator, Kate is able to empathize with other parents of children with disabilities. She wants what is best for her students. She does not want them to experience the same outcomes as she and Eric.

It's just a fight, it's always a fight. And like I tell my parents in my classroom, I understand where you're coming from, I have an ESE student. I've been there. I've been there for years. And I'm doing the best that I can for your child. But please understand that we're working within a system, and I hate that. And of course I always say that you know I didn't say this but. Because you know you could get in trouble for saying something like that. Yes, you're allowed to have that commonality and they encourage

you to show that you understand and sympathize. But don't ever say that you're not giving them best or you're trying to give them the best because you know what's what and not what the [county name] wants you to think.

As a person with insider knowledge, Kate walks a fine line. She is firmly aware of what she is allowed to say to parents while serving as a district employee. She is also firmly aware of the impact that knowledge may have on decision making for other parents.

We're helping those who are likely in the same boat we are in. I mean I hate to tell you how many meetings I have, parent-teacher conferences, or IEP meetings, and I have to say, "Let's take a walk. Now that we're off campus, I'd like to recommend something. Now I'm not talking to you as Mrs. Teacher. I'm just talking to you as this random person you heard something from, just this wild rumor. You might want to do beep! Whatever it is."

These scenarios are nothing like what Kate envisioned when she decided to become an educator. Actually, she never intended to become a teacher. She had not heard positive stories about the educational system. She began as a para-professional and then one thing led to another. Though, as the saying goes, hindsight is always 20-20.

I wish I would've known what it was like to be a teacher and in the same field as my child's needs. Because I think I would've been better off mentally, not as frustrated, not as down. There's a lot of days I go home and I just want to drink a bottle of wine. But I don't drink because that means they won. But I mean..., there's days you go home and you're just like, I failed. And I think if I were a regular ed teacher my failure wouldn't be so..., to the core of who I am. Because a lot of the things you do, you're like, well..., that's their home environment or they're so social economically challenged, they came to

me that way. But when you're the ESE teacher who's also a parent, I can help you, I can really, really help you. But I only have 180 days, or three years of 180 days depending on where you are. Can I help, can I help enough? I have too many outside influences that are not helping, that are hindering, and that often I feel like they don't care enough when I care so much.

Serving as a teacher of children with disabilities while also parenting a child with a disability, has been taxing for Kate. She often found the need to serve the best interest of Eric at odds with being a teacher. While at the same time, being a teacher for children with special needs was at odds with her desire to advocate from the inside out for the parents of the students she served.

Perception of job security in relation to advocacy. As the dual roles as a parent and educator intertwined, the responsibilities and barriers associated with those positions placed Kate in a space not many other educators experienced. My two previous co-researchers, Ruby and Judith, both experienced specific scenarios where they were called into their principal's office and questioned about their advocacy for their children in other settings. Kate did not experience this. Yet within our interviews she expressed concerns regarding her perception of job security while advocating in the same school district where she worked. She wanted to advocate for Eric and her students, but she perceived a barrier unlike all the others. She worried about the implications in speaking up for her students and advocating for her son. Figure 9 provides a visual representation of the two themes which emerged within Kate's case regarding her perception of job security in relation to her advocacy efforts.

Fear of speaking up for her students. Using her role as a teacher who is also the parent of a child with a disability, Kate advocated for her students in ways others could not. She shared

information with parents, which she indicated would be frowned upon by the district. Such as her off the record conversations which never really happened if anyone asked. But knowing her students needed someone in their corner placed her in a predicament, especially when sitting in an IEP meeting and disagreeing with the events which unfold.

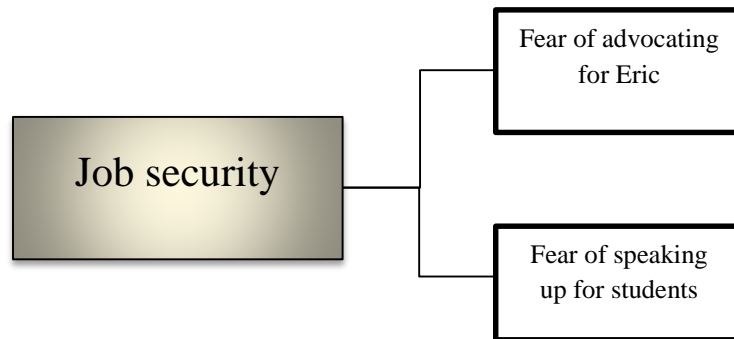


Figure 9. Kate’s perception of job security in relation to advocacy.

It’s like tippy-toeing around broken glass. Sometimes I have a light. I mean it just depends, like if you get, like we have a brand-new staffing specialist in [district]. I wouldn’t know how to act with her in terms of being the parent, because she’s mean. Professionally we were fine. As a parent she’s mean and I’ve seen her attack parents. I’ve seen her deny parents services.

Being a participant in moments like that has made Kate feel “inadequate” as a teacher. “You know you can do it, but then you get shot down.” Meetings which conclude with the denial of services are of particular concern to Kate when she has provided documentation and supporting evidence for special education supports. Despite her contention with the decisions, she has remained quiet, without speaking up.

I mean I’ve seen it, and not seen it just because I’m on this side of the table as the parent. I’ve seen it as I’m the ESE teacher, the case manager, and you just said they can’t have it.

And I've got all of this documentation that's also supported by the FBA [functional behavior assessment]. You just said they can't have it. What were you thinking?

They're thinking [county name] wants me to do this, so I will do it.

Fear of losing her job advocating for Eric. Even though she never experienced any direct examples of repercussions, she did express the fear of losing her job as a district employee if she pushed too far in advocating for Eric's needs.

And unfortunately for me, I know that my job, whether they say it or not, is in limbo if I throw the biggest hissy fit on earth. Because you know you've had those IEP meetings where the mom is like, it's smack down time and she's going to drag you through the mud, because she's getting what she wants, because this is her kid. But if I did that what would happen?

Kate explained what she perceived might happen if she raised concerns during an IEP meeting based on past history. She expressed a level of elevated tensions as the result of simply having access to insider information while sitting at the IEP table.

If I brought my husband with me, because he is a confrontational person, um, I've always gotten shut down, always. Um, it sucks. You know you know stuff, you know..., that this is right and this is wrong. But if you tell them, sorry you're wrong, it's like the walls come up and we're a fortress. And you're not going to get anywhere. Well, we're going to table this meeting and we will come back another day. Nothing was solved. But because I acted like I know what I'm doing, hello, how many lawyers did they bring in that day [referring to my IEP meeting experience]? That's frustrating too and it makes me worry how it will affect me professionally and Eric in class.

Following our interviews and during the member checking process of this case, Kate added that including her husband in advocating for Eric might help at times, but that “he is uninformed and still frustrated.”

It’s not a good meeting when he comes because I feel like I am playing both sides of the table. Talking him down, yet supporting him and knowing just how far to push. I know enough to tie my hands and know they are tied.

Even though Kate never experienced specific situations where she felt her job was in jeopardy, she did refer to the experience of other parent/educators who knew they were putting their jobs on the line to advocate.

I had a parent, we had a conference on Tuesday, they didn’t show up. She went to the district to demand that he has a one-on-one, because she doesn’t care if she gets fired or not. I care if I get fired. I like to eat, how about you? So she went and complained and advocated for her grandson. And you know I’m really happy that you did that although it was totally inappropriate because he doesn’t need a one-on-one. But the thing is you don’t care if you lose your job. Now with me and Eric, I need my job.

The implications of becoming a vocal advocate for Eric was something Kate was able to sense. Therefore worries about losing her job forced her to sidestep the lack of alternative service options for Eric and go straight to his teachers. She felt the real advocating could be done outside the confines of the IEP meeting “because there’s always that chance of losing your job because you made a wave that was just too big and sunk your battleship.”

Summary of Kate and Eric’s Fight Within

For Kate and Eric the *fight within* has become the fight without; the fight without the alternative services which Kate feels most appropriately addresses Eric’s behavioral needs rather

than issuing him a label which may carry long term implications. As a parent of a child with an identified disability, Kate has had the opportunity to see varied service options from one state to another. She and Eric experienced a self-contained special education pre-kindergarten class unlike what Kate has taught in her current state. As a teacher for children with disabilities much like Eric's, she has fought for her students to maintain an appropriate level of services and not let happen what happened to Eric occur again.

For Kate it is not about Eric no longer needing such special education services. Instead her fight is about losing access to help when Eric still needed it. His social-emotional difficulty in the classroom is noted in the present level narratives of his IEP, albeit the information is not as plentiful, but it is printed in black and white. He still has a diagnosis of two disorders which directly impact his ability work through frustrating situations without losing behavioral control.

My kid has behavior issues. Not as bad as other people. I mean he's thrown some tables, and he's redecorated. Not destructively. Never broken any walls or anything like that. Never permanently broken materials..., like tables or something. It's always been something..., we can fix it. And even then, that was a long time ago and rare.

What cannot be fixed at this point in Eric's educational career is his diminishing access to special education supports. He lost the eligibility which provided him access to a special education teacher following his first year in his new state. His prior experience in another state gave him access to several individuals, according to Kate, who implemented interventions for speech, language, independent functioning, social-emotional and academic concerns, some of which were furnished in his current state. Following Eric's exit from kindergarten and the services provided under Developmental Delay, he retained limited access to classroom and testing accommodations.

Eric could be eligible for support as a student diagnosed with autism. But it is a road Kate initially did not know enough about and did not wish to pursue because of her concerns regarding the long term implications of such a label on Eric's future. Yet, in her attempt to secure what little access to special education support remained for Eric, Kate has pushed hard for his needs both in and out of the classroom. "I have to make up for what the district doesn't provide." Not only is she making up for the services Eric lost, she is making up for feeling like she failed him. She works hard helping Eric learn to cope with frustrating moments in school. Just the same, she works hard helping her students.

As a dedicated teacher of students in self-contained settings, preschool through fourth grade, who struggle themselves with challenging behaviors, Kate has accepted the added role as an advocate. Just as with Ruby and Judith in the two previous cases, her advocacy is directed towards making right the wrongs experienced by her and her son. This mother of a child with a disability and school district employee advocates so her students can maintain their access to special education supports once they graduate from her self-contained pre-school class and move into a more inclusive kindergarten setting. Those settings are less restrictive, with more students and less teacher assistance, and not what Kate expects will meet the needs of all children, particularly those with disabilities. "So, because I've seen a lot of crap going on, I can advocate. Because a lot of people are saying this is happening, and it's not happening, I can correct the misconception."

Kate has also resorted to secretly advocating for her students through off-campus conversations. She spoke more than once of having dialogue which ideally never happened, allowing parents a glimpse of the inner workings and guidelines which restricted certain

discussions from occurring at the IEP table. “There’s more available than what we are willing to offer.”

More importantly, Kate’s insider status allowed her own glimpse of the restrictions which limited Eric’s options for continued special education behavioral support.

I’ve learned a lot and how Eric got screwed over. Remember the ultimate goal is that he can be a contributing member of society by his 18th year, independently, without any assistance. That being said, I know he should have way more than he does. But I also need to allow for typical settings, typical expectations, and figure out a way to get my son where he needs to be with as little support and scaffolding as possible, yet enough to protect his growth and who he truly is as a person.

Our Voices, in Unison

In accordance with maintaining true to the heuristic process, I retreated into the immersion phase yet again to analyze the co-researchers and myself as individuals, but also the experiences, barriers, and perceptions we held as a group of individuals. Only after each co-researcher read and approved their individual depictions did I move forward with this next phase in the heuristic process. As I stated in previous chapters of this study, I wondered if I was alone. Was my *fight within*, my fight only? Or was my experience shared by others, who like me, had to advocate for their children with disabilities inside the school district where they worked? As I explored each case in its entirety, the answer to my wondering became evident. There were other school district employees who struggled to advocate for their children, at least three others. Their individual cases were unique in their own ways, yet the challenges they faced, the barriers they encountered, and the perceptions they held in relation to their job security were unmistakably parallel.

The following narrative is a depiction of our voices, in unison, highlighting the similarities in our stories and our experiences as a group. It is told with excerpts from their interviews, journals, and documentation, as well as incorporating elements of my reflexive journal and features of my own story which I explored and analyzed just as I did with Ruby, Judith, and Kate. The subsequent illustration is our *fight within*.

The uncanny resemblances in who we are and why we do what we do may provide an explanation supporting the overall meaning of our experiences. As you, the reader, got to know each of us, you were able to ascertain we are all mothers; mothers of boys with disabilities. Each of us had a different career prior to education. Ruby was a journalist, as was I. Judith worked in the healthcare field and Kate, a former soldier, had planned to go into the human services industry. None of us ever imagined becoming a teacher. Ruby never dreamed of it, “Why would I want to be teacher?” Kate had deliberate reasons not to. “I didn’t want anything to do with the school system. No, you hear horror stories about the school system. You don’t want to work for them.”

But circumstances changed the course of all our lives. Our boys needed help in their academic settings. “Going into it, I was like, because I could help him.” (Ruby) Chuck and Eric were both diagnosed with Autism Spectrum Disorder. Hence, their needs were identified in their preschool years and they received early interventions in therapeutic settings. Barry’s and Kristopher’s struggles with learning disabilities were not identified until after they began their journey in an academic setting, when learning was a challenge and they could not maintain the same educational pace as their peers. Those challenges all of our boys faced became the driving force which drew us into a profession we never imagined. “I got into education and I was [teacher’s name] para, and I really liked it.” (Kate) Each one of us made the life altering

decision to leave behind a previous professional course and become an educator, while our boys were all in elementary school.

For Ruby, Judith, and me, we have continued as educators as our boys progressed into high school and have become young men. For each of us, none plans to remain. Our advocacy for our children has cultivated into something much more than our own stories. Ruby wishes to pursue avenues of parental advocacy, outside the walls of the school system. “I just want to change the world and the way that they perceive the needs of our children, being the needs of our children have not changed.” Judith has propelled herself into law school with a purpose in mind, “I need to be that voice, I need to be that person that says no, no, no, no, no, no, this child deserves this.” Kate plans to leave behind special education and the conflicts of being a parent and educator for children with disabilities to pursue a new love, a reading coach. And me, I made a promise to Kristopher when he was in seventh grade to research the struggles of children like him. I cannot achieve that goal while remaining inside the school system, which has not only tied my hands, but tied the hands of my co-researchers as well.

In listening to my co-researchers speak throughout our interviews, I also began to observe what I had noticed in my own story; the fight to advocate only encompassed our children with disabilities. This was the focus of the study. However, no one gave any indication of troubles anywhere other than within special education. Three of us, including myself, have other children. Judith has an older son who is graduating from high school with honors. Kate has an older daughter who is attending a magnet school. And I have an older son and younger daughter who both excelled. None of us expressed any difficulty regarding the education of our other children. Instead our discussions centered only on navigating the world of special education, as I discussed in my reflexive journal, “Why have we had so many [poor experiences] with

Kristopher? [Daughter's] advanced classes have all been positive experiences. Fluke? Probably not. My poor experiences are mostly associated with ESE [Exceptional Student Education].”

It is these poor experiences which have left us all frustrated by the system in which we work and where our boys have received their education. And the sentiments regarding our frustrations were similar in drawing ire, “I’ve had enough of banging my head against that district wall.” (Judith) “There are lots of other jobs out there that are less headache, less fear, less frustration. Frustration is the big one.” (Kate) “It was like beating my head against a brick wall.” (Ruby) For me, I look forward to the day my son exits the system because “I’m getting tired of problems.” (8/16/2013)

Our experiences in challenging school districts. As outlined in each co-researcher’s individual depictions, the experiences were not always poor. Naturally, there would have to be positive experiences in order to know when negative experiences did occur. There were stories throughout the co-researcher’s cases where life was good and the children were receiving a meaningful education. As well, there were moments when that was not the case, and tensions flared, leaving us at odds with serving in the role of being a parent and an educator. Figure 10 provides a visual depiction of the experiences my co-researchers and I shared in advocating for our children, and how those experiences shaped our identity as we became advocates, not only for our own children, but for the numerous others whose lives we touched.

