

**ONE FAMILY'S PERSPECTIVE OF THEIR EXPERIENCES WITH SCHOOL  
AND DISTRICT PERSONNEL OVER TIME RELATED TO INCLUSIVE  
EDUCATIONAL SERVICES FOR A FAMILY MEMBER WITH  
SIGNIFICANT DISABILITIES**

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*This phenomenological case study examines one family's lived experience as they advocated for appropriate and effective services in inclusive classes for a member of their family who had significant disabilities. Findings suggest the need for effective professional development if school personnel are to effectively educate students with significant disabilities in inclusive contexts, as well as a need for policy changes related to improved professional development opportunities and support systems for families who have children with significant disabilities.*

## Introduction

Since the passage of special education legislation (i.e., P.L. 94-142 [U.S. Department of Education, 1975], Individuals with Disabilities Education Act [U.S. Department of Education, 2004]), many parents have advocated for their children with disabilities to spend more time in learning environments that least restrict their child's access to general education and to peers without disabilities. Federal regulations mandate that schools first consider whether the needs of a student with disabilities could be met in inclusive general education contexts, prior to considering more restrictive contexts. In spite of this many families struggle to have special education services and supports provided for their children with significant disabilities in general education contexts (Soodak & Erwin, 2000).

Research conducted in inclusive general education contexts has described positive outcomes for students with significant disabilities (Fisher & Meyer, 2002; Fryxell & Kennedy, 1995; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Ryndak, Downing, Jacqueline, & Morrison, 1995; Ryndak, Morrison, & Sommerstein, 1999). For example, when the location for the provision of services for students with significant disabilities have been changed from self-contained special education classes to inclusive general education classes, some parents have indicated that their children made more progress, leading to the parents becoming more hopeful about their children's futures (Ryndak et al., 1995; Ryndak et al., 1999). In addition, studies have indicated that students with significant disabilities have demonstrated growth in such areas as literacy (Ryndak et al., 1999), social competence, and independence (Fisher & Meyer, 2002).

Although such studies suggest improved outcomes for students with significant disabilities when they are educated in contexts that least restricts their access to general education and peers without disabilities, there is little evidence about differences in parental or familial experiences with the special education system and process. For example, research from the late 1980s found that parents were concerned about (a) their children's safety in inclusive settings, (b) the ability of general education teachers to instruct their children, and (c) their children's potential for social isolation and rejection by classmates (Hanline & Halvorsen, 1989; McDonnell, 1987). Many of the parents' concerns dissipated, however, after their children had received services and supports in inclusive general education contexts and, overall, the parents were pleased with the gains their children had made. These studies offer "snapshots" of multiple families' perceptions of their own experiences at a specific point in their involvement with their children's education career.

More recent research suggests that although some parents were pleased with their children's experiences in inclusive general education contexts, other families continued struggling to obtain services for their children with significant disabilities in inclusive general education contexts (Kluth et al, 2007; Soodak & Erwin, 2000). Many parents report feeling frustrated and disempowered while attempting to secure such educational services for their children with significant disabilities (Kluth et al., 2007;

Soodak & Erwin, 2000). In addition, many families who attempt to work with school and district personnel to secure educational services for their children in inclusive general education contexts have found that some teachers and administrators do not welcome their involvement (Davern, 1999). Parents have indicated that they struggle to determine how actively involved they can be without being perceived as a burden by school personnel, or as seeking too much of a leadership role on their children's educational teams (Soodak & Erwin, 2000). Again, these studies offer "snapshots" of multiple families' perceptions of their own experiences at specific points in their children's educational careers.

