

**A Mother's Perceptions of Her Ongoing Advocacy Efforts  
for Her Son with Significant Disabilities: Her Twelve-Year Journey**

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### **Abstract**

IDEIA mandates that parents be active participants in the educational decision-making process for their children. It is recommended that parents and professionals collaborate for individualized educational services for students with disabilities, especially for students with significant disabilities. Research suggests that parents must advocate for the curriculum content, instructional services, and placement they believe to be appropriate for their child. The purpose of this retrospective study was to explore the experiences of one mother as she advocated over a twelve-year period for effective special education services for her son with significant disabilities. This study used a series of interviews to explore one mother's perceptions of: (a) educational service providers who served her son; (b) the services provided for her son; (c) her decision-making process that resulted in her son transferring between schools multiple times; and (d) her reflections about her family's experiences with the education system. Two primary themes emerged: (a) the perception of congruence or conflict between the mother's views of her son and the educational service providers' views; and (b) family stress during transitions. Limitations of the study and suggestions for future research are presented.

**A MOTHER'S PERCEPTIONS OF HER ONGOING ADVOCACY EFFORTS  
FOR HER SON WITH SIGNIFICANT DISABILITIES:  
HER TWELVE-YEAR JOURNEY**

Students with significant disabilities represent less than one percent of the overall population of individuals with disabilities in the United States (Alper, 2003). Many of these students first enter the special education service delivery system by receiving early intervention services in response to the complexity of their physical, cognitive, or sensory needs (Bailey et al., 1998). In addition to the public educational services mandated by the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 for both Part C (i.e., birth to three years of age) and Part B (i.e., 3 through 21 years of age), children with significant disabilities and their families often require additional supports and services across the lifespan. Singer (2002) asserted that, while intended to support families and their children with significant disabilities, these services actually can be perceived by families as stressors if there is not a goodness of fit between those services and the family's perceptions of their own needs and priorities. Researchers also have identified that families potentially experience stressors as their children with significant disabilities transition from early intervention services in natural settings to special education services in schools (Fowler, Chandler, Johnson, & Stella, 1988; Rous, Myers, & Stricklin, 2007; Soodak & Erwin, 2000).

When children with disabilities enter the school-based special education service delivery system, the IDEIA mandates their parents be included as active participants in the educational decision-making and planning process. When considering the highest level of family participation in special education services for their children, it is recommended that parents and professionals collaborate to identify appropriate curriculum content, plan appropriate special education and related services to provide effective instruction on that content, and ensure placement in the least restrictive environment. Researchers assert, however, that the degree to which parents actively participate in their child's educational decision-making process might be determined in part by two factors: (a) the procedures used by their school system to meet this legal mandate; and (b) barriers to parent-professional collaboration perceived by the parents, particularly parents of low socioeconomic status and with culturally diverse backgrounds (Harry, Klingner, & Hart, 2005; Kalyanpur, Harry, & Skrtic, 2000). For example, one barrier to parent-professional collaboration perceived by parents is limited efforts from professionals to obtain the parents' input during the decision-making process related to their child's special education and related services, and placement options (Harry, Allen, & McLaughlin, 1995).

Research suggests that families with a child who has significant disabilities frequently must advocate for the most appropriate curriculum content, instructional services, and educational placement. For example, parents reported feelings of exhaustion and frustration when advocating for placement in the environment they believed to be the most appropriate educational setting for their child, such as inclusive general education settings (Soodak & Erwin, 2000). The ongoing need for parents to advocate for such educational placements for their child might take an emotional and a financial toll on families (Kluth, Biklen, English-Sand, & Smukler, 2007; Ryndak, Storch, & Hoppey, 2008). Additionally, it is suggested that parental advocacy and active participation in the educational decision-making process for their child may be negatively affected by cultural constructs of disability (Cho & Gannotti, 2005; Harry et al., 2005). That is, cultural differences among parents and professionals, including differences in beliefs about disabilities, might affect the extent to which parents of children with significant

disabilities have consistent opportunities for active participation in the decision-making process related to curriculum content, instructional services, and placement in the least restrictive environment.

Research also indicates that parents play a critical role in making decisions about effective educational services for their child with significant disabilities (Duhaney & Salend, 2000). It is argued that it is essential for professionals to understand the perspectives of parents related to the curriculum content, instructional services, and placement of their child with significant disabilities, as well as parents' perceptions of their family's needs and priorities. To this regard, the purpose of this study was to explore the experiences of one mother as she consistently advocated over a twelve-year period for effective special education services for her son with significant disabilities. Specifically, this study used a series of interviews to explore one mother's perceptions of: (a) the early intervention and school-age personnel that served her son; (b) the educational services provided for her son by those personnel within and across settings; (c) her decision-making process that resulted in her son transferring between schools multiple times; and (d) her reflections about her son's experiences with the public education system. These are discussed in relation to her family's experiences during twelve years of early intervention and school-aged educational services.