Positive experiences which worked well. In immersing myself within the data once again and the individual depictions of Ruby, Judith, and Kate, themes emerged related to why our experiences were considered positive. We were all satisfied when the needs of our boys were either met or addressed, when educators listened and communicated with us inside and outside of the IEP meetings, and when our children encountered someone like us, who advocated

from the inside for their needs. It is important to point out, that what creates these positive experiences and leaves us feeling content with our children’s education also inflames the negative experiences when those very same factors are withdrawn. In other words, there were

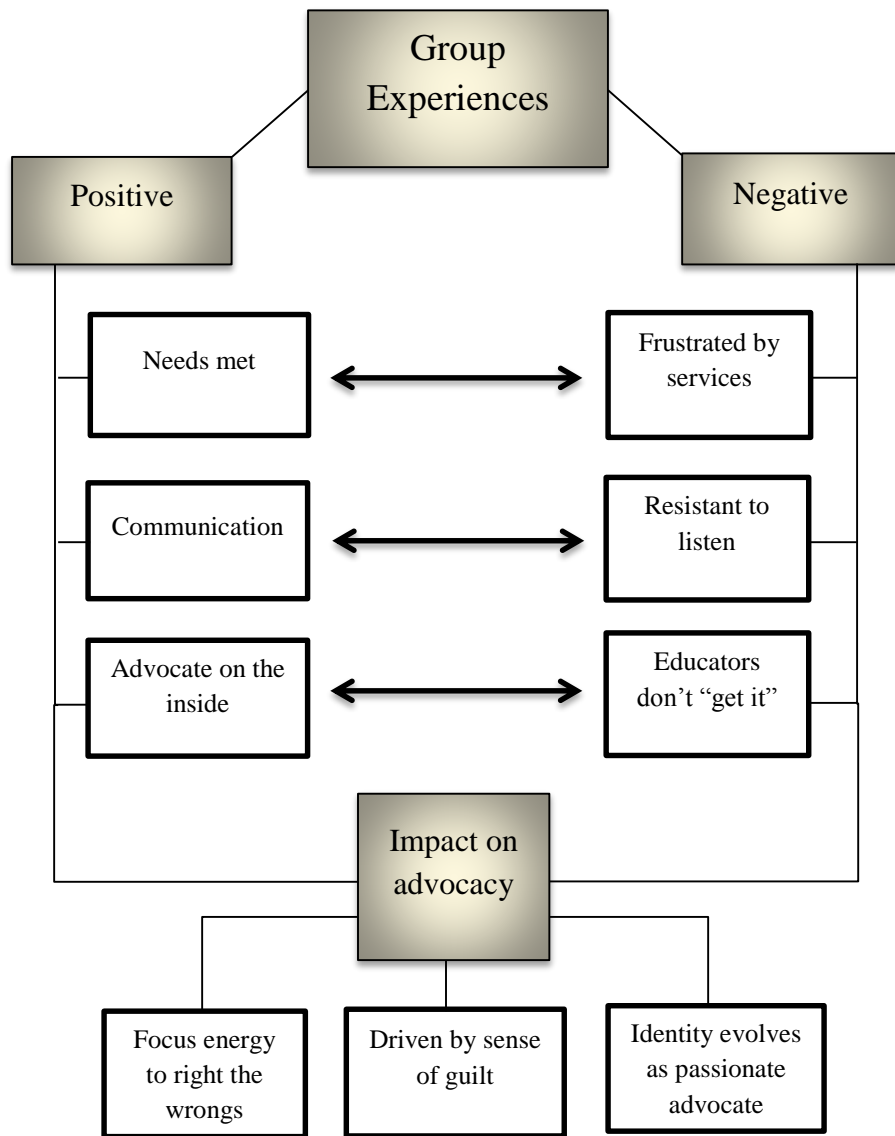


Figure 10. Group experiences in challenging school districts.

**Arrows indicate a reciprocal relationship between the themes associated with positive and negative experiences.*

relationships between positive and negative experiences in our cases, dependent on whether educators met the needs of our children with disabilities, communicated with us as parents at all levels, and if our children had access to an insider who would go the extra mile.

Our children's needs met. Perhaps the most important piece of the puzzle in our positive experiences relates to having our children's educational needs met. Ruby explained how Chuck's needs were met when the district in another state paid for his placement and transferred him into a therapeutic, all special education school. "It was all perfect. It was at his level of need." For Ruby, Chuck's needs at the time centered on his access to a social worker, an occupational therapist, a speech therapist, as well as administrators and teachers who were well versed in special education practices. In all of Ruby's experiences in three different states, this was the one she pointed to the most when sharing some of Chuck's more encouraging memories as a student. Interestingly, at the time of this study, Chuck was once again in a specially designed setting which provided him access to services where the public school did not. Ruby spoke of the difference such a decision has made for both she and Chuck.

My role as a parent is very..., now that he's in charter school, because I feel more like I can just be a parent. But that's also because at the charter school his needs are being met. And so his needs being met allows me to just kind of be a parent of a kid with a disability, and to where the educators and I..., have more of a..., shared vision.

In an effort to get her son's needs met, Kate considered removing Eric from the public school and placing him into a similar setting which he previously experienced in preschool. Eric first entered school as a preschool student in a therapeutic, self-contained program in his previous state. Kate too spoke highly of those days. "They got him the services and he had every flipping service known to man that was appropriate, appropriate [with emphasis] for him."

The services the IEP team deemed appropriate for Eric included an occupational therapist, a speech therapist, a separate language therapist, and one-on-one services to teach him inhibitory commands. “There were more available services for him. And he got what he needed.”

For Judith, getting Barry’s needs met was a frequent occurrence in elementary school. But once in middle and high school, she found it took someone with more authority to make sure those needs were addressed, particularly when accommodating the need through the IEP, such as colored overlays, was not a usual request.

The principal, said, “I will allot you [teacher] monies from the school budget to buy yellow paper if that’s what this child needs. If he needs yellow paper, get him yellow paper, end of story there should be no discussion about that. He needs yellow paper, he needs yellow paper. You don’t want to purchase it for your classroom then you come down and say I have a child whose IEP says he needs everything and yellow paper. We’ll give you yellow paper.”

Kristopher did not have such a need to assist with his visual processing, though he did struggle with processing altogether. Copying notes from the board was a particular challenge because children with learning disabilities have to make sense of what they are hearing and seeing as the teacher delivers instruction. They must then determine which elements are more important and filter out unnecessary information as they write notes. As they attempt to process multiple elements of information, the teacher may have advanced to a new topic and important information may have been lost. For Kristopher, this was typically the case. Instead of leaving him to struggle with the note taking process, the IEP team suggested the school district issue him a Smartpen. It gave him a tool which exponentially simplified his note taking, allowing him to

focus on the lesson, record what was said using the pen, and transcribe necessary information onto a specially designed notebook at a later time.

Situations such as these allowed Ruby, Judith, Kate, and I to feel the school was designing services towards our children to meet their needs, something which is afforded to them through IDEA, something we did not have to fight for.

Communication makes the world a better place. Prior to the tailoring of services to meet the needs of our boys was a link we all found valuable, that of communication; whether it was teachers who utilized reciprocal communication as a means of maintaining contact with us, those who preferred routine collaborative partnerships to identify what worked for our children in the classroom, or educators who listened and made us feel as equal members at the IEP table. “If you don’t inform me, I can’t advocate for you, and I can’t advocate for him.” (Kate) Just opening up, listening to our concerns, and communicating made us feel valuable in the process.

When it comes to his teachers they email me at my school email address. They know they can call my school, they can communicate. And you get that courtesy of you’re a teacher, I’m a teacher, let’s talk. You know, you understand the situation, you’ve been there. How can I help Eric? And sometimes, really cool situation, with the teachers.
(Kate)

Judith explained how a teacher’s willingness to communicate when Barry was having difficulty adapting in middle school is a memory which stands out amid a sea of less than pleasant moments.

I had a particular teacher go out of her way to sit with Barry and let him cry his eyes out because he was upset about being puny and some of the other kids were making fun of him because he was tiny. It was seventh-grade. To the point where she called me on the

phone and said, “I have Barry in my room and, he’s sitting on a beanbag chair, he’s very upset, he’s crying. I wanted you to know.”

For Judith, the effort of a teacher to reciprocate concerns regarding Barry was all she wanted. “I just want to keep the lines of communication open.” And when those lines of communication come with open ears, it not only delivers a sense that someone is listening, it sends a powerful message which we value. “I think that the biggest difference is understanding, open mind, flexibility..., and I think just understanding and then the willingness to..., accept my ideas as a parent.” (Ruby)

Even when the news regarding our children’s behavior is not stellar in our eyes as educators, we still want to know. We want teachers to communicate with us so we can switch from our teacher roles and address the situations as parents.

So we have parent-teacher conferences. And I let the teacher know as a parent I am completely accessible. And we had meetings and I sent notes and we had the agenda. And the agenda gets used at home. I mean it’s one of those things, “Did you [Eric] see what you did?” Follow through. Always follow through. And there’s a consequence. (Kate)

As parents we are all aware our children need help in school, whether it is for behavior, academics, or social-emotional aspects. We want to help. It is why we became educators ourselves. But we can help those on the other side, those we work with, only when the communication window remains open allowing for two-way conversation.

Advocate on the other side. Among all the common themes and factors of my co-researchers and me, the one point which gains attention is our intense desire to ensure our boys receive a meaningful education. Interestingly enough, our frustrations with navigating the

turbulent waters of special education were settled when we encountered a light in the sea of darkness, someone who was willing to go the extra mile for their students, someone with passion and commitment much like us, an advocate on the other side.

For Ruby, it was a principal in a previous state who recognized Ruby's insecurities regarding Chuck's classroom setting. For Judith it was a teacher who gave Barry the instruction he needed in the setting which worked better for him. For Kate it was an assistant principal who kept her informed and understood Eric's difficulties without issuing unnecessary consequences. For me, it was a district level educator who provided his expertise, when I knew not where to go.

Ruby's advocate sat on the other side of the IEP table when Chuck was in third grade. Fueled by her mother's intuition, Ruby attempted to voice her concerns and wanted Chuck removed from his self-contained classroom and placed elsewhere. She met resistance from the IEP team, until the principal advocated for Chuck to be moved to a regular education environment with an aide.

The principal listened to me, but her hands were kind of tied, and she was a first year principal at..., this school. And she didn't have the best reputation for whatever reason, but she listened to me. I sat in a meeting and I said something is wrong. He needs a different setting and they said this is the only option that we have.

Ruby's mother's intuition was validated just two weeks later, when she says the teacher in the self-contained classroom was arrested.

Judith's advocate on the inside acted outside of the IEP meetings when Barry was in elementary. Instead she asked for IEP meetings in order to make necessary changes to Barry's services, allowing her to deliver specialized instruction for reading and math in a resource setting. As a result, Barry went from reading on a second grade level while in third grade to

reading on grade level by fifth grade. “Had she not said something, he probably would have sat up there in [regular education] class and they would have had to go serve him in class and he wouldn’t have made the gains that he made.”

Kate found her advocate on the inside in an unsuspecting place. She previously had confrontational situations with the principal regarding Eric’s behavior, but found the assistant principal was more understanding of Eric’s behavioral outbursts as a result of his disability.

Do I still have problems with the principal? Yeah. Did I ever have problems with [assistant principal] with him [Eric]. No. She’s like, “I know it’s Eric and this is Eric and we get it,” and she always understood. “We have a long history with Eric, how can we help him? I just want to let you know that this happened today. Can you talk to Eric at the end of the day?” Yep, totally will talk to him.

My advocate on the inside not only found Kristopher’s missing IEP so the school could start providing the services he had not been receiving, but his knowledge and undertaking to help my son steered my husband and I both toward special education. He was also the one I reached out to when we returned to the district from another county. He worked with administrators and adjusted Kristopher’s schedule, removing him from a Geometry class where Kristopher was failing, left without special education assistance, and had a regular education teacher who was not providing his accommodations for guided notes.

This person helped us navigate the world of a large institution. Within that institution I felt as if there was no one who would listen. When things were challenging and I was running into a brick wall, I always felt as if fighting the policies of the district would be insurmountable. I saw it as a mountain which could not be climbed. I would seek out

help, but I wondered if the help would be strong enough to go up against the district.

(2/26/2014)

The themes identified in this group depiction created positive experiences for Ruby, Judith, Kate, and me. They are all moments we share, moments we speak highly about, and moments which we felt worked when other experiences did not. Getting the needs met for our boys inside their classrooms and at the IEP table are first and foremost important to each of us. But those needs are only met when we and our fellow colleagues create open lines of communication with a vested interest in listening and when we encounter a teacher, a principal, an assistant principal, or a district level representative who value our concerns and advocate with us to meet those needs. It is what worked.

Negative experiences which did not work well. Yet it is the negative experiences which left us fighting from within to advocate for our sons. Experiences which frustrated us regarding services that were not provided, IEPs which were not followed in the classrooms, resistance to our concerns as parents, and inattention to the needs of our children. These are collective themes which we have all encountered in advocating for our children inside the school districts where we are employed. They are experiences which we believed did not work and remain in the front of our minds.

Frustrated by services. When speaking to my co-researchers throughout the interview phases, each one of them discussed a level of aggravation regarding the services their child received in relation to their IEPs. It is interesting to point out that all of them spoke highly of experiences where their children were served in either self-contained classrooms or in resource pullout settings. We all related our negative experiences to services received in regular

education environments, which particularly declined as our children moved into the secondary settings of middle and high schools.

Ruby, Judith, and I have crossed into those secondary settings, and the experiences there related to expectations from educators that our children no longer needed similar levels of support.

In middle school and high school the teachers are completely different. I don't mean to make it..., only about teachers but, it's a mindset because the kids are older and they forget that these are still kids with cognitive deficits. (Ruby)

You get to middle school and it falls apart. I don't know if it's because of the multiple teachers, that how big the campus is, how many kids they have, I don't know what it is about middle school, but gradually it starts to fall apart. (Judith)

For Kate, she and Eric are on the verge of middle school, a thought which terrifies her knowing Eric needs more behavioral support than is provided through his IEP. "Middle school, we're going to totally tank. And I pray to God he graduates one day." At the conclusion of this study, Kate began looking into the possibility of eligibility for Other Health Impaired. If he meets criteria with his diagnosis under the autism spectrum, he would once again have access to services from a special education teacher and his classroom accommodations would return as well. And Kate would know that her son would have an eligibility category which she could live with. Since the eligibility process is time consuming and the school year is drawing to a close, Eric will move into middle school without those supports.

Not only did the group of co-researchers express discontent with the shift in mentality between elementary and secondary levels of educations, Ruby, Judith, and I also expressed frustration with accommodations not being provided and IEPs not being followed. "How do we

help them be successful? Well first we need to look at actually delivering the things that they're supposed to have." (Ruby)

I think that some of it was an expectation that they're getting..., a standard diploma so they..., shouldn't be given these things, they shouldn't need them, even those on the IEP.

And then some of it was, "I didn't even know he had an IEP." (Ruby)

The barriers even became proper accommodations in the classroom, such as no guided notes and extended time on tests. I even had to find a way to inform a Spanish teacher that she needed to make sure Kristopher had more than five minutes to take tests and quizzes. He failed her class and we had to remove him because she didn't have the accommodating feeling. (2/26/2014)

Judith said it more bluntly in regards to the feelings she has acquired when Barry and others have not received the accommodations which outlined in their IEPs.

You're not following what federal law says you need to follow for my child. So therefore my child isn't succeeding in your class. But I can show you six other classes that my child is succeeding in because they're using it [accommodations]. They're doing what it says. They're giving him the extra help. And if you don't feel like you can do that, then don't teach. Because you're always going to have that one kid, whether it's on paper or not, that's going to need some kind of extra support. If you can't do it, then don't teach.

Not receptive to parent concerns and child's needs. Not only do our negative experiences correlate within the delivery of services and accommodations outlined in our children's IEPs, I also found similarities among our beliefs that educators are not receptive to our concerns or the needs of our children and their disabilities.

Judith experienced such resistance before Barry was even eligible for special education services. She said her request for a psychological evaluation for Barry to investigate his learning difficulties in elementary school was refused by the school. “I asked, they said, ‘We do not test for learning disabilities until third grade and they have been retained’.” Instead, Judith paid for her own evaluation outside of the school system. The result, Barry had a learning disability. In middle school she also asked for an occupational therapy evaluation since, according to her, Barry’s handwriting was illegible. The school discounted her concerns. Instead, Judith found a friend who was an occupational therapist to work with Barry and taught him skills to hold his pencil differently and solve the problem.

Kate’s situation was a little different. Eric had an IEP which only addressed eligibility for Speech Impairment. He used to have other areas of eligibility which provided him further special education support in the classroom. Void of such services, Eric struggled with behavioral outbursts associated with autism. However, the school did not pursue other areas of eligibility such as ASD or EBD and Kate was afraid of the long term implications of such eligibility categories on Eric’s future, so she did not pursue it as well. Though she did express concerns with the removal of services associated with Eric’s IEP, leaving him vulnerable without mandated behavioral supports. Yet she has been promised classroom support and testing accommodations through a 504 Plan. “All right Kate, [guidance counselor] says. ‘Oh well we’ll bring the paperwork in and we’ll get it done.’ I gave her four copies in that school year.” According to Kate, the promise was made by the school in Eric’s first grade year. It has gone unfulfilled.