Despite the positive effects that advocacy for one's child may have in obtaining services in general education contexts, advocacy for inclusive services can result in increased anxiety for parents who may already be stressed about having a child with a significant disability (Keller & Honing, 2004; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Parents who are not offered services and supports in inclusive general education contexts for their children with significant disabilities often resort to due process, mediation, and even relocation to alternative school districts in order to obtain such experiences for their children (Feinberg, Beyer, & Moses, 2002; Kluth et al., 2007). Blue-Banning, Summer, Frankland, Nelson, and Beegle (2004) and Feinberg et al., (2002) suggested that it is possible that the more costly actions (e.g., mediation, due process hearings, litigation) could be prevented if families and school district personnel establish positive two-way communication and trust. When families chose relocating to alternative schools or school districts they frequently have reported facing emotional and financial hardships (Kluth et al., 2007; Soodak & Erwin, 2000). For example, Williamson, McLeskey, Hoppey, and Rentz (2006) indicated that, in large part, where a family resides can influence whether a child with a significant disability receives services and supports in inclusive general education contexts. As a result, the pursuit of services and supports in inclusive general education classes can be a daunting task for many families who have children with significant disabilities. In fact, parents have reported the need to separate from one another, with one parent moving so their child with a significant disability can receive services in inclusive general education classes (Kluth et al., 2007). Again, these studies reflect the perspectives of families about their own experiences at a specific point in their children's educational career.

While parents play an important role in making decisions about their children's educational experiences and the development of services in inclusive general education contexts, they also play an important role in school reform initiatives (Fullan, 2001; Garrick, Duhaney & Salend, 2000; Giles, 1998; Henderson, 2003; Ryndak, Reardon, Benner, & Ward, in press). Given this, it is essential to understand families' perceptions of their own experiences with schools and school districts as they pursue services in inclusive general education contexts for their children who have significant disabilities.

In contrast with earlier studies, this qualitative study provides an in-depth account of one family's experiences across the years of the educational career of a family member labeled as having significant disabilities. The study seeks to understand the family's

perspectives of their long term experiences with schools and their school district over time. More specifically, the study aimed to understand the impact of placement and special education services provided for their family member, especially in relation to receiving services in inclusive general education classes.

## Method

Since in-depth studies of the experiences over time of parents and families of students with significant disabilities is a relatively unexplored issue in the research literature, the researchers sought to examine the experiences of one family that included a member with significant disabilities. To match this intent, the study uses a phenomenological lens to explore the experiences of one family (i.e., a mother, father, son, and daughter with significant disabilities) as they sought, lived through, and reflected upon placement and services for their family member. A phenomenological study seeks to “determine what an experience means for a person who has had the experience and is able to provide a comprehensive description of it” (Moustakas, 1994, p.13). In much the same way, Patton (2002) explicitly articulates a foundational question that guides all phenomenological research --“*What is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?*” (p. 104, emphasis in original). Therefore, this study focused on how the family understood, developed, and socially constructed meanings from the events and interactions that occurred over time as one of their family members moved from receiving special education services and supports in a more restrictive context (i.e., a self-contained special education class) to receiving special education services and supports in more inclusive contexts (i.e., general education classes) (Moustakas, 1994; Patton 2002).

## Participants

In the section that follows, first we share a brief description of Stephanie and her family, as well as an overview of educational services Stephanie received throughout the years in both self-contained special education classes and inclusive general education classes. This information sets the stage for the study and its findings. Given the focus on understanding the lived experience of a family with a child who had significant disabilities, the participants for this study were selected using purposeful sampling (Patton, 2002). When using this non-random method of sampling, the researcher selects information-rich cases for in-depth study based on some defining characteristic (Patton). Information-rich cases are chosen because one can gather a large amount of data about the topics and issues of central importance to the purpose of the research. For this study, a family with a child who had significant disabilities, and who had received special education services and supports for numerous years in both self-contained classes and inclusive general education classes, was sought. The first author purposefully selected this family because they were known to have a member with significant disabilities, Stephanie, who had received special education and related services in self-contained classes for 10 consecutive years (i.e., from age 5

-15) and in inclusive general education classes for the following 7 consecutive years (i.e., from age 15-22).

### *Stephanie*

Throughout her educational career Stephanie had been labeled as having a variety of handicapping conditions and learning problems either singly or in various combinations (e.g., severe speech impairment, severe learning disability, physical disabilities, neurological impairments, mental retardation, and multiple handicaps). These labels, however, did not describe either the nature or complexities of Stephanie's learning characteristics or her performance levels. Because of this, Stephanie's parents had come to believe that IQ scores limited teachers' perceptions of her abilities, instead of reflecting her potential. Therefore, since she was 10 years old Stephanie's parents did not allow an IQ test score to be recorded in her school files. The possibility of any cognitive impairment after that time, therefore, could only be inferred from her performance on academic and norm-referenced tests which consistently indicated 2<sup>nd</sup> to 3<sup>rd</sup> grade levels for reading and math from approximately age 10 through age 22. Although Stephanie was at her best when with groups of people, trying hard to fit in and please others, her speech and language problems kept her from communicating effectively about all but the most concrete and immediate topics. In spite of these difficulties, when provided the opportunity she consistently chose to participate across environments with extended family members, friends, peers, and co-workers who did not have disabilities.