### **Method**

For this retrospective study, qualitative research methods were used to solicit detailed perceptions of the experiences of one participant and her family over a 12-year period. Specifically, semi-structured interview protocols were used during a series of three interviews (Kvale, 1996; Mason, 1996; Rubin & Rubin, 1995; Strauss & Corbin, 1998). Consistent with qualitative research methods, biases of the researchers must be acknowledged if readers are to form valid and meaningful conclusions from the interview data (Kvale, 1994). For this study, the set of researchers included professors, doctoral students, and an undergraduate student in a special education program focused on the needs of students with significant disabilities. Each of these researchers studies the impact of instructional context and content on the learning of students with significant disabilities. In addition, two of the researchers independently had a relationship with the participants for approximately 10 years; however, during those years and data collection for this study, those two researchers were not acquainted. The remaining researchers had no prior acquaintance with the participants.

### **Participants**

Sarah lived in a college town in a southeastern state with her husband and their two sons, one of whom, Jonathan, had significant disabilities. Sarah was selected purposively for this study because of her interactions with the authors over a 10-year period. These interactions were professional in nature, but casual and periodic, with all of the interactions related to Jonathan's educational needs and services. These interactions resulted in the researchers seeking information about the decision-making process used by Jonathan's parents related to his special education and related services, and educational placement. For this reason Sarah was approached about sharing her perceptions of family's and Jonathan's experiences with the early childhood and school-aged service systems.

At birth, Jonathan had been determined to have Down syndrome and subsequently was diagnosed with Pervasive Developmental Disorder. Following these diagnoses Jonathan received special education services in settings that reflected varying curriculum foci and levels of restrictiveness in multiple schools, with the transfers between schools initiated by Sarah. These frequent transfers raised questions for the researchers about the decision-making processes used by Sarah and her rationale for changing curriculum content foci, services, and placements for Jonathan.

Sarah and her husband both held advanced college degrees. She held a master's degree in a behavioral sciences field and her husband held a doctoral degree in a hard science. Both parents had backgrounds that reflected the mainstream culture in their community; that is, neither parent represented a culturally or linguistically diverse group. Throughout the 12-year period Sarah chose to work as a private service provider either part- or full-time, or to not work and provide more support at home, depending on her perceptions about Jonathan's needs. Her husband consistently was a full-time faculty member at a university. While no formal assessment of socio-economic status (SES) was conducted due to the sensitive nature of the information, the family's SES could be inferred from the parents' employment choices as either high-middle or high. Jonathan's younger brother was typically developing and attended their neighborhood public school.

During the 12-year period addressed in this study, Sarah and her husband experienced a temporary marital separation, resulting in a period when Jonathan was living with his mother and brother in a single-parent household. During this period, however, Jonathan's father continued to play a vital role in every aspect of Jonathan's life. For instance, he regularly attended meetings at school to actively participate in the decision-making processes related to his son's educational experiences. Jonathan's father was not excluded purposefully from participating in this study. Rather, since Sarah was considered the lead advocate in all aspects of Jonathan's education, participation in community life, and participation with family, she was asked to participate in the study and agreed to share her perceptions of the family's experiences.

## **Procedure**

A series of three interviews were used to capture Sarah's perceptions about her family's experiences related to Jonathan's educational programs and decision-making processes. Each interview lasted 90-120 minutes and the series of interviews was conducted over a 3-week period at a neutral location in the community selected by Sarah. One of the authors conducted each of the interviews, with support from one other author for each interview. The authors used guiding questions for each interview, designed to assist Sarah in describing: (a) the educational services that Jonathan had received; (b) the settings in which Jonathan received those educational services; (c) the decision-making processes used to determine Jonathan's curriculum content, educational services, and settings in which those services would be provided; and (d) her family's experiences with those services, in those settings, and with those decision-making processes. The guiding questions were structured to solicit information from Sarah related to each contextual transition made during Jonathan's educational services; that is, from preschool services to school-age services in a self-contained context, to school-age services in an inclusive general education context, and to school-age services that were home-based. Thus, the interview content was ordered chronologically consistent with the changes in Jonathan's educational services. In addition to her own perceptions, thoughts, and feelings Sarah was asked to describe

her perceptions of her family's experiences. Each interview was audio-taped and transcribed verbatim. The transcripts then were shared with Sarah so she could make corrections, additions, and deletions to her comments, ensuring that the transcripts were an accurate reflection of her thoughts.