Educators don’t “get it”. Since we mothers are very in tune with the needs of our boys, we struggle with educators who are unfamiliar with the characteristics of disabilities and who we

consider to be inattentive to their needs. This feeling appeared to intensify as our boys got older and their disabilities were still existent. “I had..., teachers [in middle school] who say things..., joking around and then not understanding..., that he’s more literal and then..., teachers expecting..., a lot with little accommodation.” (Ruby)

Written documentation of Ruby’s struggle with educators who exhibited limited understanding of students with disabilities was evident in a teacher planning note for an IEP meeting when Chuck was in high school.

Regarding in class paperwork – I have returned to him each assignment that he did not get a grade on. These assignments were turned in very incomplete. I have explained the procedure and gave him as much time as needed to do them. (I never see them again). Quizzes are very difficult for him and it was very challenging to even fill out a scantron. In the end I did [underline intended] have to take the scantron and fill it out. (Teacher planning note 9/27/2012)

The IEP which was in effect at the time of this meeting had a testing accommodation which allowed Chuck to write on the test because he struggled with the fine motor skills and his ability to bubble answers. His present level narrative also discussed difficulty with organization and his need for an organizational system as a classroom accommodation to help him maintain his classwork and homework so not to lose it.

Judith found that some teachers Barry encountered did not understand why he would need assistance with instruction and learning skills when he was not asking them for help in the classroom. As a result, he was being overlooked. “I think that’s my biggest thing is that, because he can sit in class and..., if he doesn’t understand something he can just sit. So they [teachers] miss it, they just overlook it, they don’t get it.” Barry’s initial psychological

evaluation identified higher levels of anxiety and internalizing behaviors. Hence, according to Judith, he will not give any indication that he needs help.

I even encountered a similar situation one conference night with a teacher who I felt did not want to *get it*. I was concerned about Kristopher's grades in his junior level English class. I questioned the teacher whether Kristopher understood the literary devices they were studying. As she fumbled through her graded papers, I told her that Kristopher generally will not let anyone know when he does not understand a concept. Therefore being attentive to the lost look on his face would be a sign he needed help. She snapped back at me that it was not her job to do that, and that was why she had a special education teacher with her in the classroom. Holding back my instant anger, I questioned her whether the classroom was assigned as a co-teaching classroom. She responded that it was. So I proceeded to politely, yet sternly, inform her that when there are two teachers assigned to a co-teaching classroom, that it was the responsibility of both teachers to meet the needs of their students. I had only introduced myself as Kristopher's mother prior to our conversation. But at that very moment, I told her what I did for a living and that I knew exactly what should be occurring inside a co-teaching classroom. She never looked up at me again and I walked out, fuming, because it was evident to me that my son had a teacher who just did not understand children with disabilities. Unfortunately for Kristopher, we could not change his schedule. He had to remain in that class since that was where he received his support from the special education teacher.

Impact on advocacy. No matter the amount of frustration we experienced based on the level of services, the resistance to our concerns, and limited understanding of our children's disabilities, my co-researchers and I never gave up. We kept on fighting. When we did not need to fight for our own children, we fought elsewhere. We fought for the students we served. We

became advocates in our own right. Whether we advocated while sitting in the doctor's office or whether we advocated outside the walls of the IEP meeting room, we all found a means to channel the knowledge we attained about disabilities, about the laws, and about the inner workings of the school districts where we worked in order to help others who did not know.

As I continued to immerse in the data of all our experiences, a theme which became apparent to me aside from directly answering the research questions, was an identity which emerged from advocating for our own children. We all entered education because we wanted to help our children at a time they needed us the most. In turn, we were thrust into a world bound by laws and expectations. We learned, we grew, and we became mothers with passion for the profession, driven with a sense of guilt, to right the wrongs experienced by our children. The remaining portion of the group depiction related to experiences focuses on how those experiences impacted our advocacy.

Developed identity as passionate advocates. As mothers on a mission to ensure a meaningful education for our children with disabilities, Ruby, Judith, Kate, and I have all become advocates, and passionate advocates at that. We not only want what is best for our own children, we work hard in our schools to provide the best for our students. For the three of us who are teachers, Ruby, Kate, and I, we advocated inside our classrooms and outside the walls of the IEP meetings.

I don't want to be the person who has to go home knowing I didn't do what was best for that kid. Because where I'm at, I can look at the IEP, and I can follow the IEP, or I can get an IEP like I got a couple weeks ago that says, what kid is this because that's not the kid I have in my class. And do what I know is right for that kid. (Kate)

My role as a teacher is to educate within the boundaries of the state that I work for. And my role is for me personally, I feel like..., I don't take it as a job. To me it's my life, it's my passion. It's what I do. (Ruby)

I best use my advocacy skills as a teacher by identifying the needs of my students and providing support in those areas. Of particular interest to me are the social-emotional needs of my students. I'm always trying to find a way to connect with them and helping them to feel successful. It's what Kristopher has struggled with, and it's what I have personally struggled with. I want my students to know someone cares, and someone is there to help as much as possible. (2/26/2014)

With less daily access to students in her position as a para-professional, Judith finds the means to advocate using other avenues. As someone whose job it is to manage paperwork for the special education department, she uses the knowledge she has acquired in her position to help explain to other parents the importance of making sure their child gets what they need.

I think it just makes you more aware of the kids that you're with and the kids that you work with, what their needs are. And that you want to meet those needs because you want that parent to know their kid is getting what they need. You don't want to be on the other end of that, because you've been on the other end of that. You want to be that person that is making sure this is what they're IEP says, this is what we're going to do. (Judith)

Driven by sense of guilt. We all would not be the passionate advocates that we are without something somewhere supporting our commitment to keep on pushing for what we believe our children need. As I outlined in Ruby and Kate's individual depictions, there is a

sense of guilt which fuels their passion. A passion not only designed to help their children, but a passion which is also aimed for others.

Kate frequently expressed a feeling of failing Eric. Four times within our second interview she spoke of failing a young man with whom she has devoted her life to help.

I feel like I did fail Eric. I don't know if you feel that way with Kristopher, but at the end of the day, a day passed and I can't get that day back. And all I can say is my greatest achievement in Eric's education is I pushed and pushed and pushed.

Kate's feelings appeared to be linked back to the time a doctor referred to her as a bad parent for not seeking help for Eric sooner. Those feelings reverberated in Kate's mind, even though she had been searching for answers and going from doctor to doctor for many years. But it was the words, not the inaccuracy, which hurt this mother who recognized early that something was different about Eric's development. Consequently, Kate has used that memory to push herself and make a difference.

So I had to go through all of that fight and now let me help other kids because I don't want other parents, I don't want other moms to fight and be told that I'm a bad parent because I didn't do what was right for my kid.

Ruby carries feelings of guilt as well, fearing she did not do enough for Chuck. She made reference to beating herself up, worrying whether she provided enough support for him at home. "I think that as a parent I often focus on..., how I haven't done enough. And I feel like what more could I have done? I spend so much time questioning people and fighting for what he needs." Propelled by her feelings, she provides advice in online support groups for other parents of students with disabilities. "I feel like I need to take that advocacy and help other people."

I am no different than my co-researchers in this regard. I too am driven by guilt. The heuristic process and search for meaning in my advocating forced me to uncover pieces of mine and Kristopher's past, which I had chosen to either bury or ignore. As I began to tell my own story in my journal, a story which took me days to gather enough strength to write, I had to be willing to visit past memories which I indicated in Chapter Three. I also had to be open and honest with myself. My co-researchers were forthcoming in their revelations. I was not. Perhaps because of the embarrassment of choices I made as a young mother-to-be, which may or may not have led to the development of Kristopher's learning disabilities. Or because of the embarrassment for him in releasing a piece of his past which placed me in a forever protective mode. Nevertheless, those reasons which clearly fuel my feelings of guilt will continue to remain under lock and key. But I now know why I am a passionate advocate in special education, and I now know why I have pushed myself to protect my son from a system which at times I felt took advantage of my limited, yet growing degree of knowledge. I am no different than my co-researchers. As I noted in my reflexive journal, we are all mothers of children with disabilities, and we are all driven to push ourselves for a greater purpose.

I was questioned yesterday about pushing myself too hard in this study. Of course I'm pushing myself hard. I owe it to my co-researchers. All of us have dedicated our working careers to our children. All of us entered education because our children needed help. All of us keep fighting because we feel our children didn't get their fair shake in life. We are all mothers of boys. We are all advocates for them and others just like them. We have all pushed ourselves more than the typical parents we have encountered in our school settings. It's what we do; we push ourselves for them and accept nothing less, so they can have more. I have a deadline to meet. I want to defend this study on the day my

son exits the public school system. The same system which at times left him feeling isolated and worthless; the same system which I vowed to fight from within on the very day he told me, ‘Mom, I feel like they put me in this class because I’m retarded.’ I have lived, my co-researchers have lived, and our boys have all lived inside the walls of an institution called a school system. We have all fought our employers with fears of repercussions because we owed it to our sons. Defending this study on my son’s graduation day will complete the heuristic process for me, because I can finally grant him the gift of fulfilling these very words I used many years prior: ‘I promise you Kristopher, in time our dream will come, because I’m researching the struggles of kids’. So ask me again whether I’m pushing myself too hard. (2/26/2014)

Focus energy to right the wrongs we experienced. Supplied by the passion which energizes our advocacy, Ruby, Judith, Kate, and I appear to be channeling our efforts to *right the wrongs* experienced by our children. Within the immersion phase of the heuristic process for my co-researchers, I began to take note in my reflexive journal how their advocacy efforts were focused in areas where they felt their children experienced the most difficulty.

I began to think how each of those within this study attempt to right the wrongs we have experienced in advocating for our own children by working harder for those we teach. Judith attempts to get more parents to understand the inner workings because she doesn’t have as much direct contact with students. But the rest of us, Ruby, Kate, and me, all find an avenue to do a better job for our students than what occurred for our own children. Ruby tries to make sure her students with IEPs get every accommodation listed on their IEP, as well as providing accommodations for children she knows are not yet identified with a disability. Kate tries to keep open lines of communication with the

parents of her students. She wants them to hear the good with the bad, because she has heard mostly the bad concerning Eric and his behavior. And me, I want just to make sure I do the right thing for each of my students, particularly when parents ask. I listen to their concerns and hope to make sure they are pleased with the delivery of our services and provide ideas on what else they can do, and sometimes that means having off the record conversations. (1/25/2014)

The *fight within* began for my co-researchers and me the moment we knew our children needed help in an academic environment. We had to struggle with ourselves and the thought that learning was not going to be easy for them. So we joined forces with those who would teach them. We entered education to improve the process for our children and others, but instead we were met with problems of the process that we cannot and could not single-handedly improve. Yet despite the unending frustrations, we have continued to fight from within.

Barriers to advocating as a parent and as an educator. Fighting from within a system has not been an easy task for any of us. We serve two roles, that of a parent of a child with a disability and that of an employee within the same school district where we advocate for our children. I asked Ruby, Judith, and Kate to explain their thoughts about advocating for their sons inside the school districts where they worked. Their answers did not convey a sense of satisfaction.

It sucks, like it's really bad. It feels like..., I can say that I guess that it could..., depend on..., if we're talking about basic advocacy..., to where..., you always advocate for your child. But when we are talking about when things are not being done correctly, accommodations are not being followed, what he needs is not being given to him, and you have to advocate for that..., it is more like..., I got to fight. (Ruby)

I love my students and I love my class, but it's a hindrance, and I would love to leave and go to a different school district that I don't know, that I don't work for, and be that psychotic parent that gets what they want. (Kate)

It's a no-win situation. Because they know you work for the district. They know you value your job and..., most moms that work need their job for whatever reason. And they kind of use that against you, so to speak. (Judith)

Each co-researcher experienced multiple barriers which impacted their advocacy for their children inside the school district. But as a group, we experienced similar barriers as seen in Figure 11. We all entered public education with varied levels of knowledge of the laws which supported special education. Once we learned the language, we found our in-depth knowledge of our children's disability at odds with the constraints of an institution and condensed views of exceptional students held by many teachers. The dichotomous roles of parent and educator left us feeling conflicted and fearful of our job security when needing to advocate for our children.

Learning curve in our new field. Education was a second career for each and every single one of us. Since that was the case, none of us were privy to the inner workings of a school system prior to becoming educators. Ruby and Kate had an earlier introduction to special education than did Judith and I. Their boys received early interventions prior to kindergarten. Regardless, we all experienced a steep learning curve which impacted our ability to advocate for what our children needed.

For me, I had no idea that the school losing Kristopher's IEP and not providing him academic services was a problem. I was also unaware of the severity of not having speech therapists for multiple weeks at a time, or not having contract therapists fill the void on repeated occasions. I did not know enough to recognize it as a violation. But by the time Kristopher was

in high school, I understood the language of FAPE and that missing services could lead to procedural violations.

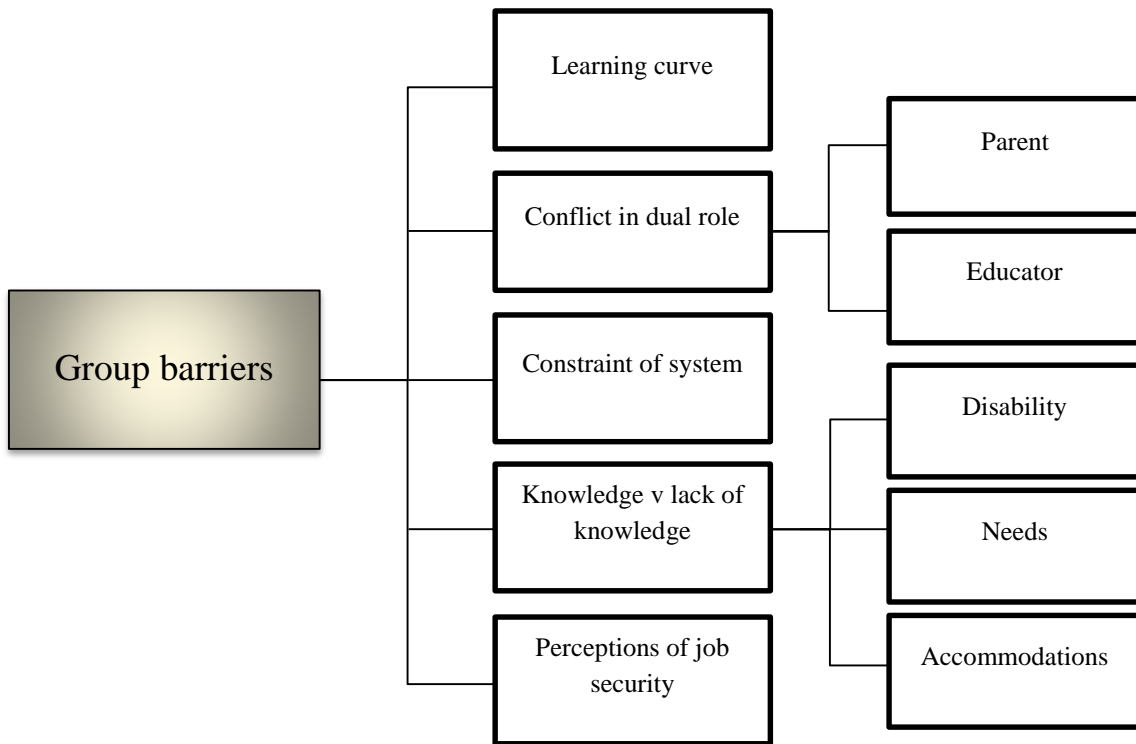


Figure 11. Barriers encountered by the group in advocating for their children.

Judith did not know the school system was obligated by law to provide an evaluation once a parent requests it in writing.

Not knowing that they should have been liable to pay because I had specifically asked them to test him. I put it in writing for them to test him and was told no, they didn't do that until they were retained third-graders. And then I paid for outside testing and even when I had his initial staffing nobody said to me, do you realize that because you paid for this outside school district and you had requested the school to do it, that the district needs to reimburse you for that? Absolutely not.

As a mother who is attending law school to become an education attorney, Judith now knows what parents of children with disabilities are entitled to receive.

Ruby was more knowledgeable in the early years, but in first grade she found herself having to advocate against a more restrictive environment for Chuck when she “wasn’t quite sure of IDEA and what exactly it was about.” She since developed a strong understanding of the language within IDEA and the rights afforded under the least restrictive environment. Ruby was able to articulate her knowledge of such when she developed a letter for the IEP team prior to a meeting where she wanted Chuck to be removed from a self-contained setting.