While Stephanie's social skills were considered a relative strength, when under intense and ongoing stress she had a history of specific inappropriate behaviors when interacting with others, as well as behaviors that could be considered self-injurious (i.e., peeling the skin around her fingernails). During her attendance in the last self-contained special education classroom Stephanie was exhibiting these and some newly acquired inappropriate behaviors (e.g., refusal to work; speaking very loudly across the classroom throughout instructional activities). In addition to these inappropriate behaviors, Stephanie's parents had documented their concerns about her educational placement and services, her age-inappropriate instructional content and materials, the apparent impact these were having on Stephanie's behavior, and her lack of academic progress at school.

Since her parents were conscious of the importance of Stephanie appearing and acting in ways that were consistent with her same-age peers who did not have disabilities, they assisted her in being aware of her own appearance. Stephanie was small in stature and struggled with her weight but was always well-groomed and dressed like her same-age peers who did not have disabilities. In addition Stephanie had many experiences within her community and was well-traveled both in the United States and in other countries. As a result, Stephanie projected a worldliness and middle class sophistication that was inconsistent with her language use, academic performance, and behaviors. People described Stephanie as self-confident, enthusiastic, outgoing, and independent by nature. She enjoyed having responsibility and preferred to work on

tasks independently, especially tasks for which there were high expectations. To be successful on these tasks, however, Stephanie required role models and relevant accommodations.

### *Stephanie's family*

Stephanie's family could best be described as a high middle-income traditional family comprised of her Caucasian parents and her brother who was two years older than she. They lived in a suburb of a mid-size city and had weekly contact with extended family members (e.g., grandmother, aunts and uncles, cousins, close family friends) who lived in local communities. Her father was an attorney, and her mother held a graduate degree, although she was not working while Stephanie was of school-age. Both of her parents were extremely knowledgeable about disability-related advocacy issues and practices. They believed that Stephanie should have the same opportunities in her life as she would have had if she did not have a disability, and used her older brother's life as a guide. Because of this Stephanie participated both in all family events and in numerous organized and informal age-appropriate activities in the community (e.g., soccer; going to the movies) with peers who did not have disabilities.

### *Overall Educational Services*

During her placement in self-contained special education classes Stephanie attended 10 different classes, with 10 different special education teachers, in 8 different school districts that comprised a regional intermediate cooperative agency. These school districts were in middle class suburbs of a mid-size city and surrounding towns in more rural areas. For such placements to occur, a local school district would recommend that a student receive services in a self-contained class administered by the cooperative agency. At the beginning of each school year the cooperative agency would determine the number and ages of students for whom they had been requested to provide services. Based on those students' needs, they would be grouped on class rosters and available classroom space then would be solicited for each class roster from the districts that comprised the cooperative agency. The available classrooms then would be rented by the cooperative agency and the groups of students would be placed in those classrooms. This practice resulted in Stephanie attending a new school 8 out of 10 consecutive years, until she was 15 years old. When she was placed in inclusive general education classes Stephanie attended the middle and high schools she would have attended if she did not have disabilities, and eventually a private college out-of-state.

At the time that Stephanie's educational placement changed from self-contained special education to inclusive general education classes her local school district had no experience with providing special education and related services for students with significant disabilities in general education classes. Most of the students with significant disabilities were placed in self-contained classes administered by the cooperative agency, although a few were placed in self-contained classes administered by the district. Because of this the special and general education teachers had no

experience with, and thus no professional development related to, inclusive education practices for students with significant disabilities. In contrast, however, the special and general education teachers had participated in professional development activities that related to inclusive education practices for students with mild disabilities and used those practices as they serviced students with mild disabilities in inclusive general education classes.