### **Data Analysis**

The data analysis followed a process for constant comparative analysis as described by Strauss (1987). First, the authors independently read the transcripts and noted categories of content. Second, the authors compared their perceptions of categories and combined their various categories into one set of themes. Next, the authors independently reread the transcripts and identified sections of the transcripts that matched each theme. Finally, the authors compared the sections of the transcripts they had independently identified as matching each theme to check for agreement. Throughout this comparison process, the authors engaged in discussions as they sought to collectively pinpoint the meanings of each of Sarah's comments. While no discrepancies of substance were identified, these discussions assisted the authors in reaching clearer interpretations and a deeper understanding of Sarah's individual comments, as well as the collective set of comments. Those interpretations and understanding were described in narratives and shared with Sarah to check for accuracy. When a statement in the narrative was unclear to her or inconsistent with her meaning, Sarah was asked to clarify the discrepancy for the authors. Through this process, however, Sarah indicated that she was in agreement with the author's interpretation; therefore no substantive edits were made in the narrative.

### **Results**

Two primary themes emerged through the content analysis of Sarah's perceptions about her son's educational services, the settings in which those educational services were delivered, the decision-making processes used to determine those services and settings, and her family's experiences with those services, settings, and decision-making processes. These themes were: (a) the perception of congruence or conflict between Sarah's views of Jonathan and the educational service providers' views; and (b) family stress during transitions. The discussion of the first theme (i.e., perception of congruence or conflict) incorporates a description of a cycle of hope, awareness, frustration, despair, information gathering, and decision-making, all of which were based on Sarah's perceptions of congruence or conflict between her view and the views of educational service providers.

#### **Perceptions of Congruence or Conflict and the Resulting Cycle**

One of the themes that emerged was congruence or conflict between Sarah's perceptions of how educational service providers' viewed Jonathan and how she viewed her son, and a second theme was a cycle of emotions and activities that followed. Early in Jonathan's life, Sarah perceived that the service providers' views about her son matched her own views of him. As he matured, however, there was a shift in Sarah's perceptions of the service providers' views and expectations of her son. Specifically, when Jonathan was between the ages of birth to 5 years Sarah felt that his service providers saw her son and cared about him in the same way that she did. She perceived that this resulted in Jonathan getting the services he needed during that

time and benefiting from those services. As Jonathan progressed through elementary school, however, Sarah perceived a difference between her view of and expectations for her son, and the views of his educational service providers.

**Perceptions of congruence: The early years.** Sarah described her perceptions of Jonathan's educational experiences in temporal sequence. Her comments about Jonathan's early intervention and early childhood experiences indicated that she perceived congruence between her views of Jonathan and the views of the service providers. The following sections describe her perceptions during these two types of services during his early years.

***Birth-to-three years old: Early intervention.*** Like most children, Jonathan was adored and loved by his family. As noted by his mother, the diagnosis of Down syndrome did not diminish that feeling for Jonathan's family:

I'm sure he fits into the Guinness Book of World Records somewhere with "Most Kissed." Now he's an adolescent so a little bit of the babying and the roles are changing, but it still doesn't change the force of the feeling.

Because Jonathan had an established condition of Down syndrome, he received intervention services very early in his life. Sarah reflected on the time after Jonathan was diagnosed and began receiving early intervention services as a time of happiness and of a sense of having good fortune. At a few months of age, Jonathan began receiving physical therapy provided in the home and, shortly thereafter, also began receiving occupational and speech therapy. Sarah felt that the professionals working with Jonathan had the needed expertise, applied that expertise to meet Jonathan's needs, and adored him as much as she did. When one of the therapists expressed concerns about Jonathan's play skills and suggested more intensive intervention, Sarah enrolled him in an early intervention program for infants and toddlers at a private non-profit center.

Sarah recalls feeling lucky as Jonathan continued to receive physical, occupation, and speech therapy at the private non-profit center. She felt the professionals there were happy, well-educated, and positive, and that the morale at the center was high. "Everything there was clean and bright," she said. She felt there was a curriculum in place and that effective intervention was being provided for her son.

***Three-to-five years old: Pre-kindergarten.*** After two years of early intervention at the private non-profit center, Jonathan transitioned to a pre-kindergarten class for 3-to 5-year-olds with disabilities. Because there was no pre-kindergarten class at Jonathan's zoned school he attended a pre-kindergarten comprised of students from several school zones. The class was one of many such pre-kindergarten classes located in typical elementary schools. Sarah perceived that the teacher and therapists viewed Jonathan as she did and that they cared for him. She also was struck by the room's cleanliness. Sarah noticed that the other students in the classroom were talking and thought that they seemed to function at a higher level than Jonathan. She thought this "...was okay because he could learn from them." Throughout this pre-kindergarten experience Sarah "felt supported" and "pretty lucky" because the school was providing the

services that Jonathan needed and because the teachers and therapists “really cared about these kids.”