Kate’s first experience with reading IDEA came after the district by law had to remove Eric’s eligibility for Developmental Delay. I asked what she thought when she read it. “Ah [expletive], I’m screwed.” Eric’s eligibility had already been determined to be speech and language impaired and nothing else. She was not at that eligibility meeting because of her duties as a school district employee and did not know her rights. Kate says she had asked for the meeting to be moved, but was told by the school psychologist that it could not.

Conflicted in our roles as parents and educators. Once on the inside of the system my co-researchers and I learned the language and the laws surrounding special education. But we also began to feel conflicted in our roles. We became educators so we could learn how to help our children. Instead what we learned how those two roles collide.

It can be emotional for me as a parent because I’m a teacher and it can be emotional for me as a teacher because I’m a parent. And I don’t think that I would be as emotional if I just had one of those roles. (Ruby)

I have experienced my roles as an educator and a parent of a child with a disability come into conflict sitting in an IEP meeting. While listening to a parent describe a bad experience at

another school concerning her daughter, my heart went out to the mother. I could only sympathize because I had those experiences myself. As the other educators at the table looked at me to ask whether my school would accept the child on a special assignment, I lifted my head, with tears in my eyes and responded, “We’ll take her with open arms.”

Though our conflicts not only come from empathizing with the parents while attempting to remain objective in our roles as educators, our dilemmas have also encompassed what we believed were inconsistencies in the decision making process for children with disabilities. Ruby explained that she frequently found herself at odds with what she knew regarding the laws and IDEA as opposed to the decisions she saw being made within the school district and at the IEP table. “Why is this happening over here but it’s not happening for my kid? Or you know I don’t really think that’s quite right but what can I do about it?”

I tell my parents in my classroom, I understand where you’re coming from, I have an ESE student. I’ve been there. I’ve been there for years. And I’m doing the best that I can for your child. But please understand that we’re working within a system, and I hate that. (Kate)

Even Judith explained that she kept herself tight lipped with her knowledge and insider information. That is until a parent asked.

And then when you get into the, okay now I’m an educator and now I know, sometimes you want to look at that parent and say, please oh please, ask this question. You can’t come right out and say it but you’re looking at them and you’re thinking please ask this question so I can give you the answer, because I can tell by that look on your face, but I can’t until you ask me.

Kate found a means to solve her internal conflict between her roles, having conversations outside the IEP room doors. “Now that we’re off campus, I’d like to recommend something. Now I’m not talking to you as Mrs. Teacher, I’m just talking to you as this random person.”

As parents of children with disabilities, we experienced internal conflicts which we never could have predicted when we decided to become educators. We struggled in those roles sitting at IEP tables, while having experienced the other side. We felt the parents’ pain and as educators we wanted to speak up when decisions were made which crossed with our experience as parents. “And then you get smacked down. Really? I know what’s right for this kid. I’ve been there. I’ve got the kid at home.” (Kate)

Restrained by the system of options. Also presenting as a barrier in our advocacy within our school districts was a general feeling of being restrained by a system of options. Whether that system did not allow our children to access all the affordances given under IDEA or whether fellow educators were unaware of their obligations to provide what was governed by federal law.

Ruby was introduced to a system of restrained options the moment she registered Chuck for high school. With his IEP in hand, outlining resource classes for math, science, and language arts, she says she was told, “I don’t know why they put that on the IEP in middle school because we don’t... have that, and he’ll be okay.” The words “we can’t, we won’t, we don’t” were referenced by Ruby within our interviews as barriers she encountered in various locations, particularly at the secondary level. Instead, she found herself advocating for what she knew was right, “And my response is usually, hmmm, it doesn’t matter if it’s high school..., he still has a need that has to be met whether he’s in high school or not.”

High school provided its own set of barriers for me as my family returned to our previous county from another district prior to Kristopher’s sophomore year. His transferring IEP was

written with special education support in math, which was going to be Geometry for him that year. It was his proven least restrictive and most successful environment for many years dating back to middle school. With the right support he was able to maintain C's or better. Yet when we returned to our previous district, he was placed on consultative status, because the only other option was Geometry in a resource classroom. In other words, the school did not have a regular education Geometry class supported with a special education teacher. Consequently, it was a disastrous decision for Kristopher. He had a teacher who did not provide accommodations, particularly his guided notes, and he was failing. The situation ignited a chain of events which carried over into the next school year and caught the attention of the district and state level compliance specialists. In the end, the school had to make alterations in its service delivery and start providing special education support in Geometry and Algebra II classes, which were state mandated graduation requirements.

Judith found barriers in the manner the system restrained the rate at which students with disabilities are expected to learn. She spoke adamantly about her battle with adjusted pacing and Barry's need to slow down the curriculum timeline to allow him the opportunity to process the rapid amount of information so he could master the skills.

Adjusted pacing means, if my kid doesn't get it in a week, then you're supposed to keep teaching it to him until he does get it. No matter what the district says, because my child's document is a federal document.

I also found constraints within the district regarding accommodations for my son and a student of mine. Kristopher had yet to pass the 10th grade state standardized test in reading. The district moved to computerized assessments, but Kristopher complained during his IEP meeting that he did not like taking tests on the computer. Not to mention, he had years of documented

concerns of text anxiety within his IEPs. We requested for him to take the test using pencil and paper, which was an allowable accommodation within the state accommodations manual. The district denied our request. I even asked for the same accommodation for a student of mine who said the words on the computer screen looked *pixelized*, and had difficulty reading from the screen. The district assessment department told my school no. This year, upon Kristopher's second request for a pencil and paper state test, the IEP team determined it was their sole responsibility to outline testing accommodations, regardless of past district decisions, and placed a pencil and paper accommodation on Kristopher's IEP. With such a clearly stated accommodation and my checking in with the school to ensure follow through, Kristopher took the state standardized assessment for the last time as a public school student using a pencil and paper test, rather than on the computer. For me and Kristopher, we rejoiced in a simple victory, finally.

Our knowledge of our children versus educator lack of knowledge. In analyzing multiple documents from my three co-researchers as well as the mass of documents I have collected regarding Kristopher, I have found it fascinating to understand the multitudes of information, something I could not even fathom more than a decade ago. Ruby, Judith, and Kate all spoke of a learning curve upon their entry into education. Since the days we all became educators, our knowledge level has increased exponentially. We not only know the inner workings of the school system, but we also know and understand our children's disabilities, how to meet their needs, and what type of accommodations help them the best. And perhaps what hinders us the most in advocating for our children is when we encounter other educators who do not carry a certain degree of knowledge related to students with disabilities. It is what infuriates us.

The biggest challenge and you're going to understand this one, is when you talk to somebody who's in administration, and they act like they know ESE and they've had zero minutes. They once sat in an IEP meeting, but they probably didn't do anything because they had higher ups there to cover it. Umm [principal name], years of that. "Oh I understand..." Do you really? I mean you're just like patting me on the back and sending me out the door. You didn't understand [expletive]. (Kate)

Ruby even found the lack of knowledge in settings which surprised her. When Chuck was in fourth grade in another state, he had a special education teacher who Ruby says did not understand aspects of Chuck's disability.

He had a resource teacher who just did not understand the autism part of it. And..., just the constant..., this and this and this and..., I just..., don't have patience for that. Like you're the educator, you're supposed to know about autism. These are related behaviors, a manifestation of his disability. Like why are we having this conversation?

I myself wondered why I was having conversations with certain people. I found myself emailing a guidance counselor who sent home a letter informing Kristopher that he was in jeopardy of not graduating because he had not yet passed the state assessment in reading. So a conversation ensued with me needing to remind that guidance counselor that Kristopher was entitled to a waiver, which would not impact his graduation. In the meantime, I had to calm my son who, with an anxiety disorder, nearly panicked. I had to repeat the same procedure when the same guidance counselor then informed Kristopher he could not join the military if he graduated with that waiver. Again not true, but I had to forgive her for what she did not know about special education. In the meantime, I could not believe someone with limited knowledge was advising students.

My increased level of knowledge associated with my pursuit of higher education even resulted in an IEP meeting with uninvited guests. I knew the language of the law and I was alleging both procedural and substantive violations of FAPE related to Kristopher's declining performance without special education support, IEP progress inserts not being provided as stipulated by law, and multiple requests for an IEP meeting which went unanswered. I had laid out my evidence and even had the support of a state compliance specialist. The district responded by sending two attorneys to the IEP meeting. I questioned their attendance at the meeting and was told, "We thought you were bringing someone." Using my insider knowledge of procedures, I responded, "I know the rules. If I was going to bring someone I would have informed you." The attorneys then scurried out the door.

Being a para-professional and not a teacher, Judith found educators underestimated her level of knowledge. But she was quick to point out to them in detail what the school was and was not allowed to do by law.

For me I was able to say well wait a minute, stop. IDEA says that you can't increase his services without my prior knowledge. You can't just decide that he needs more services and start giving it to him and say nothing to me as the parent until I show up to this IEP meeting and you've been doing it for a month. And they look at you like, "Oh, umm, yes ma'am you're right, we thought this is what was best." And they start backtracking because they know you know. Okay we have parent that actually is aware of such a thing as IDEA. They know what it is and they know where to look. So now we need to kind of be a little more cautious on our end as to what we're putting on this paper, because she's going to pick it apart.

Our perceived fear for our job security. Despite the constraints and conflicts which made it challenging to advocate for our children while working inside the same school districts where they attended school, there was a common theme which permeated all of our stories. As I approached this study and developed my research questions, I wanted to know whether anyone else experienced troubles like Kristopher and I. I also wanted to know what barriers other parents, who were educators like me, felt impeded their ability to ensure positive academic outcomes for their children. I also wanted to know whether anyone else worried about job security as they stood up for what they believed was right for their children. While immersing in the transcripts and journals, it became clear to me that we all carried a level of fear about negatively impacting our jobs while advocating. It was also unmistakable that fear was itself a barrier within our advocacy efforts. And as all of my co-researchers have shared, that fear played an ever so apparent role in their decision making process. “I know that my job, whether they say it or not, is in limbo if I throw the biggest hissy fit on earth.” (Kate)

And they make you feel like if you push it, that you’re in jeopardy of not getting promoted, of not getting that next interview, not being able to move up the ladder..., almost like you’ve got a target on your back. Because they know you work for the district, but they also know that you are somebody’s parent. (Judith)

Whether it is a perceived barrier, or whether that perception is a reality. Both Ruby and Judith were called in to their principals’ offices and questioned about advocating for their children who were attending other schools.

She shouldn’t have been in that position. I shouldn’t have been in that position. None of us should have been in that position. And I didn’t do anything wrong. And even if I had, it shouldn’t have been brought to my boss. (Ruby)

I personally did not experience situations where I was questioned about my advocacy. However, I was the one who questioned others whether my advocacy would impact my job. At one point my husband and I were faced with pursuing legal action when Kristopher was hazed in a serious incident while a member of his high school wrestling team. The incident was a significant factor in our decision to return to our previous school district and it is documented in detail in my reflexive journal. The second time I questioned a good friend and district level administrator whether pursuing a state complaint over violations of FAPE regarding Kristopher's IEP would impact my future in the district. He said no. I was not so sure.

In the end, it is our own perceptions of job security in relation to our advocacy which formed one of many barriers for us parents and educators of children with disabilities. And yet it is those very barriers which formed our experiences. Therefore the lines between barriers and experiences are not clearly defined. In actuality, they are all pieces of the puzzle, but demarcated within this study in relation to the research questions to assist the reader. When I developed the research questions, I could not have predicted the relationship among them. Though upon completion, the connections are evident. Fighting from within the system has been a challenge for all of us. This group depiction outlines our experiences as a whole and identifies common threads which serve as a source of frustration. Despite those barriers, we fight on and *fight within*.

Now that our stories have been told in concert together, a heuristic researcher is to return to the raw data and the individual depictions one last time. This is the final phase in the written depictions of a heuristic study. Moustakas (1990) suggests choosing two or three exemplary individuals who are representative of the group. The intent is for the exemplary depiction to portray the experience which was investigated and the co-researchers in a unified manner. Due

to the limited sample size in this study, choosing exemplary individuals would mean choosing only one or two. My co-researchers all entered this study with me, and we progressed through the phases together, explaining our *fight within*, which we experienced not alone, but in unison. Our voices came together in the group depiction, simultaneously fulfilling the intention of the exemplary depiction. Therefore the group depiction also serves as the exemplary depiction.

Creative Synthesis

The final step in heuristic research is the development of a creative synthesis, which combines the researcher's intuition with the data from the co-researchers. According to Moustakas (1990), the researcher is free of boundaries to develop what comes from within, with a wide collection of possibilities. In my case I originally scoffed at the idea of developing a poem or any piece of material considered artistic. It did not seem fitting for me. But as I immersed in the words of my co-researchers, I began to hear similarities not only in the themes surrounding their experiences, but in the words they used to convey their message. I heard many of them over and over again. The more I immersed the more those words imprinted in my memory. I began to feel I needed to develop a found poem. A found poem takes words and phrases found in non-poetic situations and reframes them into poetry. As I began developing the group depiction, and thinking I was still days away from making decisions on my creative synthesis, I experienced an overwhelming feeling from within. It was instantaneous, and perhaps can best be described as coming from the depths of my soul. I grabbed a piece of paper and started writing without thinking. Within minutes I had developed a poem, with each and every word used directly from the interviews with my co-researchers. Moustakas (1990) states the creative synthesis "invites a recognition of a tacit-intuitive awareness of the researcher." A

seemingly endless immersion cycle throughout the course of this study led me to develop this poem with hardly any conscious assistance, the key component in conducting heuristic research.

Our Voices from Within

We are one voice together,
Hear us, hear us now.

Why won't someone listen?
Why won't someone care?

We are frustrated, we are fed up,
Hear us, hear us now.

Why does life seem so hard?
Why does the system seem so unfair?

We push, we pull, we try, we cry,
Hear us, hear us now.

Why do we feel so restricted?
Why do we feel so full of despair?

We advocate for them, we advocate for you,
Hear us, hear us now.

Why do we know so much?
Why do others not know we are there?

We want to communicate, we want to educate,
Hear us, hear us now.

Why don't you give them what they are entitled to?
Why don't you see us for who we are?

We just want their needs met,
Hear us, hear us now.

Why can't you, why won't you, why don't you?

Why do you make us *fight within*?... it leaves a scar.

Chapter Five:

Discussion

My intention with this study was to uncover not only the meaning of my experience in advocating for Kristopher inside the school district where I worked, but also the meaning behind the experience of other mothers of children with disabilities who were educators like me, who advocated for their children like me. I introduced you to three mothers, Ruby, Judith, and Kate, who all advocated for their children while serving as parents and educators. As I explored their experiences, I connected my own. In this chapter, I continue to bridge all of our experiences and relate them within the context of research in the field of parents of children with disabilities. I also discuss the implications of my findings on the practice of special education and provide suggestions for future research in this area.

My chosen method to inquire within using a heuristic case study design allowed me to tell the story of others using an individual perspective, while also focusing on my own inner being, others, and the world around me. It combines the emotions, memories, and images of my experience with the experiences of three co-researchers. Gertler (2003) called it the “undefinable tacitness of being (there)” (p. 75). The inquiry is autobiographical in nature and holds social significance (Sela-Smith, 2002) for me the researcher.

In the interest of uncovering the deeper meaning using my own tacit understanding, my wondering led to the evolution of three research questions which guided the focus of this inquiry.

They were:

- 1) What are the experiences of school district employees who challenge their own districts in the interest of their children with disabilities?
- 2) What barriers do these parents/district employees feel they encounter in advocating within their own districts?
- 3) How do these parents and district employees perceive their involvement in advocating for their own children in relation to their job security?

In Chapter Four, I introduced the reader to three mothers and their children. These mothers were selected using purposive, critical case sampling. They were known to me prior to this study, though I was unfamiliar with most of their struggles within the school districts. As well, they met the criteria I set forth for participation so I could inquire from within. They were current employees of a school district in the southeast United States; they were parents of a child with a disability, currently served with an IEP; and the services of their child's IEP occurred within the same school district where the co-researchers worked. These parameters were set forth to create a bounded case, much like my own, so I could better examine the phenomenon which led me to wonder.

As I set forth on my journey to uncover and explore case by case, I met with my three co-researchers for three separate interview sessions. I sat with Ruby over the course of all our interviews in the comfort of her living room. I met Judith and Kate at mutually convenient public locations. Ruby seemed relaxed and confident while speaking to me in her living room. I was concerned meeting my other two co-researchers in a more public setting would lack warmth and lose access to the wealth of information I was hoping to obtain. I was wrong. The topic

alone seemed to elicit a willingness to speak passionately about their children and their experiences in advocating for their needs, regardless of where they shared their stories with me.