## **Interviews**

Phenomenological interviews were conducted three times with each of Stephanie's family members (i.e., mother, father, and brother). These interviews used open-ended questions to build upon and explore each participant's past and present (Rubin & Rubin, 1995). Interviews were scheduled approximately two weeks apart for each family member. This timeline allowed the researchers to inquire in depth into the family's lived experience, while at the same time providing space for the family members to share their own unique insights, stories, and experiences (Patton, 2002). Thus, the study focused on the goal of phenomenological interviewing, allowing each participant to reconstruct his or her own experience over time and construct meanings of their own experiences (Seidman, 1991). These individual experiences then were viewed collectively in an attempt to understand the meaning and essence of the family members' collective experiences.

## **Data Analysis**

All interviews were audiotaped and transcribed verbatim. After each interview, the researcher shared the transcript with the interviewee and requested that the family member check the transcript for accuracy, making additions and deletions to further clarify their experiences and perspectives. The few edits suggested by the participants were made in the transcripts.

Using Wolcott's (1994) approach of description, analysis, and interpretation as a method for making sense of interview data, the three researchers first read each participant's set of interview transcripts searching for general themes and patterns to emerge. During this initial analysis, the content of each family member's interview transcript was coded and categorized thematically by two of the researchers (Spradley, 1979). After individual analysis, all three researchers met and raised questions, limitations, and insights on the emerging themes that resulted in a collaboratively constructed taxonomy of key ideas, themes, and patterns that represent a vivid picture of the lived experience of the family. Furthermore, member checks were used to corroborate and help strengthen the researchers' findings by asking each family member to read drafts of the findings. In sum, the constant comparison method of reflecting and exploring the data allowed emerging patterns to collectively come into focus (Strauss & Corbin, 1998). This analysis resulted in the construction of a portrait of the experience of the family as they sought, lived through, and reflected upon the educational services and supports their family member received in both self-contained special education classes and inclusive general education classes.

In an effort to strengthen the credibility and trustworthiness of this study, efforts were made to enhance the quality of this phenomenological case study. For instance, research triangulation, as a result of independent and collaborative analysis by the three researchers, improved the trustworthiness of this research study (Patton, 2002). Additionally, member checks completed by the participants reading the transcripts and drafts of the findings also added credibility. As a result, the family's participation in this study paints a vivid picture that illustrates their hopes, dreams, barriers, triumphs, and struggles over time related to their experiences with the educational system and the educational services provided by that system for their family member with significant disabilities.

## **Findings**

In the following sections the research findings are shared chronologically, since each family member was prompted to discuss their experiences and the experiences of the family sequentially. Therefore, findings are organized in three sections: (a) before the family's pursuit of inclusive education services for Stephanie, (b) during and shortly after transition to inclusive education services for Stephanie, and (c) after Stephanie had experienced inclusive education services and transitioned to adult life. Three major themes emerged from the interviews and are evident in each of these time periods: stress and frustration, knowledge and assertiveness, and optimism and strength.

### ***Before the Family's Pursuit of Inclusive Education Services***

#### *Stress and frustration*

Family members indicated that throughout Stephanie's early educational experiences her father and mother actively had been involved in developing her Individualized Education Program (IEP), and regularly had attended both team meetings and parent-teacher conferences. Initially they had viewed self-contained special education classes as appropriate for Stephanie because these classes had been recommended by their district personnel, who the parents viewed as experts. Based on this perception the family had agreed to Stephanie's placement in self-contained classes through the regional intermediate cooperative agency. These self-contained special education classes were housed in eight different school districts that surrounded their home district. All three family members described how, over time, her parents expressed concern over Stephanie's lack of progress in both functional and academic content, as well as concern over an increase in her inappropriate behaviors described earlier. Her family highlighted the fact that the nature of Stephanie's self-contained special education classes resulted in a lack of positive role models for participation in functional activities, participation in instruction on academic content, and demonstration of appropriate social behaviors. Stephanie's mother expressed her stress and frustration about these self-contained special education classes in the following way:



Self-contained placement never felt right. I desperately was keeping Stephanie in contact with the kids in the neighborhood. I spent all of my time thinking of ways to get my daughter with them. It was quite literally an obsession because I was talking to their moms, finding out where their kids were after school, and getting my daughter there. She had to go to the right dance teacher, and to the right soccer team, and to the right everything.