Sarah’s discussion about the family’s experiences with these service providers indicated she perceived that the service providers viewed Jonathan’s needs in a manner that was congruent with her own views of his needs. Specifically, Sarah felt Jonathan: (a) needed therapy services and early intervention provided by qualified personnel; (b) needed to be in a setting that was clean, bright, and demonstrated high morale; and (c) needed to be cared about and cared for by the service providers. Sarah’s descriptions of the service providers in both the infant and toddler program and pre-kindergarten revealed an overall feeling of confidence in their abilities to meet her son’s needs and to care for him.

**Perceptions of conflict: The later years.** As Sarah discussed Jonathan’s experiences in elementary school, she described an apparent shift in her perceptions of the service providers’ views about her son which conflicted with her own views about his needs, and how and where he should receive educational services to meet those needs. Specifically, Sarah believed that Jonathan would benefit from being educated with his same-age peers in general education classes and she expected elementary school personnel to share that belief. Sarah’s discussions about her attempts to resolve this conflict with the elementary school personnel included descriptions of various stages in a cycle, comprising times of hope, awareness, frustration, despair, information gathering, and decision-making. The stages of this cycle were repeated several times during Jonathan’s educational experiences as Sarah tried to find what she believed to be the most appropriate educational services for her son.

**Kindergarten to 2nd grade in general and special education classes.** Sarah’s first perception of conflict and the cycle that followed it occurred when Jonathan transitioned from pre-kindergarten to kindergarten. In Sarah’s district, when students leave pre-kindergarten they return to their zoned school to begin their elementary years with kindergarten. Sarah, however, was interested in Jonathan attending a school that was not his zoned school. She had heard that in a particular out-of-zone school pairs of general and special education teachers co-taught classes that served students both with and without disabilities, and she believed that Jonathan could benefit from this type of instructional team and setting. When Sarah spoke with a representative from Jonathan’s zoned school about scheduling a meeting at the out-of-zone school to begin the transition to that school the response was not very pleasant. She described the school representative as saying:

‘Well, his IEP is scheduled for this day at [the zoned school].’ And I said ‘No, no, no. We’re not going to be going to [the zoned school].’ And she goes ‘That’s where you’re zoned and you will be going to [the zoned school].’ There was such disempowerment. Not only did I not have options, but she talked to me like I was a pig.

In the end Jonathan was allowed to attend the out-of-zone school. Sarah remembered, “We were all excited because it was this co-teaching model and I was thinking ‘These people are cutting edge!’ ” Although Sarah was hopeful about the co-teaching model, she recalled that on the second day of school the kindergarten teacher said to her:



‘I just want you to know that Jonathan has the mental capacity of a 10-month old.’ And I mean, my heart just went on the floor because I knew that wasn’t true, but this woman is telling me this, in the cafeteria, and she has known him one day. And I’m like, ‘Well, did you read any reports, what is this based on?’ And she said, ‘Because he puts everything in his mouth and that is what a 10-month-old does.’

By visiting and observing in the classroom, Sarah became aware that Jonathan was spending one period of the day in the kindergarten class with his same-age classmates who did not have disabilities. He spent the rest of the school day in a self-contained classroom for students with “varying disabilities” The term self-contained is used to describe a special education classroom where students with disabilities are educated for most of the school day). Sarah believed there was so much more that the teachers could have done to provide Jonathan access to classmates who did not have disabilities, particularly because it was kindergarten. While she had no formal training in special education, Sarah intuitively believed there were potential benefits to be gained from her son participating in meaningful instructional and non-instructional activities with classmates who did not have disabilities.

While spending most of his school day in the self-contained special education setting Jonathan droned (i.e., made a deep humming sound while grinding his teeth). This became an issue for his special education teacher who responded by giving him pretzels to eat. Sarah recalled that “My instincts told me there was something wrong with this teacher but I didn’t have the cognitive piece to confirm my own instincts.”

At the end of the school year the special education teacher was transferred to another school and the principal was having difficulty finding a replacement. When Sarah asked about progress in identifying a new special education teacher the principal indicated that they could hire only the “bottom of the barrel” at this time of year, since all the good teachers already had positions. After two years of teacher changes and limited access to general education settings and curriculum content, Sarah felt there was no continuity in Jonathan’s curriculum, particularly in reading. In spite of this Sarah thought Jonathan could read, although she had to convince the educational personnel who worked with him that this was the case.