Following the transcription of the co-researcher audio interviews, I immersed myself in multiple rounds of listening and reading each word in each interview. I cycled through the heuristic phases of immersion, incubation, illumination, and explication on a daily basis. Moustakas (1990) outlines the phases as periods, but gives no direction as to the length of each piece of the process. I conducted this research while working a full-time job in an elementary school. I would immerse for hours on end at night, incubate while at work by day, and then illuminate and explicate when I arrived back home and reopened my frame of thinking on the topic. I questioned whether this daily cycle was right at the time. But I found I could not stop the ideas which flowed each time I returned to the data. Not ever having experienced this form of research, I felt a conscious urge to squelch my thinking, but soon realized this was natural and this was the process. Moustakas (1990) indicates illumination is a breakthrough involving an awakening to the experience or corrections in previous understandings. These breakthroughs allowed me to take notes and identify qualities and themes leading to each individual depiction.

Not only did I re-involve my co-researchers in the cross-checking of their interview transcripts, I also asked them to member check their depictions for accuracy and make any suggested additions or deletions. Once Ruby, Judith, and Kate were all pleased with their depictions, I again immersed in their experiences, re-examining the raw data and individual depictions until I understood the qualities and themes of the group as a whole.

It was at this point, where our voices and our stories came together, and where I no longer began to feel alone in my *fight within*. There were individual differences within our stories, but there were also common threads which ran throughout. The uniting of our

experiences through the group depiction and ensuing creative synthesis completed the presentation of the data in Chapter Four. I elected to not carry out the final written depiction, that of someone whose experience exemplified the group as a whole. This decision was made due to the limited number of participants and the determination that not one person represented the experience of the group as a whole. The experience was that of the group as one.

Before discussing the findings of this inquiry process, I must address the use of a word which was heard within Judith's individual depictions as well as in my explanation of Kristopher's experience which brought me to higher education. That word is retarded. It is a word both Judith and I loathe. But it was a word used by our own children in a moment when they themselves struggled from within. They were both young and feeling inadequate in a world surrounded by non-disabled peers. Though, they have since developed an improved sense of self-efficacy and learned to become advocates like their mothers, resenting the word retarded, and advocating to put an end to its use.

Findings Which Emerged from the Data

The objective of this heuristic case study using a storytelling approach was to uncover a phenomenon related to an experience and discover meaning. As such, the intent of intuitive research is not to correlate to a cause (Corbin & Strauss, 2008). Therefore these findings are not meant to generalize for all. Rather they are to allow you, the reader, to feel the experience and hear the voices so you may generalize in your own context.

Experiences in advocating for our children. In considering people and their experiences, no two set of circumstances will ever be identical. My co-researchers and I experienced a variety of situations in our efforts to advocate for our children. There were differences among us, but many similarities as well. We all experienced positive moments

where we were pleased with the support and services provided for our children. Likewise, we all experienced events where we were less than pleased and left feeling frustrated and fed up.

I immersed myself in the raw data from each of my co-researchers, analyzing their experiences, looking for common themes. Within those common themes were indications of what worked from our perspective for the benefit of our children: services and supports which we felt addressed the needs of our children's disabilities, open lines of communication, and having someone else on the inside who knew what needed to be done and advocated for our children as much as we did.

There were negative experiences as well which we believed did not serve the best interest of our children: the delivery of or the lack of services and supports which left us frustrated, resistance to listening to our concerns and know-how in working with our children, and educators who did not understand the nature of disabilities, the needs associated with those disabilities, and the accommodations which best support those disabilities.

Within analyzing and interpreting these experiences, there appeared to be an interdependent relationship between what created positive experiences as opposed to what produced negative experiences. Such as when we felt our children's needs were being addressed, we associated it with the services and supports which were put in place. When those same services and supports were not what we believed to be the best case scenario for our children, we became frustrated and fed up with the situations which we encountered.

Happy when needs met or frustrated when services decline. Within the literature Lake and Billingsley (2000) indicated that conflict arises among parents and school officials when designing and implementing appropriate programs for students with disabilities. Parental attempts to advocate for needs based decisions while implementing programs for students with

disabilities have been stymied by structural barriers and/or disregarded by school personnel (Harry & Klingner, 2006), leaving students left in inappropriate placements or with poor levels of service delivery. A lack of available class programming options (Hess et al., 2006) has also been noted as a source of frustrations for parents when working with school IEP teams. These very situations seemed to be the root of the barriers for me and my co-researchers.

Ruby felt she could perform the tasks of her most important job, being a parent, when she and school personnel held a shared vision of what Chuck needed. She spoke of such moments in her previous state. Yet when educators, in her case middle and high school teachers, conveyed a mindset that Chuck was older and no longer in need of supports to address the long-standing effects of his autism, conflict arose. She refused to allow his services to decline, while school personnel did not in her mind, listen to her concerns. Judith was pleased once Barry finally started receiving special education services to address his weaknesses in reading and math. She later found herself frustrated as the level of services declined at the secondary level as well, where she had to push school decision makers to assign Barry to math classes, with a regular education teacher and a special education teacher co-teaching together. She encountered this battle more than once and insisted it was Chuck's least restrictive environment, because when he was being provided that level of support according to her, he flourished academically. Kate could only speak highly of Eric's therapeutic preschool services in a prior state, which were designed to meet his needs for autism and disruptive behavior disorder, though he was eligible only for services under Developmental Delay as defined by law. Unwilling to consider eligibility under Autism or Emotional and Behavioral Disorders, she too found Eric's services decline from Speech and Language Impairment, to Speech Impairment alone. Hoping for

continued classroom supports for his behavior in a 504 Plan, she became increasingly frustrated as the school promised, but had yet to develop the 504 Plan.

I had positive moments as well where Kristopher's needs were met, particularly in elementary school. I did have to advocate when the school lost a paper copy of his IEP leaving him without special education services. He was also the victim of turnover in speech therapists and limited therapy sessions. But at the time I did not know the legalities of those situations. What I did know was that when his services were provided, it addressed his academic difficulties, allowing him to meet district benchmarks. When those services were withdrawn in high school, because the school did not provide special education support for Geometry and Algebra II in regular education classes, Kristopher began to fail. Conflict developed between me and the school and as a result I sought assistance from a state compliance specialist.

Happy with open communication or frustrated when no one listens to our concerns. In 2004, lawmakers expanded the role of parents in the special education process when they re-authorized IDEA. In a study by Angell et. al. (2009), mothers of children with disabilities identified collaboration as most important for establishing trust. They related frequent and honest communication to building positive parent and school partnerships. Yet little attention has been given to the voice of families in the decision making processes (Kalyanpur & Harry, 2004).

Of particular note within my findings was communication, a theme we all found valuable. Ruby discussed how she felt like an important member of the decision making team when school personnel accepted her ideas as a parent. Following her mother's intuition, Ruby knew Chuck needed a change of placement from his self-contained setting back into regular education with assistance from a one-on-one aide. Yet she met resistance from educators on the

other side of the table. Her concerns were only heard by the school principal, who Ruby says listened and granted her request. Judith described how Barry's special education teacher in elementary school maintained constant contact and informed her when Barry was struggling and needed a change in his service delivery. She even pointed to a middle school teacher who went out of her way to call Judith and alert her when Barry was struggling with other students who were making fun of him. Judith was quick to point out that no one listened to her concerns when Barry was falling behind in his reading skills and needed to be evaluated for special education services. They listened after she had him evaluated by a private psychologist and provided proof of a learning disability. Kate too spoke of open lines of communication and backdoor conversations with teachers. With dwindling special education services, she spoke of reciprocal communication between her and Eric's teachers in order to support his behavioral needs. And even though Kate was concerned with Eric's continued difficulties regarding his behavior, Kate was still waiting for someone to understand the importance of ensuring his access to continued classroom accommodations.

My open lines of communication typically came when I worked in the same school where Kristopher attended. I experienced a certain level of professional courtesy as his teachers came to me and kept me informed. Those lines of communication closed when I no longer worked in his school. And when I did not, I found myself sending emails asking for mandated IEP Progress inserts to be sent home and an IEP meeting when he was failing. I became frustrated and felt like I was banging my head on a brick wall because no one would answer.

Happy when someone advocated from the inside or frustrated when educators did not know enough to try. Advocating for our children became a positive experience when we encountered someone much like us on the inside. Parents value positive relationships with the

people who provide services and supports for their children (Hess et al., 2006). And those who have someone to advocate for their needs are the ones who receive the most appropriate services (Fiedler, 2000). Ruby, Judith, Kate, and I all found moments of satisfaction for our children when someone on the inside took action and advocated for our sons. For Ruby, it was the principal who advocated alongside her when others were not listening. For Judith, it was an elementary special education teacher who identified Barry's needs and asked if she could adjust his services. The end result for Barry was catching up to grade level expectations in reading. Kate found an advocate on the inside in an assistant principal who understood Eric and the complexities of his behavior difficulties, while my advocate was a trusted friend inside the school system who came to Kristopher's rescue on more than one occasion.

Those advocates seemed to understand our children's disabilities, their needs, and the accommodations which best supported those needs. Yet, when educators did not know enough to understand the disability, needs, and accommodations conflict arose. Ruby encountered teachers in high school who complained about Chuck's disorganization and difficulty filling in bubbles on answer sheets. These were areas where Chuck had difficulties his entire academic career and his IEP, which Ruby provided to me, indicated he needed classroom accommodations for those very items. Judith and I both came across teachers in middle and high school who did not understand why our boys would not advocate for themselves when they needed help, even though both suffered from anxiety and internalized their feelings and to the point of withdrawing when unsure in a classroom. Kate faced a teacher who did not understand why it would be so difficult for Eric to sit on the classroom carpet, despite his difficulty with particular sensory items.

Within all our experiences along the way in various settings and states, it was our knowledge and relationships with people which made our advocating either acceptable or frustrating. The social and cultural capital theory (Bourdieu, 1986) supports this notion in that we accessed a means of social capital through the relationships we developed with other educators, who listened to our concerns and advocated from the inside. We also accessed the increasing knowledge we gained while working within the school districts to use as cultural capital in our fight to obtain a meaningful education for our children.

Our struggles and experiences are also supported by studies which focused on perceptions of special education outcomes by parents who were not also teachers. Angell et. al. (2009) found themes important to parents in establishing positive experiences were related to care toward the children and parents, frequent communication, and teacher's abilities to provide appropriate accommodations in the classroom based on their knowledge of the child's disability. The findings in this inquiry on the experiences of school district employees who advocate for their children inside the school districts where they work parallel those in the Angell, et. al. study.

Barriers to advocating for our children. According to Harry and Klingner (2006), parental advocacy within special education systems have often been curtailed by structural barriers and/or disregarded by school personnel, resulting in a different outlook on their level of satisfaction than that of educators. My co-researchers and I share common barriers which impeded our advocacy efforts. They are: our own learning curve, the conflict we experienced while serving in our dual roles as parents and educators, constraints of the system itself, and our level of knowledge of the system and our child's needs. Our perceptions of job security which

relates to the third research question in this study was a barrier as well, but will be discussed separately.

Our own learning curve. Since we were all parents with previous careers prior to entering education, we all had a lot of learning to do. Ruby a former journalist went back to school and earned a degree in education. I returned to school to earn my bachelor's degree and continued on to receive a master's degree in special education. Kate, a former soldier, earned a degree in Human Services Management. We all did this while working as aides in the same schools where our children received their educations. Judith began as a para-professional and remained so throughout Barry's education. However, she was pursuing a degree in education law at the time of this study.

At the time we joined forces with fellow educators to help our children succeed academically, we did not know what we did not know. Initially Ruby was not well versed in IDEA and found she needed to learn the language regarding Chuck's rights after she encountered her first difficult IEP meeting. Judith did not know the school system was obligated by law to conduct an evaluation once she requested one in writing. Kate did not know she had the right to insist on a new meeting date when Eric's eligibility for Developmental Delay was removed so she could be in attendance. And I did not know that it was a problem for Kristopher when the school personnel lost his IEP leaving him without his special education services.

Had we all known then what we know now, the outcomes from those experiences may have been different. The technical language within special education has been noted by parents as a barrier which has left them confused and frustrated (National Council on Disability, 1995). As I conceptualized my findings in this area, I began to visualize an explanation of what Ruby, Judith, and I potentially experienced. Since Eric was still in elementary school, Kate had not yet

gone through as many experiences at each school level, even though she could foresee concerns of a further drop in services to me once he progressed to middle school.

Considering our level of knowledge, which was initially limited and increased as our sons progressed in their years in education, I started to connect the concerns we expressed with a decline in their level of services. I began to visualize an inverse relationship over time between our growing level of knowledge of the school system and our perceptions of a decline in the amount and nature of special education services as our sons progressed from elementary to middle to high school. Figure 12 is a representation of my visualization of the relationship of our knowledge and the intersection with the special education services we perceived our children received. Initially, Ruby, Judith, and I felt the level of special education services provided for our sons was higher in elementary and declined in the years preceding high school. During those times we were generally content with our experiences, though they were not always great. While at the same time our knowledge of the school system and IDEA was limited but increased through the years prior to high school. It is the high school years where I felt we experienced the most conflict and frustration.

Conflict in dual role. Our learning curve turned to conflict in our dual roles as parents of children with disabilities and educators. For Ruby, Kate, and I, we were challenged by the need to keep the parent in us separate from our roles as educators while sitting at the IEP table. Judith felt compelled to inform parents about services and supports she felt they needed to know, but remained quiet until the parents asked. We wanted to advocate for students because it is what we did for our children. But we found ourselves restricted by district norms and policies on what we should or should not say or do. Kate would even attempt to have off-campus conversations with parents so she could pass along what she believed to be much needed information.

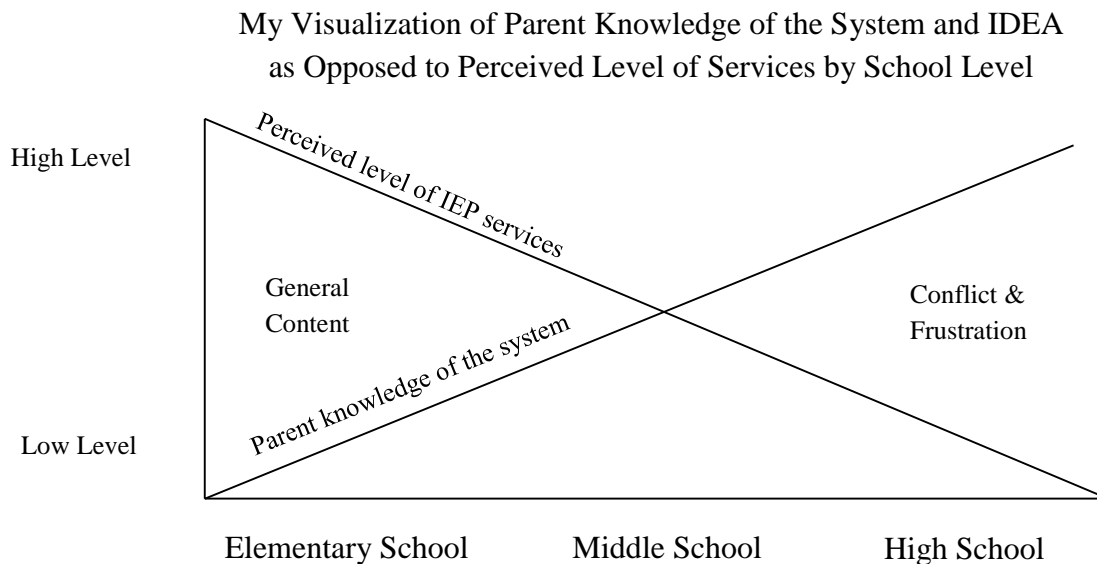


Figure 12. Relationship of our level of knowledge and the special education services of our children with disabilities.

Likewise, we also noticed while attending IEP meetings as educators that services were not issued in a uniform manner. Granted, the “I” in the IEP stands for individualized, but we all recognized that if we could “throw the biggest hissy fit on earth” (Kate) like other parents, then maybe our children would have received what we felt were appropriate services. Even though Judith did not attend IEP meetings as an educator while in her position, she still voiced frustration with being told, “Well you know how it is, you work for the district.”

Therefore, not only did we experience internal turmoil with wanting to advocate for our students as much as we did for our children, we also struggled with knowing what supports and services other students received while ours did not. Our internal conflict connects with the result of a study by Koch (2011) which revealed the struggle in the dual role of being a parent and a teacher of children with disabilities while attempting to obtain appropriate services.