After ten years of services in self-contained special education classes their district personnel “offered” the option of Stephanie attending a self-contained special education class described as comprising “higher functioning students.” The family was optimistic that services in this particular self-contained class would provide more of an academic challenge for Stephanie, as well as better role models for participating in instruction and interacting with others. Although still administered by the cooperative agency, this class was located in the middle school Stephanie would have attended if she did not have disabilities. Both of her parents expressed their hope and expectations that by attending this class Stephanie would have her first opportunity to attend the same school as the children in her neighborhood, providing her both role models for age-appropriate instructional and non-instructional activities and potential friends. In addition she would have access to teachers who had taught her brother and, thus, already had a relationship with Stephanie’s parents.

With Stephanie’s placement in this class her family reported an initial decrease in stress. After one-year in this setting, however, her parents reported that Stephanie did not demonstrate performance improvements in either the academic and functional content on her IEP, or her in-class behaviors. All three family members felt conflicted because they believed the special education curriculum and self-contained class still were not meeting Stephanie’s needs. Again they interpreted this as a result of the lack of appropriate role models for Stephanie, and their stress and frustration increased. In turn, their stress and frustration resulted in an increased need to understand why Stephanie was not progressing in her acquisition and use of functional, academic, and social skills.

#### *Knowledge and assertiveness*

When describing the roles she filled related to her daughter’s educational services Stephanie’s mother stated: “I’m the advocate. I’m the researcher. I’m the disciplinarian. I’m the follow-up person. That’s my role.” As she continued to doubt the efficacy of services Stephanie received in her self-contained special education classes, Stephanie’s mother described how she fought to identify educational goals that were challenging and relevant for her daughter, as well as instructional strategies that were effective for Stephanie. For instance, she described one IEP meeting during which she advocated for her daughter to have speech therapy that reflected a pragmatic language approach she had learned about through Stephanie’s private speech-language pathologist:

I thought “This is exactly what my daughter needs! She can’t talk to people!” So I wanted pragmatic language services for her at school. But the speech

therapist at school wanted to work on her own approach. I remember having a pencil in my hand, I was sort of pointing with the eraser saying, “Would you please write this down?” Finally the district Director of Special Education had to intervene and say “We want this in the IEP. Just put it in.”

Stephanie’s mother described how she began to attend local and national conferences related to educational services and instructional strategies for students with moderate to severe disabilities. She explained that she was seeking information that would either (a) support or refute her current beliefs about how to meet her daughter’s needs, or (b) add research-based instructional strategies to her knowledge base. She felt she could share this knowledge with Stephanie’s education team and increase Stephanie’s acquisition and use of functional, academic, and social skills. She discussed how, concurrently, she began to rely on individuals and families in their community who included Stephanie in many activities with their own children. Both parents described that it was through these outside activities (e.g., dance, Girl Scouts) that the family realized the discrepancy between Stephanie’s demonstrated capabilities in her self-contained special education classes with other students who had disabilities, and her demonstrated capabilities in the community with friends, neighbors, and family members who did not have disabilities. Her mother indicated that “The outside [non-school based] activities were the things that saved us because we had something we could point to and say, ‘Wow! Look! She excels in this!’ ”

To become more informed about the educational decisions and policies made by her district, and about the district’s philosophy related to inclusive education services, Stephanie’s mother discussed becoming a member of their district’s Special Education Committee (SEC). The SEC was comprised of representatives for district and school administrators, special and general educators, related services providers, and parents of students with disabilities. It was responsible for meeting with the parents of each student who had a disability in the district and finalizing their child’s IEP, including instructional content, services, and placement. The following example depicts Stephanie’s mother’s personal reflections about her experiences and her realizations after contributing to this Committee:

My husband and I always played a significant role in selecting a class for Stephanie, but district personnel only said, “Well, we have this self-contained class in her neighborhood school, or we have this self-contained class outside her neighborhood school.” You see, they limited our choices. That was why I got on the SEC. I knew that I had to figure out how things really worked and find out what was going on behind the scenes. I went on the Committee and I learned a world of stuff. I learned that my kid wasn’t going to get a [regular] diploma. I learned that people made comments like, “Well, this kid can’t do any better. Look at the IQ scores.” The SEC was the place where I learned why I didn’t have what I wanted for my daughter. I got to hear the inside comments of what people thought.