A few months into his third year (i.e., second grade) at the out-of-zone school, a paraprofessional told Sarah that Jonathan was not getting any instruction; that he was being grouped with students who had behavior problems and was not getting the instruction or attention he needed. Once again, Sarah perceived conflict between her views about her son’s educational needs and priorities and the views of his service providers. She frequently met with the principal and guidance counselor about her concerns and felt she was perceived as a “constant complainer.” Eventually, Sarah became frustrated by the lack of improvement in Jonathan’s outcomes and lack of change in his educational services. She also became frustrated in her own inability to effect any change in his educational services. Sarah developed feelings of guilt as she identified an increasing number of “red flags,” which she used to identify incidences, variables, or issues that were of concern to her. During this time Sarah began to gather information from outside resources by attending meetings and conferences about current best practices and services for students with significant disabilities in inclusive general education settings.

***Second to fourth grade in general education classes and resource room.*** As Jonathan finished second grade Sarah and her husband finished building a house in a different school zone. The move to this house would mean a change in school zones for Jonathan, which offered the family renewed hope for what they believed would be effective educational services in a new school with a new teacher. In his new school his educational team felt it would be best for Jonathan to repeat second grade in this new setting, so Jonathan was placed in a second grade general education setting for part of the school day and in a resource room for students with “varying disabilities” for the remainder of the school day. “Resource room” is used here to describe a classroom for students to receive intensive intervention on a specific subject, such as reading, while spending the majority of the school day in general education classrooms. After a few weeks, the school decided to release Jonathan early every day because of his low muscle tone and physical limitations, which caused him to be very fatigued part way through the day. Sarah, however, believed he was released early every day because of the school’s lack of knowledge about how to serve Jonathan in the general education setting. She stated:

In those years I really learned about schools that were trained and schools that were not trained . . . I would say one of the things that was just amazing about the inclusion years is that I had virtually no relationship with the general education teacher, that my relationship was with his paraprofessional. And that they did not encourage a relationship with me, they seemed scared of me. I’m like an eggshell walker because I’m so grateful that they took my child to begin with. . . .but they seemed scared. Now looking back on it, I think they were petrified of the whole situation.

During his second year at the school, Jonathan began third grade with a new “varying disabilities” teacher whom Sarah felt worked very hard to help her son. Again, he was in the resource room for part of the school day and the general education setting for the remainder of the school day. As the year progressed, however, Sarah realized that the curriculum used in the resource room was not designed to meet Jonathan’s needs and that he was not being included in instruction with the other students in the resource room or the general education setting. Instead he spent most of his day working one-to-one with a paraprofessional behind a partition in the back of the resource room. Again, Sarah felt Jonathan was not making academic progress and she “couldn’t trust that the paraprofessional had enough education” to teach her son.

As Jonathan began fourth grade the next school year Sarah thought that he would be with a general education teacher who had expressed a desire to work with him. Instead, Jonathan had been assigned to a different general education teacher, and none of the friends he made in third grade had been placed in his fourth grade class. Sarah believed that placing him with a teacher who had requested to work with him and in a setting with his friends was a “no brainer.” She thought the school should have “made sure these things were in place for him” because they had been discussed. As the year progressed Sarah believed that Jonathan’s academic situation had not improved and she saw him start to have behavioral issues. “He would be on the floor screaming.” Sarah then realized that Jonathan did not want to be at school. His challenging behavior continued to escalate and the school team recommended that Sarah consider the district’s self-contained school for students with severe or multiple disabilities. “It wasn’t until I took him out of the situation that he was doing better.”

Sarah entered each year of Jonathan's educational experience at his zoned school with high hopes for appropriate curriculum content, effective services from new teachers who cared about her son and had the expertise to provide effective instruction for him, and meaningful opportunities for him to interact with same-age peers who did not have disabilities. However, each year she became aware of the "red flags" and continued to gather information in attempts to create what she perceived to be an appropriate education for her son. Armed with these conflicting sets of information, she annually participated in the decision-making process to determine curriculum content for Jonathan, the services he would receive to provide instruction on that content, and the location in which those services would be delivered. In addition, annually she needed to decide how involved she would need to be in her son's educational program: "The last thing I wanted was for him to be at the self-contained school. In my mind, a self-contained school had to be three times worse than the self-contained classroom. The self-contained classrooms were a zoo."

In spite of her skepticism, Sarah decided to observe classes in the district's self-contained school for students with severe or multiple disabilities:

I went, and I saw very talented teachers. Every single child was sitting quietly and when it was their turn to answer questions they raised their hand and answered an academic question. I was floored. And it was a new building.

Even after observing in the self-contained school Sarah did not want Jonathan to attend that school. She believed that if she took charge of Jonathan's education and was able to keep his current paraprofessional for the next school year that his educational experiences would improve. Sarah met with what she called the "high-powered moms" (i.e., mothers who were involved, informed, and advocated strongly for their children) whose children were included in general education settings and received effective accommodations or modifications. After this meeting, Sarah stated "I felt that making accommodations and modifications was what I was supposed to do, because the school wasn't doing it. I was racing and running, trying to figure out what I could do and hoping I could do all these accommodations." In spite of all her efforts, however, Jonathan continued to make no progress in his zoned school. Although Sarah wanted Jonathan to continue in his zoned school she felt that she was running out of time. "We didn't have time to fix it and I didn't have time to let Jonathan be a guinea pig any more." By mid-school year, she transferred him to the district's self-contained school for students with severe or multiple disabilities.