Constraint of system. Knowing what supports our children needed, let alone were entitled to, was a point of conflict for us as well when we felt restrained by a system lacking in options. Ruby was met with “we don’t have that” when she registered Chuck for high school with an IEP written by the middle school stating he needed resource classes in high school. She said she heard the words, “we can’t, we won’t, we don’t” numerous times in various locations throughout Chuck’s education, leaving her feeling frustrated. I encountered a system which also restricted the available math classes for Kristopher. Upon our return to the district where he finished his remaining years in the public school system, Kristopher was to enroll in Geometry, and per his IEP, with support provided by a special education teacher in a regular education class. The school did not have that structure in place. Instead, they placed him on consultative status with no direct special education support and he failed. Judith increasingly became angry with the district’s expectations that all classes remain on the same pacing calendar. She contended that Barry needed adjusted pacing, as did other students, and he benefitted by learning math at a slower pace. The adjusted pace was a proven accommodation for Barry. According to Judith, when he was given that right, he scored the highest in the district on the end of the year test. Issues related to the lack of available class programming options are also described as a point of contention for parents of children with disabilities by Hess et. al. (2006). This barrier for us was no different.

Kate’s situation was somewhat unlike the rest of us, but she too spoke of feeling constrained by a system with little options. She did not want Eric to be found eligible under ASD or EBD to address his behavior concerns. Even though Eric had a diagnosis under Autism Spectrum Disorders, she was concerned with the long-term implications of such a label. Yet she felt she had no other options as Eric lost other areas of eligibility over time which gave him

access to classroom and testing accommodations, and the 504 Plan which had been promised had yet to materialize.

It is interesting to note previous research studies the last two decades (e.g., Leiter & Krauss, 2004; Leyser & Kirk, 2004; Ryndack et al., 2001; Soodak & Erwin, 2000) where authors have reported feelings of frustration on the part of parents when attempting to secure their child's least restrictive environment in inclusive settings. Yet for those of us in this study, we found ourselves frustrated when the constraints of the system forced school personnel to take LRE too far up the continuum in our minds and not provide enough supports for our children. Ruby heard "we can't" when Chuck needed his IEP assigned resources classes as she registered him for high school. He did not receive all the resource services which were outlined and she placed him in a charter school after just one semester because he was struggling too much. On two separate occasions, Judith had to insist the middle and high schools return Barry to math classes with co-teachers after they placed him in classrooms without special education support at the beginning of the year. I had to reach out to a state compliance specialist and indirectly force the high school to provide special education support in Geometry and Algebra II when Kristopher failed without those supports. To us the constraints of the system which were designed to promote inclusion interfered with needs based decisions, limiting the success of our boys and forcing further advocacy efforts on our parts.

Our knowledge versus other's lack of knowledge. Our lack of knowledge early in our careers was also a barrier in advocating for our children as we did not know enough to advocate when IEPs were lost, schools declined requests for evaluations or they maintained the meetings must still be held when the parent could not attend, and when more restrictive environments were being requested. But when we did learn, our knowledge of the system and the needs of our

children began to clash with what others did not know, nor understand. Kate talked about her challenge with administrators who sat in IEP meetings, yet did not know about special education. Ruby was dumbfounded when she encountered a special education teacher who did not understand the nature of autism or the associated characteristics. I encountered a guidance counselor who was advising my son incorrectly, without understanding he was entitled to a special education waiver if he did not pass the state standardized assessment and that the waiver would not impact his desire to enlist in the military. Judith even had to point out to the IEP team at Barry's school that they were not allowed to change his services without notifying her.

These were just a few of several examples from Ruby, Judith, Kate, and me. To us, it just seemed on many occasions that we knew more than some of the educators who were working with our children. When that happened, it not only forced us into action as advocates, it left us annoyed and questioning the abilities of those on the other side. Not surprising in relation to the findings in this study, Hess et. al. (2006) identified ill-prepared special education teachers as a source of discontent among parents.

As a whole, the barriers we all felt we encountered while advocating for our children were not what we were expecting when we joined forces and became educators within the same school systems which provided services for our children. In a way, we all believed we were doing it for the sake of our children by learning how to become educators and learning how the system of special education functioned. We never expected our roles as educators to contend with that of being parents. Nor did we expect the system, which we became a part of, to limit the rights of our children through the very actions of the people who represent it. Parents within the literature have reported feeling "disenfranchised and alienated" (Kroth & Edge, 1997, p. 14) by the systems which are designed to help their children. We were no different, even though we

became a part of that system. What might be different is our frustration because as insiders we now carry a certain level of knowledge which allows us to understand the law and how services and situations should be addressed regarding the needs of our children. We may know what many other parents do not know, but when we experience similar barriers as others, we feel extremely frustrated because we know it should not happen that way.

Perceptions of job security on advocacy. The third research question associated with this inquiry focused on the perceptions of job security when we advocated for the rights of our children. For two of us, we hold a perception that we must be careful in the manner which we advocate. For the other two, their perception was a reality. Both Ruby and Judith talked candidly about their fear of losing their job because of the advocating they had to do for Chuck and Barry. But they both shared separate experiences of those fears being validated when they were questioned by their principals for fighting for the services of their children who were being served in different locations. Both were left to wonder who notified their principal and why that would happen to begin with when they both called contact numbers provided by the district for parents to access. Kate never experienced such situations, but she spoke about the fear of losing her job if she made waves advocating for Eric. I too was concerned about my need to advocate for Kristopher. In two different situations in two different districts I found myself questioning the impact on me. I was concerned so much so that I specifically asked a principal and a district administrator about the impact on my position or future positions.

This perceived fear, shared by us all, essentially served as a barrier in our advocacy as parents because we contemplated the outcomes on our positions as educators. For Ruby and Kate, it also limited the extent to which they advocated for their students as well. Ruby talked about role conflict in relation to her perceptions of job security. She found herself wanting to

advocate for other students while attending IEP meetings, yet questioned the resulting consequences of speaking up. Kate questioned those consequences as well. Instead she offered suggestions to parents away from IEP meetings and off school campus where she was free from potential repercussions on her position as a teacher.

Lawrence (1995) identified differences in perspectives between parents and professionals when it comes to the role of parents in special education. For Ruby, Judith, Kate, and me, those roles are combined, yet create a level of conflict as we attempt to advocate for our children. More so, that internal conflict has left us wondering about the potential for external strife while working within school districts where we have encountered many barriers. Those barriers seemingly limit how well we *fight within* the system and fight for the rights of our children.

Evolution as advocates. Our experiences within the school districts where we worked created multiple states of emotion, perhaps none more pronounced than the feeling of being frustrated. What resulted from those feelings are mothers who have not walked away and have maintained persistency in attempting to ensure our children received the rights afforded to them within their IEPs.

For some of us, our roles as parents and teachers became one, giving us a defined sense of identity as advocates. We became passionate and committed to not only our children, but the other children who touched our lives. We advocated inside our classrooms, inside IEP meetings, and outside the walls of our schools. For the three of us who sat in IEP meetings serving as educators, Ruby, Kate, and me, we found that we could identify with the parents and the children who were essentially our customers. Kate described how she would try to do what she knew was right for her students by means of seeking needs based decision making from the IEP team. Ruby illustrated how her passion for children with disabilities impacted the decisions she made

as a teacher, not seeing it as her job, but as her life's passion. I too used my experiences in helping Kristopher grow in relation to his challenges as an individual to connect with my students, helping them feel successful despite their struggles. And Judith shared her experiences as a parent with other parents she came into contact with while working within her role as a paraprofessional in her special education department.

And for each of my co-researchers and me, our advocacy efforts appeared to focus in a particular direction. We focused on channeling our energy to *right the wrongs* experienced by our children. Ruby spoke extensively about her claims that Chuck was not receiving all his accommodations at the middle and high school levels, mostly because teachers did not understand how those accommodations associated with his needs or that teachers no longer felt he was in need because of his age. As a result, she indicated how she makes sure her students receive all their accommodations. She even accommodates students who have not been identified as needing special education services, but demonstrate a need regardless. Kate focuses on maintaining open lines of communication with parents and providing data to prove her students still need specific supports. It was the supports which diminished for Eric leaving him at a loss for accommodations to assist with his behavioral needs and the communication with teachers which Kate has relied on to aide Eric in the classroom since those supports had been withdrawn. Judith has focused on helping parents understand the inner workings of the school system because of the difficulty she has experienced herself when school personnel expected her to understand the systematic barriers and relinquish her requests that they provide Barry what he needed.

Amid all the frustrations and fighting against ourselves and the system is a passion which keeps each of us focused and driven toward achieving success in attaining what we believe is

right for our children, so they may experience success for themselves. Underlying that passion is a sense of guilt which fuels our fire. Ruby, Kate, and I carry these feelings. Ruby felt guilty as she referenced whether she provided enough support for Chuck at home while she advocated for his needs in school. She conveyed the message of thinking she had not done enough even though she had spent countless hours advocating for her son. Her worry whether she had done a good enough job propels her as a parent and as a teacher. Kate spoke numerous times of failing Eric, beginning with being called a bad parent by a doctor, despite years of searching for answers to explain Eric's challenges. She seemed to carry that hurtful experience with her each passing day, not letting go. It is her driving force. The heuristic process allowed me to open up feelings which I had buried and uncover previously unconscious, yet similar perceptions of guilt. My choice making as an unknowing mother-to-be motivated me to extremes and find the means to help Kristopher and also carry on in the field of special education on his behalf.

Whether Ruby, Judith, Kate, and I advocated for our sons or advocated for the students we came across, none of us could ever foresee the identities which we have taken on today. None of us dreamed of becoming a parent as an educator, and certainly none of us ever imagined evolving into something much more, a parent as an advocate.

Evolution of me, the parent, teacher, researcher, and advocate. *The Fight Within* clearly defines to me the battles I experienced in advocating for my own son within the same district where I worked. It was a title I came up with early in the research process, well before data collection and meaning making. The title rolled right off my tongue as soon as I embarked on the long journey in this project. It fit, a little too easily, or so I thought. At the time there was much more to the name, and it had much more to do with me, than anything or anyone else. It had to do with my own conflict, which was once hidden from view. Not but a couple years prior,

I had a professor in my doctoral program who indicated to me on more than one occasion that I seemed conflicted whenever I approached the subject of writing about my experience. I listened, but never understood. What did she mean? What did she see in me that made her say that? I knew I was passionate about my purpose for being in the doctoral program. I wanted to help my son and help kids like him who found that academics did not come easy. But once I began to make meaning of the overall experience, I realized *The Fight Within* initially meant my conflict within me and the guilt I did not realize I was carrying. Throughout the course of this study, *The Fight Within* came to mean much more than me. It signified us all, mothers and sons.

My co-researchers and I evolved from simply mothers of four young men into advocates for those young men and our students. It is and was our experience. For me, my experience has gone beyond the initial conceptualization of this inquiry. It began with a wondering question, and has ended with my own evolution of who I am as a parent, an educator, and a researcher, all for children with disabilities. Prior to entering into this study I recognized the unique role I filled. What I did not recognize was what truly brought me to this point to begin with.

Crastnopol (2009) speaks of raising a child with an invisible disability, a learning disability. She discusses the hidden appearance of LD and how time after time, there is re-experiencing, re-explaining, and re-digesting to each new teacher, in each new setting. As I read her passionate story, I myself have re-experienced those identical moments. Year after year, Kristopher had to meet his new teacher, ahead of the rest. We had to spend the time to get him to speak to her. Were it not for those opportunities, so much more time would be lost as the school year progressed.

Little by little over the remaining years we had to take this pro-active approach less often, while having to respond and advocate for his needs through his IEP more often. He and I created

new experiences during those moments. And as the negative experiences began to build, we re-experienced, re-explained, and re-digested time and time again. Upon his very last IEP meeting, which occurred during the course of this study, I noted in my journal the extreme level of anxiety I felt prior to entering that meeting for the very last time as a parent. I should have been excited. Instead I wrote, “I think I’m just over having to fight. I’m sick of pushing for obtaining what he needs. I just want it all to end!!!” Clearly, I was tired of re-experiencing frustrations in fighting the system.

At the time of that IEP meeting, I was immersed in the interview process with Ruby. And at the time, little did I realize, I was going to re-experience my frustrations with the system as I interviewed her, then moved on to interview Judith, and eventually Kate. I re-experienced my own feelings each and every time, particularly with Ruby as her experiences with Chuck more closely matched those of my own and Kristopher. I projected this possibility in Chapter Three as I discussed how qualitative research topics are emotionally laden and come at a price for the researcher (Rager, 2005). This was exactly the case for me. And it worsened as I moved closer and closer to having to finally come to terms with pieces of my past and write down my story in an heuristic attempt to understand the meaning of who I was as a parent, a teacher, a researcher, and an advocate. I did not know that those pieces were the ones which defined me and everything I had worked to become in special education.

Throughout the meaning making experience, I struggled with the realization of guilt as the underlying meaning. I had buried my feelings in order to stay strong and focus on what I could do to protect Kristopher and ease his academic difficulties. Fleet (2012) discusses how pieces of one’s past will not remain buried forever. “If you skip over any part of your life, at some point in time, you will go back to retrieve it” (pg. 15). When I did, it was painful. Pieces

of my past which I so badly wanted to stay there were staring me in the face. It all made sense to me why I had become a teacher, researcher, and advocate. I had to admit it to myself, and now I must admit it to the one who has inspired me to go this far. And that is a moment I dread.

Ironically to me, the personal feelings I encountered in the final weeks of data collection accompanied me through an illumination and explication phase which embodied the entire heuristic process of this study, that of the culminating creative synthesis. Since the intention of this inquiry was to connect experiences with the multiple sets of memories, emotions, and actions underlying my story and those of my co-researchers, I experienced an unmistakable awakening of consciousness, allowing me to produce a poem with little thought or effort using the very words which were spoken to me by Ruby, Judith, and Kate.

Nevertheless, the completion of this study does not complete the heuristic process for me. It has helped me identify my purpose in everything I had accomplished in education and ascertain what drove me to continue with this study while maintaining a full-time job as a teacher, no matter the immense hours of data collection, analysis, and presentation and the numerous sleepless nights. As it turned out, this entire journey has been personal. It was personal when I became a teacher, it was personal every time I had to advocate for Kristopher, and it was personal when I ventured out on the journey to become a researcher. It is and will always be personal, because I now know why I pushed to protect him academically and fight for his meaningful education.

Implications for Practice

In addition to helping me understand my lived experience in relation to other parents of students with disabilities who are parents like me, is the opportunity to provide perspectives from a unique group of individuals, while at the same time attempting to inform the field of special

education and the institutions which guide the practice of educating children. Research on advocacy in educational decision making indicates that parents want their voices heard. “If we only give voice to the idea of empowerment without taking action, we are not truly providing families with opportunities to become equal partners in decision making for their children” (Hess et al., 2006, pg.156).

Ruby, Judith, Kate, and I are no different. I asked each of my co-researchers what the district could do to improve relations with parents like us. And each one responded with the same answer. We want someone to listen to our voices as we advocate for our boys. “I think that they have to listen and fully..., equate that parent as an equal member of the IEP team” (Ruby). After all, the findings from this study indicate that when no one listens, we become frustrated, something which has already been identified within the literature as a point of contention for parents (Angell, Stoner, & Sheldon, 2009). Therefore this places an added level of importance on communication and collaboration among individual educators and the districts themselves.

Yet we are not just parents of children with disabilities. We are educators as well. Thus, we have more to offer in speaking to us. We live both sides and we understand both sides. Kate suggested districts create forums for employees like us so as to create a collective voice and hear what we have to say. Providing such an opportunity would allow the district to identify areas of improvement, because if we *insiders* are confronted with challenges within the system, then one can infer that it is equally as hard for parents on the outside, or potentially even worse.

In considering the negative experiences and the barriers which impeded our ability to advocate successfully for Chuck, Barry, Eric, and Kristopher, there are identifiable flaws which could leave districts open for potential litigation and due process hearings associated with

violations of IDEA, such as teachers not providing accommodations in the classroom, schools not performing evaluations after receiving written notice from the parents, and IEP team members informing a parent that an eligibility meeting cannot be rescheduled due to a conflict. Whether they were teachers, administrators, or other school level personnel, my co-researchers and I encountered educators who did not know the law and did not know how to work with children with disabilities. Our level of knowledge not only conflicted with the lack of knowledge from other educators, it also presented scenarios which could have been pursued under the procedural safeguards which Congress included when it enacted P.L. 94-142, the Education for All Handicapped Children Act of 1975 (Yell, 2012).

Even though parents in a study conducted by Duquette et. al. (2011) indicated the threat of legal action would not be effective in pushing for special education services, it is imperative for districts to evaluate the scenarios which may leave them open to legal action and become proactive. Improving professional development to address special education practices and policies as well as district level trainings focused on collaboration with parents of students with disabilities would be a step toward raising knowledge and understanding among those in the education ranks. Educator misunderstandings or lack of awareness has been linked to failed collaboration between educators and parents (Hess et al., 2006). Therefore raising awareness of parental concerns and the legalities associated in working with students with disabilities could lead to more informed educators and the cultivation of better relations with parents.