By advocating for Stephanie, her mother described carrying forward the family's vision of inclusive educational services in general education contexts. Her role on the SEC allowed her to understand the decision-making processes associated with educational services for students with moderate to severe disabilities in their school district. By becoming more knowledgeable about district practices and procedures Stephanie's mother explained that she was able to advocate more effectively on her daughter's behalf. In turn, this increased knowledge and understanding of the district's practices and procedures, as well as observations of Stephanie successfully participating in community activities, increased the family's hope for a more relevant IEP, more effective educational services, and better long term outcomes for Stephanie.

### *Optimism and strength*

Despite the frustration and stress reported by her family during Stephanie's early and middle school years, they also reported remaining optimistic and finding strength within their community. For instance, Stephanie's mother described how she relied on other parents in the community:

I was really lucky because I had some women in my community who were very wonderful. Part of the reason I think that they were wonderful... was because I was very open with them about Stephanie. I used to explain Stephanie to them all the time. I used to share with them her accomplishments and her difficulties --- and they were wonderful! They always wanted to help and always wanted her to be a part of them. So, I mean I was really lucky in that way. There were some really great people around.

All three family members discussed how the knowledge that they gained through Stephanie's mother participating on the SEC, the strength they gained from other parents in their community, and the optimism they felt after gathering information about inclusive education empowered them to pursue Stephanie's inclusion with same-age peers in the school and general education classes she would be attending if she did not have disabilities. The family members described how they began to ask both for more meaningful and grade-appropriate instructional content, and for services that facilitated Stephanie's interaction with classmates who did not have disabilities. They discussed how they met with resistance from the school district which continued to recommend that Stephanie remain in a self-contained special education class administered by the cooperative agency. They explained that the district indicated that Stephanie could not be moved out of a self-contained class until she made adequate progress on her IEP goals and consistently demonstrated appropriate behavior; in essence, until Stephanie earned her way out of the self-contained special education classes. The family members explained that they refused to accept Stephanie's placement in a self-contained class, believing that the placement itself was partially responsible for Stephanie's lack of progress on academic, functional, and social skills. After several months of disagreement between the family and educational personnel a due process hearing was scheduled. All three family members described that the day before the hearing was to begin the school district decided that at the age of 15 they

would allow Stephanie's placement in general education classes at her local middle school, although no support would be provided for instructional activities, development of adaptations of instructional content or materials, or evaluation of performance.

During Stephanie's elementary and early middle school years her mother and father had trusted the decisions that the school district personnel recommended for her. They both had attended their daughter's IEP meetings and took active roles in her educational program. Yet, over time, both parents reported uncertainty about the appropriateness of her educational services and placement. They each described seeing how differently Stephanie behaved and performed when participating in social activities outside of the school with typical peers, making them optimistic about her future in their community. These community observations, along with gathering information by attending national conferences and local committees, inspired her parents to request and advocate for a less restrictive placement for Stephanie. Throughout this time, Stephanie's brother maintained more of a supportive role within the family, as indicated by pointed comments, such as the following:

A lot of the support that was needed was for my mom, a lot more than Stephanie. The person that needed the most support during that time was definitely my mom, and that's probably where I played the biggest part in this whole [process].

### ***During and Shortly After Transition to Inclusive Education Services***

#### ***Stress and frustration***

Upon learning that Stephanie would attend general education classes at her local middle school, the participants indicated how her entire family initially felt relief. They explained, however, that this relief quickly was replaced with a continued sense of stress and frustration related to two issues. First, as Stephanie's new services began, all three family members discussed their realization that her teachers lacked knowledge and understanding of inclusive educational practices, including the expertise to collaborate on the development and implementation of multi-level instruction. Specifically Stephanie's parents indicated that the teachers did not understand how the curriculum, instruction, materials, and supports could be modified to address Stephanie's needs at the 2<sup>nd</sup> to 3<sup>rd</sup> grade levels, while addressing the needs of her classmates working at the 7<sup>th</sup> to 8<sup>th</sup> grade levels. Stephanie's father stated:

I guess one of the things you learn is that teachers don't know as much as you think they know, and that parents know a lot more than professionals think they know. The two should work together. I think we found that out, at least in our experiences. The professionals shouldn't be so high and mighty, and the parents should be more understanding of the professionals and the problems that they have to go through when dealing with inclusion...I think we all have

to learn to be more understanding. And that goes on in all realms of our society.