***Fifth grade at the self-contained school.*** As Sarah was in the process of transitioning Jonathan to the self-contained school he received a secondary diagnosis of pervasive developmental delay (PDD-NOS). This diagnosis made him and his family eligible for state-funded support through a local center that provided training and support for parents of and individuals with autism and related disabilities. For instance, Sarah gained access to training, resources, and technical assistance aimed at building her capacity to help and advocate for Jonathan. This was also a time of high stress for the family as Sarah was feeling more and more responsible for educating Jonathan on her own. She left her own private practice because it kept her from spending the time she felt she needed to figure out her own life and her family's needs. "Now I realized I really needed to have support." She began to attend workshops for parents and parent support group meetings. She felt the parents at these meetings, however, were

“belligerent” toward the school district and were focused on due process efforts to obtain the services they believed their children needed. Instead of taking this approach Sarah continued to want to work cooperatively with the school district to get the services she believed her son needed.

As Jonathan entered the self-contained school Sarah again was filled with hope. “I was so pleased that music, art, and P.E. were geared toward him. I thought all the fighting was over.” Sarah believed that at this school “...there were people who really knew what to do and were very comfortable with him.” At his former school, Jonathan was only at school for half days, but at the self-contained school he was expected to stay all day. “It was like going from a desert to an oasis.” During his first semester at the school, Jonathan earned the title “Citizen of the Month” and Sarah thought he was doing well. The IEP team placed Jonathan in a fifth grade class instead of the fourth grade, so he would be with his same-age peers

At IEP meetings his special education teacher came prepared with recent assessments and Sarah felt Jonathan was making academic progress; however, she still had concerns. For example, she was surprised the teacher did not need assistance from her. At the other schools, Sarah was a frequent visitor to the classroom and often was called to assist with Jonathan. She also was concerned that speech and occupational therapy services were not provided as frequently as they had been at previous schools. Further, she was bothered by the lack of socialization that occurred among the students. At the next IEP meeting Sarah shared her concerns and suggested that speech therapy focus on social skills that Jonathan needed to participate with peers during naturally-occurring events, such as eating lunch together in the cafeteria. In her own efforts to increase social interaction among the students, Sarah invited Jonathan’s classmates to his birthday party. To Sarah’s dismay and disappointment, none of his classmates either replied to the invitation or came to his birthday party.

Sarah’s worries grew when she asked to observe Jonathan at school. In her previous experiences she was allowed to observe in her son’s classes whenever she wanted, for as long as she needed. At the self-contained school she was escorted to an observation room located between classrooms and was allowed to stay for a maximum of 30 minutes. A third area of concern arose when she noticed that only a few parents were on campus to volunteer and only a few parents attended the parent-teacher organization meetings for the school. She first thought that “...parents felt confident that the self-contained school could really take care of their kids. They did not need to have as much interaction with school personnel. They believed their kids were getting what they needed. They were just really overwhelmed.” Her second thought was: “If our school district had greater skills in inclusive education, then parents could just drop their kids off at these inclusive settings and not be watch dogs.”

Red flags continued to emerge during the next school year. Sarah began to observe “inappropriate” verbal exchanges among staff members. She began to think that Jonathan’s new teacher was not meeting his needs, and Jonathan began to demonstrate challenging behaviors again. The teacher responded to these challenging behaviors by putting Jonathan in time-out, although Sarah did not believe this was an appropriate or effective intervention for her son. “I thought I was just losing my son and I needed to rope him in.” Sarah wanted Jonathan to return to the previous teacher’s class, but the school recommended he stay in the new class so he would be with his same-age peers. After assessing his reading level, the school decided to place Jonathan with his previous teacher, but only for reading instruction during one period per day. Sarah then took matters into her own hands and decided to provide home schooling for Jonathan during part of his school day. Jonathan continued to go to school for reading with his previous

teacher and for community-based instruction. During home schooling, Sarah engaged Jonathan in the community via horseback riding lessons, visits to the library, speech therapy, and shopping at local stores. Her goals for Jonathan were social in nature. She wanted him to learn to follow rules and behave like everyone else. Sarah also provided reading instruction for Jonathan to supplement the school reading program. This schedule of mixed curriculum content, services, and placement continued for the remainder of the school year. With the next school year Jonathan transitioned to a seventh grade class and a new teacher. Sarah felt this teacher could meet Jonathan's needs and again allowed him to stay for the entire school day.