Assumptions of the Researcher

I am who I am, a proud mother of a child with a disability, a passionate educator of children with disabilities, and a purposeful researcher of children with disabilities. I am all three. There is no separation. In qualitative inquiry such as this, the researcher herself is the primary

instrument. I defined my role within this study in Chapter Three as that of a researcher/participant rather than an objective observer. I freely admit I have certain innate biases associated with who I am. According to Vandembroucke (1998), one will never escape subjectivity when advancing new ideas. Hence, biases may be limited, but not eliminated.

I have attempted to limit my biases as I carried out the research phases, searching for defining themes in the experiences of my co-researchers and their sons, and the deeper meaning underlying my own experience in advocating for Kristopher. In order to do so, I triangulated my data using multiple sources of evidence, provided opportunities for my co-researchers to member check their interview transcriptions and individual written depictions, engaged in reflection through my reflexive journal, and attempted to remain as transparent as possible. I also remained cognizant of my multiple roles as I progressed through each phase of data collection, analysis, and presentation of each case. For the sake of ensuring my interpretations represented each co-researcher's lived experience, I also met with two separate peer reviewers, an educator and a researcher, to share the details and themes of each case and the culminating group depiction. The last remaining step in reducing my bias involved allowing the reader to hear the very words spoken by my co-researchers. Nevertheless, there remains a certain degree of interpretive nature to uncovering meaning within heuristic research. Therefore my subjectivity as that of a parent, educator, and researcher knowingly serves as a delimitation in this study.

DeLimitations and Directions for Future Research

The delimitations within this inquiry provide opportunities for further research in relation to the topic of this study. These areas include expansion in the number of participants, differentiation among the participants in the bounded case, evaluation of the extent to which accommodations are delivered within elementary and secondary school settings, and the

perceptions among parents and educators of how accommodations and services are delivered and whether it meet the needs of students with disabilities.

Increase the number of participants. First and foremost, future research on this topic needs to focus on expanding the number of participants. Due to the nature of the time limitations associated with completing my course of study in the doctoral program, I limited the number of participants to a manageable number, while maintaining a full-time job as an educator in an elementary setting and continuing to raise a family. Stake (2008) stated that cases are opportunities to develop greater insight into a phenomenon so as to allow a researcher to learn as much as possible in relation to the research question(s). Therefore a large sample would not have afforded me the time and resources to conduct an intensive study and discern the themes as I did. Selecting only three co-researchers allowed me to immerse myself in the volumes of transcripts, documents, and journal notes and to develop a firm understanding of the themes and meanings underlying each case. The three cases took between six to eight weeks each, consuming extensive overnight hours, weekends, holidays, and extra days off of work, beginning with the first interview through the completion of the individual depictions. The overall data collection, analysis, and presentation phases for all three cases lasted nearly six months.

Even though the purpose of case study, according to Stake (1994), is to represent the case and not the world, this study only incorporates a limited number of voices. It was my intent to investigate whether Kristopher and I were alone in our struggles within the school system. I discovered after spending time studying three other parents who were educators like me, the answer is no, we were not alone. However, I wondered the extent to which such experiences impacted the numerous other parents of children with disabilities who advocated from inside the school system. As I carried out this study, my co-researchers themselves provided me with

names of more parents who were educators and advocating for the rights of their children under IDEA. Further development would need to include more cases, allowing a researcher to evaluate whether the extent of the experiences of school district employees who advocate for their own children impacts a larger section than I previously imagined.

Differentiate participants within the study. As I embarked on this journey to uncover the answers to my own wondering questions, I set forth criteria for the selection of cases to explore in this study. I wanted my co-researchers initial experience to be as closely aligned as my own, making us all unique in respect to the defining characteristics of this study. I wanted them to be current school district employees within any school district in the southeast United States. They also had to have a child with a disability, currently or previously served through an IEP in any year following the enactment of IDEA 1990. And the services of the IEP had to have occurred within the same school district where the co-researchers work or worked.

Using purposive, critical case sampling, I selected three co-researchers who were already known to me. Their circumstances were somewhat known to me as well, more so for Ruby and Judith. And they all met my criteria. A criteria which Patton (1980) suggests leads to the greatest amount of information and development of knowledge. Because I knew these participants in our working environments, but did not know them in the sense of their backgrounds and their journey to becoming educators, I did not foresee that we would all have had previous careers. Nor did I know that we would all have begun as para-professionals while our children were in elementary school. And I never could have predicted that each and every one of us planned to alter our chosen paths in the near future. Therefore, my co-researchers were much more like me than planned and anticipated.

In order to gain a better understanding of the scope of experiences of me and my co-researchers, future research would need to encapsulate educators who were already district employees prior to their children receiving special education services. My co-researchers and I had never intended to become educators. But our intense desire to help our own struggling learners motivated us to make life changing decisions. Therefore it is unknown if our calling altered the degree to which we advocated within the school system and whether our advocacy led to distinctive experiences.

Also in taking a differentiated set of co-researchers into consideration for future research, one would need to include building level and district level administrators. Ruby, Judith, Kate and I all carried a perceived degree of impact our advocacy would potentially create on our job security. Judith spoke of the fear that advocating may have on advancement within the district. I myself worried whether this study alone would impact future opportunities within the district where I worked. Building level and district level administrators already hold advanced positions beyond that of teachers. Therefore it would be relevant to research whether such educators had different experiences in advocating for their children with disabilities, and/or whether they would even be willing to tell their own stories. At the commencement of this study, a name of an assistant principal was shared with me as someone who fit my criteria, but I was informed that person would not talk to me for this study.

Accommodations and services in elementary and secondary settings. Within mine, Ruby's, and Judith's stories were experiences where we struggled with accommodations not being provided for our sons and perceptions of a decline in the degree in special education services between elementary schools to middle and high schools. Even though we all had negative experiences in elementary school, we believed our more frustrating situations occurred

in secondary settings. Ruby and Judith related the difference to higher expectations as a result of the students' age, regardless of confounding characteristics of the disabilities. Judith wondered whether the difference had to do with the number of teachers involved in her son's education at the secondary level. Regardless, we all shared instances where Chuck, Barry, and Kristopher were not receiving accommodations in secondary level settings. We also all perceived the supports provided in elementary school exceeded those provided in later years.

Therefore, future research should focus on whether there is a difference in how accommodations and special education services are provided at the elementary level as opposed to the secondary level. Students at the middle and high school level typically have more teachers than students in elementary school. They may also have more than one special education teacher, such as one for reading/language arts, one for math, and possibly others for science and social studies. Due to the nature of such a framework, it may be difficult for teachers to continually communicate student needs, particularly for students in special education whose needs require unique skills and instructional approaches.

Differences in perceptions among parents and educators. Also in relation to accommodations and service delivery worthy of future research would be an evaluation on the perceptions among parents and whether their understandings differed from the perceptions of educators. Ruby and Kate spoke of internal conflicts within their roles as parents and educators, particularly while serving as a teacher during IEP meetings with parents. They solved their dilemmas with *off the record* conversations. I too have participated in meetings and felt restricted in my role as a school district employee, bound by institutional forces which limited what I could and could not say. Mawhinney and Smrekar (1996) found that teachers want to advocate but felt restricted in their efforts by policies or institutional structure.

Those of us in this study know the inner workings of school districts and we all also know the law and what children with disabilities are entitled to receive. To us, the parents who are not on the inside may not know any different if we did not provide them something other to consider. This clash within our being indicates parents may perceive special education services a certain way, while those who work on the inside perceive it another. Valle and Connor (2010) reported a divide between what parents expect regarding their children's special education services and what may occur. Lawrence (1995) identified varied attitudes between parents and professionals regarding perspectives on a parent's role in special education. Further investigating this phenomenon with which we have struggled would give credence to our conflict and identify whether those on the inside perceive the accommodations and services which are delivered any differently than the parents of the children who receive them.

Summary and Conclusion

Within this inquiry were the voices of four mothers of children with disabilities who were also educators as well as advocates for four young men, Chuck, Barry, Eric, and Kristopher. The intent was to uncover their experiences, the barriers they faced, and the perceptions they held regarding their job security in relation to their advocacy. The intent was also to answer whether mine and Kristopher's *fight within* the school system was a fight of our own or a fight shared by others. After listening and analyzing the experiences of my co-researchers, I can answer that we were not alone.

Horowitz et. al. (2007) called for researchers to study the perceptions of parents whose children had difficulties in the special education process. This study provides a glimpse of those perceptions. As a group, we perceived experiences which worked for the benefit of our children: moments when the special education needs of our children were met, when educators listened

and became collaborators with us as IEP team members, and when someone on the inside advocated for our children as much as we did. We also perceived experiences which did not work and negatively impacted the success of our children: moments when the special education services did not meet the needs of our children, when educators did not heed our concerns, and when educators were inattentive to the needs and accommodations which supported our children in the classroom.

Among the findings were also indications of barriers which adversely impacted our ability to advocate on children's behalf. We struggled with learning the language and the laws associated with special education upon our entrance into the teaching profession. Once we knew enough to advocate, we were challenged by our double and triple identities and the feelings of advocating for our children while serving our employers. We encountered institutional barriers and district policies which limited options for our children and we encountered educators who were not as versed in special education as us.

These barriers are nothing new within the literature, except the barrier like no other. And that is the barrier of our own jobs. The very jobs which we took so we could better advocate for our children. The jobs which we feared we could lose should we push too hard and advocate for too much. In the end, our identities as parents, educators, and advocate became our nemesis. Our resulting identity conflict is best explained by the theory of responsible advocacy which was discussed in Chapter One. The theory outlines the ethical dilemma which results from advocacy and social responsibility. It highlights the professional balance which must occur when one is held accountable to their employer by their own social conscience while at the same time serving as an advocate.

Even though Ruby, Judith, Kate, and I struggled with advocating while remaining socially responsible to our school districts, we still possess a belief we can exert a certain level of influence in the educational outcomes of our boys as supported within the social cognitive theory of parental efficacy. Bandura (1997) argues there are underlying forces of parental practices which promote a change in the courses of action parents take as they attempt to influence their child's educational outcomes. As reported within the key findings of this inquiry is an underlying sense of guilt which motivates my co-researchers and me. Those feelings continued our *fight within* as we hoped to make a difference, despite the barriers we encountered, for our children and many others.

Parents of children with disabilities respond in particular ways to the needs of their children as outlined in the parental development theory by Galinsky (1981). The theory explains how Ruby, Judith, Kate, and I have all made cognitive and psychosocial adjustments to advocate for appropriate services to address the needs of our boys. Within the theory, parents also “continually adapt to changing circumstances and needs of the child” (Hughes, 1999, p. 271). When our advocacy efforts were successful, we were able to let educators take over while we stayed on the outside. When those efforts were not as successful, we kept fighting and used our knowledge of the disability and the inner workings of the system to advocate further.

Finally, advocacy of parents like us who attempt to promote educational success for their children using acquired knowledge and educated language is supported by the social and cultural capital theory of Pierre Bourdieu (1986). Using resources linked to networks of other educators, advocacy groups, and other parents of children with disabilities, my co-researchers and I used what we learned to pursue action without accessing our own economic capital.

Previous research indicated early parental involvement is beneficial in enhancing a child's long-term academic outcomes beyond the high school years (Flouri, 2006; Fan & Chen, 2001). For the voices within this study, our early parental involvement came in the form of becoming one with the system which educated our sons. That parental involvement quickly began to extend for all of us beyond our own flesh and blood. Through the experiences which we encountered, we learned for ourselves and we learned for others. We learned we had to keep on fighting from within. We did what other parents have been noted within the literature to suggest, and that is to never give up when met with challenges (Katz-Plotkin, 2009). It not only defined what we did, it defined who we became, and who we are. We are advocates. Advocates for our own children and the children we educate.

Parents access advocacy when they realize their children have rights under the laws associated with IDEA (Alper, Schloss, & Schloss, 1995; Heiman & Berger, 2008; Duquette, Fullarton, Orders, & Robertson-Grewal, 2011). As such, four types of advocacy used by parents have been identified by Trainor (2010): the *Intuitive Advocate*, the *Disability Expert*, the *Strategist*, and the *Change Agent*. Ruby, Judith, Kate, and I are all *Intuitive Advocates*. Such advocates have a keen sense in understanding the needs and strengths of their children. My co-researchers and I believe we know what our children need in order to succeed in their academic settings. And educator attempts to meet those needs determines whether our advocating within the system emerges in a positive experience or not.

We are also the *Disability Experts*. These advocates are defined by Trainor (2010) as those who access necessary information and organizations to become experts in their child's disability. The information gleaned is then employed for advocacy efforts. Ruby, Judith, Kate, and I know the disabilities which impact our sons. Chuck and Eric are diagnosed with Autism

Spectrum Disorder. Barry and Kristopher have Specific Learning Disabilities. We mothers know how those disabilities impact the learning of our boys. It is why Ruby knows Chuck needs assistance filling in bubbles on testing sheets; why Judith knows Barry needs yellow paper to process the information he sees; why Kate knows how to identify the triggers which cause Eric's behavioral outbursts; and why I know Kristopher needs guided notes rather than attempting to listen, identify, and scribe the necessary information himself during instruction.

Not only are we able to advocate using our knowledge of their disabilities and their individually associated needs, we also are able to access what we know of IDEA and the rights afforded to Chuck, Barry, Eric, and Kristopher. Parents who acquire such a high degree of knowledge regarding the services and supports within the IEP are referred to by Trainor (2010) as the *Strategist*. These parents perceive they are not well liked because they are able to hold teachers accountable when services and supports are not carried out.

The final advocate identified by Trainor (2010) is the *Change Agent*. These parents experience frustration with the system, yet advocate for improving education for those with disabilities because they understand special education and the function of educational systems. I believe we are all *Change Agents* as well, though our advocacy for improving the system is squelched by our belief that there is a limit to how hard we can push without impacting our jobs.

Our knowledge of our children and the laws which governed their education defines us as all of Trainor's (2010) types of parental advocates. As Intuitive Agents, we have a keen sense of the needs and strengths of our children in order to develop a course of action in our advocacy. As Disability Experts, we understand the ins and outs of our sons' disabilities so we can advocate for appropriate services. As Strategists, we know IDEA and the rights afforded. And

as Change Agents, we understand the function of educational systems and are willing to advocate for improvements for those with disabilities. We are a unique blend.

The *fight within* is not only a title, it is a title which holds inner meaning, beginning with a child; a child, who entered life with odds not compared to the rest; a child, who had to struggle to learn and fight for every gain; a child with a mother who, driven by an inner sense of guilt in what life had presented, joined the fight to educate, yet found conflict within the system, within her own being; and a system, which unintentionally forced her to advocate, for her son and the many other children who touched her life. The *fight within* represents the journey of three mothers and three children, Ruby and Chuck, Judith and Barry, and Kate and Eric. It also represents the journey of me and Kristopher. Not only has our journey been about the struggles we encountered in his education, it has also been about fulfilling a promise to research the struggles of other children like him. This culmination of this study and his graduation from the public school system completes our *fight within*.

In the end, this research is about paying the price: the price one pays to hold true to a purpose and guarantee that no matter what it takes, how hard you work, and how hard you fight, success will be determined in making sure the children we represent are not left behind. It is *The Fight Within*.

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Appendices

Appendix A: Informed Consent to Participate in Research

Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

IRB Study # Pro 00013966

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, and other important information about the study are listed below.

We are asking you to take part in a research study called:

The Fight Within: Experiences of School District Employees Who Advocate for the Rights of Their Own Children with Disabilities inside the Districts Where They Work, a Heuristic Case Study.

The person who is in charge of this research study is Keri Haley. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. Mrs. Haley is being guided in this research by University of South Florida Professor, David Allsopp, Ph.D.

The research will be conducted at neutral location, such as a library, and will be determined by the participant and researcher.

Purpose of the study

The purpose of this study is to:

- Explore the experiences of parents of children with disabilities who advocate for their children inside the school district where they work.
- This study is also being conducted as a dissertation requirement pursuant to Mrs. Haley's completion of a Ph.D. in Special Education Curriculum and Instruction.