In response to the teachers' lack of preparation, Stephanie's mother described spending many hours assisting teachers in making modifications to meet her daughter's needs, while maintaining the integrity of services for her general education classmates.

Second, Stephanie's parents explained their desire that, during and after her transition to inclusive general education classes, the schools would take ownership of her educational services. They indicated that they believed this would minimize the family's need to take the lead and be responsible for the development of Stephanie's services. Stephanie's mother described how it was difficult for her when she had to fill a lead role:

Personally, for me it was hard --- really hard. There was more responsibility on me than there was before. So it might seem like the effect of inclusion on me was not good. ...in some ways it *was* not good. The onus was on me to find the information, to solve the problems, to get this thing done, and to get my daughter *into* inclusive environments. The onus *still* remains on me to do it all. So, I would say the responsibility on me increased when she changed from being in a segregated to an inclusive setting...The family has to be very, very informed. We have to be able to write a good IEP. We have to know good ideas. We have to go to conferences, etc., etc. So there's a big responsibility.

Stephanie's parents indicated that the family having this responsibility created a dilemma for them and the school-based education team members. For example, Stephanie's parents explained that because the family continued to feel the need to assist in all aspects of Stephanie's services, it was difficult, if not impossible, for them and the other members of Stephanie's education team to develop a collaborative partnership that reflected the traditional roles of family and school-based members. Instead, Stephanie's parents described feeling compelled to go beyond the family's traditional roles, which resulted in a greater sense of responsibility for the successful implementation of Stephanie's inclusive education.

#### *Knowledge and assertiveness*

Stephanie's mother explained that when she acquired knowledge through her own attendance at conferences, reading, and work with consultants, she "...was more focused on what Stephanie needed." She indicated that her confidence in her abilities to advocate for Stephanie also improved and that she "...was very sure about what Stephanie needed and how to do it." This is in stark contrast to the levels of confidence and knowledge she asserted to have had prior to Stephanie's experience in inclusive general education classes: "I didn't like what I saw, but I didn't know what the alternative was. So I felt sort of inadequate." These perceptions were supported by Stephanie's brother who indicated that his mother's knowledge about how to meet his sister's needs in inclusive general education classes helped the family "...deal with

Stephanie's education and eventually led to an understanding of the professionals' problems." Stephanie's father concurred with his son's thoughts and stated, "There are a lot of things we learned. We learned how to deal with school districts. We learned how to be tough, how to be fighters."

### *Optimism and strength*

All three family members described remaining optimistic and hopeful about Stephanie's future throughout her educational career. Over time, as Stephanie's mother participated in the SEC and attended conferences, her family "...saw options we didn't know existed...and increased our faith and belief in Stephanie's future." This optimism for Stephanie's future was sustained through the support of professionals, as indicated by her mother:

Things didn't open up for us until the new principal came at the beginning of Stephanie's junior year [in high school] and the new speech therapist came. She was a godsend to us. There was somebody who really did know how to [provide modifications to curriculum]. She didn't know how to do it in the beginning, but I never had anybody before who really listened to me...who really listened and respected what I said. That was the very first time anybody [in Stephanie's schools] listened and respected what I said.

Stephanie's parents discussed how her school-based education team members were able to make her instruction and school experiences more relevant by opening up the lines of communication and developing shared goals with the family. The newly opened lines of communication also allowed Stephanie to progress dramatically during her high school years. When discussing their new relationship with school personnel Stephanie's father stated that:

We should be learning that given proper training, people can become accepting; and with the proper training and the proper understanding, everybody can become accepted no matter who they are.

Stephanie's father also suggested that by developing a clear plan and providing the necessary supports for teachers and students, all students with moderate to severe disabilities can be successful in inclusive general education classes in their neighborhood schools.

During the transition time from more restrictive to less restrictive educational settings, Stephanie's family members came together to support one another. Despite having achieved what her parents had come to realize they desired for Stephanie's education and social progress, her mother was faced with the new challenge of supporting and educating Stephanie's teachers. Given her parents' reports of frustration with school personnel and the lack of training that teachers had regarding the provision of academic accommodations and modifications, Stephanie's brother reported embracing a support role within the family, especially for his mother. The family members also

described, however, their ability to maintain a pervasive support system within and outside of their immediate family, which helped sustain them as they continued to advocate for effective services in inclusive general education classes for Stephanie.