At the conclusion of this study Sarah had decided to continue Jonathan's placement in the self-contained school for the entire school day. In addition she had arranged for private speech therapy for Jonathan twice per week. Sarah returned part-time to her private practice and the family continued to involve Jonathan in the community. Sarah received support for respite care and behavior interventions in the home. Her next hurdle was Jonathan's transition to adult life with supported employment and living options. She already had made connections with people knowledgeable in transition services and was working with the school district to carve out a place for Jonathan in the workforce.

Sarah felt, though, that she fought an uphill battle against systemic apathy and incompetence, and that her son was caught in the crossfire. She stated:

It's hard as a parent of a child with special needs when you are overwhelmed by just surviving and getting through the day without too many messes to clean up. I feel like I've been an advocate but I haven't made a dent in the problems that I see in the school district. At some point you just have to say, 'I want my kid to get what he needs, even if I have to give it to him myself.'

### **Family Stress During Transitions**

The third theme that emerged dealt with the family's stress when Jonathan was transitioning between service delivery systems (e.g., from Part C early intervention services to Part B special education services) and between schools. Because Sarah had perceived a goodness of fit between her view of her son's needs and the views of the early intervention providers, the perceived conflict between her views and the views of personnel in Jonathan's schools was confusing and disconcerting to Sarah. She indicated that her experiences with her Jonathan's school-age service providers led her to believe that nothing she said or did short of threatening to use her right to due process would change their views of her son. In addition Sarah believed that the school personnel perceived their services as adequate and appropriate, regardless of whether those services met her son's needs. She believed, therefore, that nothing she said or did would help the school personnel accept the thought that their services should change to meet her son's needs. Instead, Sarah believed that each of the schools would continue to provide the services they had been providing for years, without consideration of whether those services addressed the needs of the students who currently were enrolled. To Sarah this reflected the schools' and district's lack of (a) knowledge about the research that demonstrates the effectiveness of services for students with significant disabilities in inclusive general education settings, (b) participation in professional development or technical assistance activities that facilitate the use of research-based practices in inclusive general education settings, and (c) commitment to educating students with significant disabilities in least restrictive environments.

## Discussion

Researchers have suggested that the degree to which parents actively participate in the decision-making and planning processes related to their child's educational services might be determined in part by the procedures used by service providers to meet the legal mandate to facilitate parents' active participation in these processes, and by barriers to parent-professional collaboration that are perceived by the parents. This study explored the experiences of one mother as she advocated over a 12-year period for effective educational services for her son with significant disabilities. The findings of this study provide insight into this mother's perceptions of the procedures used by various service providers related to facilitating her active participation in decision-making and planning, and the barriers she and her family faced as she sought to meet her son's educational needs.

Of interest is how the findings of this study relate to the concept of *goodness of fit*. Specifically, when Sarah perceived there was goodness of fit (i.e., congruence) between her views of her son and the views of his service providers, she had a higher level of satisfaction with his services, her stress was decreased, and she perceived the services to be of a higher quality. However, when Sarah perceived there was conflict between her views of her son's educational needs and the views of his service providers, her level of satisfaction decreased, her stress increased, and she perceived the services to be of a lower quality. Over the years Sarah's perceptions of her son's services fluctuated between congruence and conflict, resulting in a cycle of emotions and activities (i.e., hope, awareness, frustration, despair, information gathering, and decision-making). When she perceived conflict Sarah often felt powerless; this particularly occurred when Jonathan was receiving school-aged services. Because the procedures followed by her son's service providers were not resulting in what she perceived to be adequate educational services for Jonathan, during these years Sarah used multiple strategies to improve those services, such as seeking information, obtaining additional services, and seeking support from other parents. These findings support Singer's (2002) assertion that when there is not a good fit between a family's perceptions of their own needs and priorities and the services they receive, those services might actually act as a stressor for the family. These findings also confirm Duhaney and Salend's (2000) research which suggests that the parental role in the decision-making and planning process about curriculum content, instructional services, and placement are critical if a good fit is to be achieved between the family's needs and the services delivered, so that services will be effective for the child with significant disabilities and their family. It is essential, therefore, for service providers to understand and respect parents' perceptions of their family's needs and their views about their child's short- and long-term educational services.