Study Procedures

If you take part in this study, you will be asked to:

- Participate in three separate, interview sessions over the course of a three week period, with each interview lasting 60-90 minutes. The interviews will be recorded and take place at a mutually agreed upon location. You will also be asked to review the transcripts of each interview for accuracy, as well as read and review the written case depiction after it is developed to verify its authenticity.
- Complete a pre-interview questionnaire which will only take a few minutes to complete and will be given to you upon signed consent.
- Provide any documents (e.g., IEPs, psychological reports, parent/teacher conference forms, emails, etc.) you choose to share which offer examples of your experiences in advocating for your child.
- Use a journal to write down thoughts or memories you wish to share following the interview sessions.
- Your name will not appear on the questionnaire so you may remain anonymous. You will be asked to choose your own pseudonym which will be used on all documentation throughout the course of the study.
- This study may be published following completion. If it is, your name will **not** be included, nor any information which identify you.

Total Number of Participants

No more than four adults will participate in this study.

Alternatives

You do not have to participate in this research study and may decline consent.

Benefits

We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort

This research is considered to be of minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You will receive no payment or other compensation for taking part in this study.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely

confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, study coordinator, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure the study is being done in the right way. They also need to make sure that your rights are being protected for your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss call Keri Haley, 813-716-0071, or email, kchaley@mail.usf.edu.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

- What the study is about;
- What procedures will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent

Date

Printed Name of Person Obtaining Informed Consent

Appendix B: IRB Approval Letter



RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

September 23, 2013

Keri Haley
Special Education
Tampa, FL 33612

RE: Expedited Approval for Initial Review

IRB#: Pro00013966

Title: The Fight Within: Experiences of School District Employees Who Advocate for the Rights of Their Own Children with Disabilities Inside the Districts Where They Work, a Heuristic Case Study

Study Approval Period: 9/23/2013 to 9/23/2014

Dear Ms. Haley:

On 9/23/2013, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

Approved

Item(s): Protocol

Document(s):

[IRB Protocols ver 1 9-11-13](#)

Consent/Assent Document(s)*:

[Adult Consent Form version 1 9-11-13.pdf](#)

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2)

involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR

56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-

5638. Sincerely,

A handwritten signature in black ink, appearing to read 'Kristen Salomon', followed by a horizontal line.

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board

Appendix C: Interview Protocols

1st Interview (Oral History style)

- 1) Describe your experiences in raising a child with a disability and advocating for his/her educational needs?

Follow up: Tell me about the positive experience in advocating for your child.

Follow up: Tell me about any challenges you faced in advocating for your child.

Follow up: Why was advocating a positive experience? Why was it a challenge?

Follow up: How did you approach the positive experiences? How did you approach the challenges?

Follow up: Who did you turn to for support as you advocated for your child?

Follow up: How did you feel during both the positive and challenging times?

Follow up: What benefits do you feel your child experienced as a result of your advocacy?

Follow up for those who entered education later: Explain what brought you into education.

- 2) Is there anything else you would like to share which we haven't covered in our conversations?
-
-

2nd Interview (Parent Perspective)

- 1) Why do you think it has been so important for you to advocate for your child?

Follow up for those who were educators as a first profession: When did your advocacy efforts begin?

Follow up: How were you able to access insider knowledge of the school system when advocating for your child?

Follow up for those working in special education: How did you perceive your knowledge on the Individuals with Disabilities Education Act in relation to your advocacy? Did it help? Did it hinder your efforts? Why?

Follow up: What networks or other resources have you accessed to strengthen your advocacy efforts?

- 2) What are your thoughts on advocating for your child within the school district where you work?

Follow up: In your opinion, did your position in the school district help, hinder, or have no effect on the degree of your advocacy for your child? How?

Follow up: How did you feel in regards to your position within the school district and your advocacy efforts?

Follow up: Did you feel like you had to push hard for what your child needed? If so, can you identify what your biggest concern(s) was/were about this?

- 3) What positives concerns, if any, did/do you have regarding your position as a _____ and having to advocate?

Follow up: How does this impact what you say and do regarding your advocacy?

Follow up: Do you believe it would be any different if you were not a school district employee when you had to advocate? How so?

- 4) Describe your greatest achievement in advocating for your child's educational needs.

Follow up: What types of efforts on your part did it take for you to gain that achievement?

Follow up: Do you feel those same efforts were helpful in later attempts to advocate?

Why/why not?

- 5) How would you describe the relationships between you and your child's school(s)? And teachers?

Follow up: What, if any, barriers did you encounter?

Follow up: How did these experiences make you feel?

Follow up: What recommendations would you have to improve relationships between parents of children with disabilities and school district employees.

Follow up: What, if any, benefits did you encounter?

Follow up: How did these experiences make you feel?

- 6) Talk about any experiences where you felt the school had your child's best interest at heart.

Follow up: What would you say was the difference between that experience and more challenging experiences?

Follow up: Based on your positive experiences and the more challenging ones, how do you think schools could better work with parents?

- 7) Is there anything else you would like to share which we haven't covered in our conversations?
-

3rd Interview (Teacher Perspective)

- 1) How do you use your advocacy skills in your workplace?

2) Tell me your thoughts about parents of children with disabilities you associate with in your school(s) and how they handle issues about their children's education which concern them?

Follow up: Do you feel you've advocated in a similar manner?

Follow up: If not, how differently do you feel you had to advocate?

Follow up: Considering your job position, do you believe you can advocate as similarly compared to other parents?

3) Explain how you believe your advocacy for your child has influenced the manner you advocate for students you teach.

4) What kind of advice regarding advocacy would you have for other parents of children with disabilities who work inside the school district?

5) Is there anything else you would like to share which we haven't covered in our conversations?

Appendix D: Pre-Interview Questionnaire

Pre-Interview Questionnaire

Your chosen pseudonym: _____

Your child's chosen pseudonym: _____

How many children do you have? _____

How many children do you have with an IEP? _____

Your child's current areas of eligibility under IDEA: _____

Previous areas of eligibility: _____

Age _____ and grade _____ of child when he/she found eligible for IEP:

Is your child currently in a K-12 setting? _____ Public? _____ Private? _____

In what grade is your child currently in: _____

Do you hold a college degree: _____

If so, in what area: _____

Your age when first entered education: _____

Your current age: _____

Your identified race/ethnicity: _____

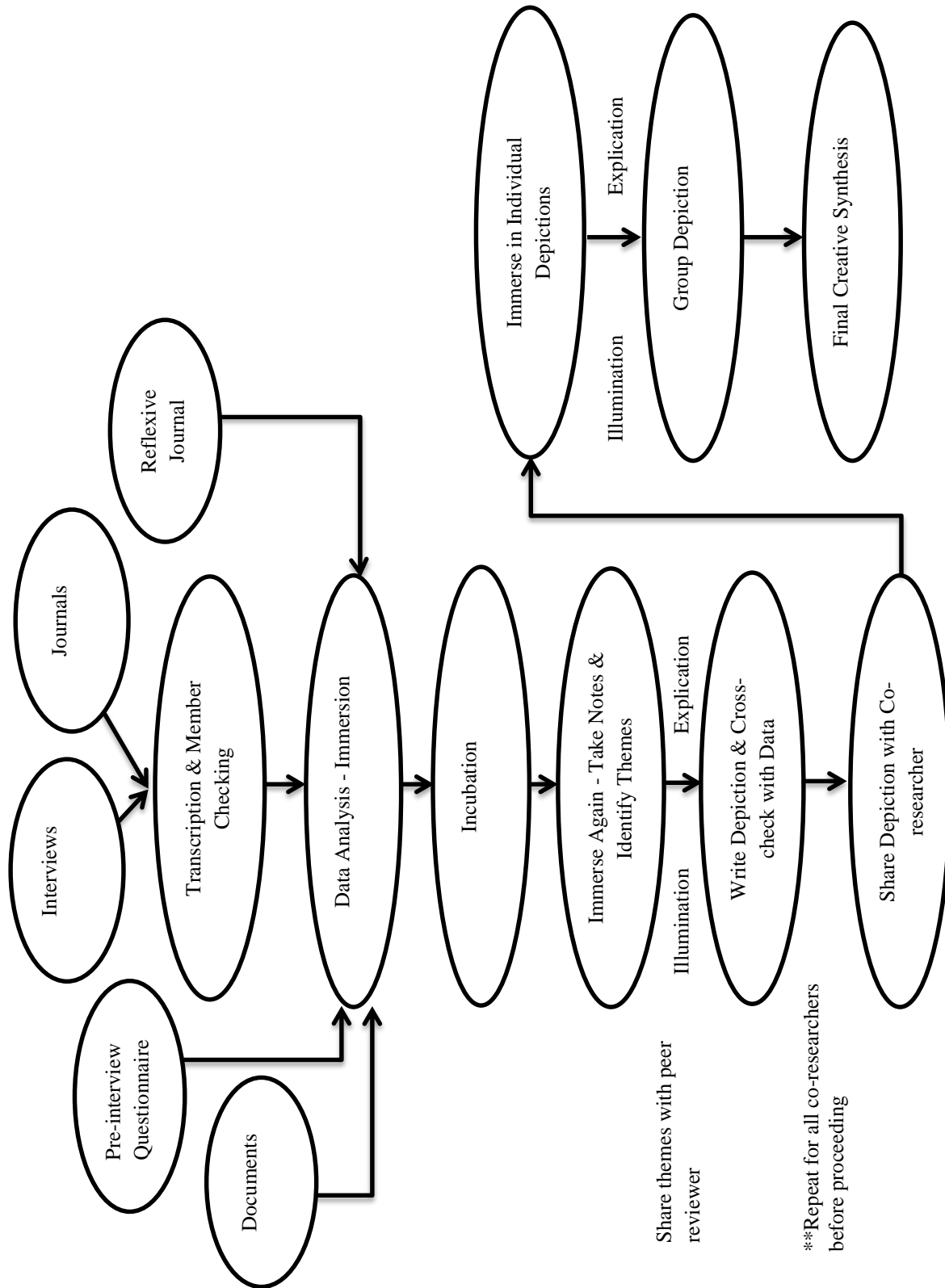
Age of your child with disability when you first entered education: _____

Number of states has your child attended school: _____ Number of school districts: _____

What is your current position within the school district: _____

Previous positions within the school district(s): _____

Appendix E: Data Collection and Analysis Process



Appendix F: Procedure for Each Co-researcher

- 1) Data collection (documents, interviews, pre-interview questionnaire, journals, reflexive journal)
 - a) Co-researchers sign consent and will be given a pre-interview questionnaire
 - b) Gather pre-interview questionnaire and documents at initial interview.
Further documents can be collected at subsequent interviews
 - c) Conduct interviews
 - Transcription followed by member checking for each interview
 - d) Gather journal notes at each interview (have co-researcher read notes)
 - Transcription followed by member checking for each interview
 - e) Maintain researcher reflexive journal throughout

- 2) Data analysis - Immersion, incubation, illumination, explication
 - a) Gather all data (documents, pre-interview questionnaire, interviews, journals, reflexive journal)
 - b) Immerse in all data until pieces are understood
 - c) Set data aside for interval of rest and return to the data – take notes and identify qualities or themes

- 3) Develop/write depiction of individual case
 - a) Return to data to determine whether individual depiction represents the experience of the case
 - b) If not, rewrite or revise depiction

**Repeat process for all co-researchers

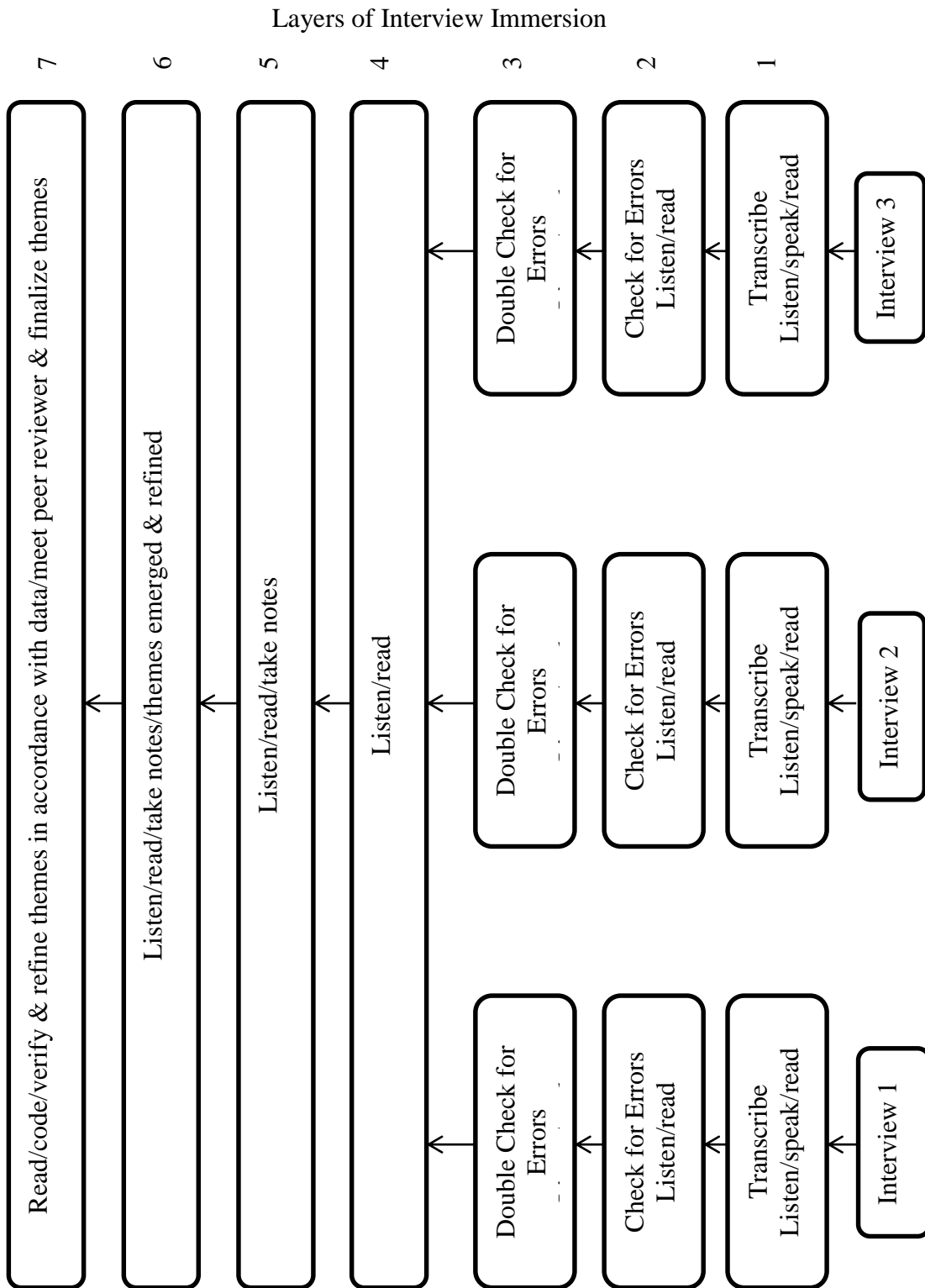
- 4) Share depiction w/co-researcher and verify whether depiction retains language and meaning

- 5) Immerse in individual depictions until understood

- 6) Develop group depiction of common qualities and themes, group evolves in unified portrait

- 7) Develop final creative synthesis – narrative, poem, painting, metaphor, etc.

Appendix G: Interview and Immersion Process



Appendix H: Study Timeline

IRB Approval & Consent Forms (September 2013)

Phase 1 (Oct. 2 to Dec. 1, 2013)

Co-researcher #1

- 3 interviews (4 weeks)
 - ✓ Transcription
 - ✓ Member checking of transcriptions (for each of 3 interviews)
 - Data analysis
 - ✓ Immersion, incubation, illumination, explication
 - Develop/write individual depiction
 - Share depiction w/co-researcher #1 and verify whether depiction retains language and meaning
-

Phase 2 (Dec. 2, 2013 to Jan. 19, 2014)

Co-researcher #2

- 3 interviews (3 weeks)
 - ✓ Transcription
 - ✓ Member checking of transcriptions (for each of 3 interviews)
 - Data Analysis
 - ✓ Immersion, incubation, illumination, explication
 - Develop/write individual depiction
 - Share depiction w/co-researcher #2 and verify whether depiction retains language and meaning
-

Phase 3 (Jan. 16 to Feb. 24, 2014)

Co-researcher #3

- 3 interviews (3 weeks)
 - ✓ Transcription
 - ✓ Member checking of transcriptions (for each of 3 interviews)

- Data analysis
 - ✓ Immersion, incubation, illumination, explication
 - Develop/write individual depiction
 - Share depiction w/co-researcher #3 and verify whether depiction retains language and meaning
-

Phase 4 (Feb 25 to March 12, 2014)

- Answer interview questions for my own case
- Data Analysis
 - ✓ Immersion, incubation, illumination, explication
- Develop/write composite depiction
- Develop creative synthesis