The findings of this study also relate to the need for educational service providers to be family-centered. The literature suggests that social capital variables such as socio-economic status, level of parent education, and cultural or linguistic background are important to consider when supporting parents through the special education system. It is asserted that parents with low socio-economic status and parents from culturally or linguistically diverse backgrounds face the greatest barriers to parent-professional collaboration (Harry et al., 2005). In this case, both Sarah and her husband had high social capital; that is, they both had high levels of education, were employed in professional positions, and did not represent a culturally or linguistically diverse population. Parents with these characteristics face fewer barriers during efforts to

collaborate with educational personnel. In addition, Sarah's professional role provided her expertise in building and sustaining collaborative relationships in both personal and professional contexts. Having this expertise, however, did not ensure that the relationship she developed with Jonathan's educational personnel was collaborative in nature. Sarah was not able to navigate the educational system and successfully advocate for services that both she and the educational service providers believed met the needs of her son and family. This finding is troublesome. To meet the IDEIA (2004) mandates for parents to be actively involved in their child's educational decision-making and planning process, it is recommended that parents and educational personnel collaborate to develop individualized education programs for students with disabilities. If educational personnel do not effectively collaborate with parents who have high levels of education and have the time, resources, and dedication to collaborate, then it is questionable whether educational personnel can be able to collaborate with parents whose demographics have been found to result in more challenges (Harry et al., 2005). This suggests that new research-based strategies are needed to improve the collaboration between parents and educational personnel in order to support the development and implementation of services that are more effective for students with disabilities and their families. This further suggests that professional development and technical assistance efforts are needed to support the development of expertise of current educational personnel to facilitate their effective collaboration with parents in relation to their child's curriculum content, instructional services, and educational placement.

Finally, the findings of this study also must be viewed in relation to public policy. The federal mandate for parent participation in the decision-making process about their child's educational services is broad and allows great variance with regard to how implementation procedures are followed. This study suggests that for some parents, this variance may result in poor collaborative relationships with their child's educational team and, possibly, less than positive outcomes for the student, especially for a student with significant disabilities.

### **Limitations with this Study and Need for Future Research**

There were several limitations with this study indicating that the results should be viewed cautiously and should not be generalized. First, the study was limited to the perceptions of only one participant who did not represent all parents of children with significant disabilities. The replication of this study with a larger sample of parents from diverse backgrounds would be beneficial. The exploration of diverse parental perceptions of their might assist with the identification of factors that influence parental perceptions of their decision-making processes related to curriculum content, instructional services, and educational placements for their children.

A second limitation is that this study employed the use of interviews with one participant in order to capture retrospectively her perceptions of past events. This data collection method potentially creates the possibility for the participant to exaggerate or limit his/her recollection of past events. The extension of this research longitudinally would be valuable to examine the perceptions of parents over time while they are actively engaged in advocacy efforts for their children with significant disabilities. A larger sample of longitudinal data yielded from this area of inquiry might serve to critically inform the development and implementation of effective ways to engage parents of diverse backgrounds in the educational decision-making process in accordance with the IDEIA (2004) mandate for active parental participation in the decision-making and planning processes.

Further research also is needed on the amount and type of variance that exists across schools, districts, and states on procedures connected with building and maintaining collaborative relationships between education personnel and parents. While previous research would suggest that future research focus on families with low socioeconomic status, with low levels of education, and from culturally or linguistically diverse backgrounds, this study indicates that future research cannot ignore the impact and effectiveness of those processes on parents who do not match these demographics.

### **Implications for Practice**

Through the experiences of one parent, this study identifies where the lack of a goodness of fit might begin between educational personnel and parents, and offers some insights into parental decision-making processes. The findings from this study support the need for ongoing opportunities for effective collaboration among educational personnel and parents of children with significant disabilities. In this study one parent perceived conflict with educational personnel only when she felt that her views of the needs of her child and family were different from the views of the educational service providers. When she perceived that her views of the needs of her child and family were consistent with the views of the educational personnel, this parent was satisfied. This finding suggests a need for early childhood and school-age educational service providers to develop better strategies for communicating more effectively and working more collaboratively with parents at every step of the educational process, including during the determination of individualized curriculum content, determination of educational services and supports needed, placement in the least restrictive environment, and the implementation of actual services for children with disabilities. Without effective communication and true collaboration, parents might perceive educational personnel as merely providing services that are familiar to them and, thus, maintaining status quo, rather than services conceived to be responsive to parents' perceptions of the needs of their children with significant disabilities and their families. This calls to question an even more basic issue -- whether educational programs exist and their constituents can receive the "services" offered by them, or educational programs exist to meet the needs of their constituents (i.e., the children and their families they "serve"). If the former is believed, then collaboration among educational service providers and parents can be viewed as helping parents understand the current services offered and how their child fits in to those services; if the latter is believed, then collaboration among educational personnel and parents must be viewed as determining how current services might need to change in order to meet the needs of an individual child. Unfortunately the debate about this is well beyond the extent of this study and leads to issues related to school reform, facilitating change in educational services, and providing effective professional development to currently practicing licensed personnel frequently identified as highly qualified. While parents like Sarah continue to search for services they perceive would meet child's needs and hope for systemic change to occur, the problem still remains. Students like Jonathon continue to wait for services that meet their needs.



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