### ***After Stephanie Experienced Inclusive Education Services and Transitioned to Adult Life***

#### *Stress and frustration*

All three of Stephanie's family members indicated that the family endured a tremendous amount of stress and frustration throughout her educational career. They explained how the family continued to be frustrated with the high level of energy Stephanie's parents needed to exert every year to advocate for and develop effective educational services for her. Their frustration was evident in her mother's comments:

Another thing that is very significant about those years is that every [school] we go to I have to do so much ground work that I just get so tired. Sometimes you want to just register [your child] and not write a book, not call, and not do an in-service. The preparation and the planning that I have to do are exhausting. I'm tired of it.

Stephanie's brother reported the intense exhaustion that his mother experienced, that resulted from her being the primary leader on Stephanie's education team throughout Stephanie's experiences in inclusive general education classes. He stated:

My mom was just very, very, very upset through all of this, and you know, even through the integration [i.e., inclusion] thing, things weren't going right. She would always get very depressed and would feel like this is never going to change. She would say, "We're never going to be able to do this." I would come home from school and she would just be collapsed on the couch, crying or just, you know, be in that type of state. The biggest thing that I did in all this was keep my mom together. She needed me to talk to. I always knew a lot about what was going on at the time because of these talks we'd have when I would get home from school. Every day was just another wall and more bad news, especially at the time that we're talking about. I was always able to provide her with the ideas, and brainstorm, and strategize. My mom and I have always had very similar ideas about a lot. For her to hear her ideas echoed in somebody else was very necessary for her. She needed to hear somebody say, you know, "No, mom, you're not crazy. You're right." That's the biggest role that I've played.

In contrast, as Stephanie left the educational system her parents voiced less frustration when discussing the outcomes with which she was leaving school, believing that Stephanie had achieved the goals that were most important for her adult life. They were anticipating, however, new sources of stress and frustration as Stephanie entered adult support services.

*Knowledge and assertiveness*

Stephanie's mother discussed how she developed relationships beyond the family's existing support network of community members and professionals by continuing to seek information that would assist her in making critical decisions about her daughter's adult experiences. Concurrently, as Stephanie was exiting education services her mother's perception of her own overall role changed. While she remained focused on her daughter's education and progress, Stephanie's mother explained that she perceived it to be equally important for her to be knowledgeable about effective services in inclusive general education classes for *all* students with disabilities. She began to educate other parents in her community and to encourage the parents who had children with moderate to severe disabilities to be proactive in their advocacy for effective services for their children in inclusive general education classes. When parents chose to do so, Stephanie's mother described how she then assisted those parents in their new advocacy activities, becoming a parent advocate.

*Optimism and strength*

Reflections from Stephanie's mother and brother after she had exited school services suggest significant optimism and hope for both Stephanie's and the family's future. After Stephanie graduated from high school, she continued her education by auditing regular undergraduate courses at a small out-of-state liberal arts college, living in a dormitory with support, and participating in community-based vocational training. During this time Stephanie's mother reflected on her own growth and how it was reflected in her perception of their vision for Stephanie. She stated that:

As the years went by I became stronger and stronger about where we were going and what we needed. [Now] I'm to the stage where I'm really clear. I don't need as much advice as I used to, though once in awhile I stumble and I need some back up from my friends. That's pretty normal though and I'm pretty confident about the path that we're on. Our vision has clarified and gotten more reliable. I guess we're surer and more confident about it [inclusion].

Stephanie's family also reflected on her progress to date. For instance, her father credited the change in Stephanie's educational programs for the family's optimism and hopefulness, as evident in comments such as the following:

The changes in Stephanie's educational programs have led to maturity, growth, and independence for her. Even for the family. I don't worry about leaving Stephanie home, or letting her go out, or anything like that. We feel very free.

Finally, Stephanie's family also reflected on how her future was promising. Consistent with this outlook, Stephanie's brother stated:



I think this [experience] had been very important for my parents. I think my mom [feels good about Stephanie] and my sister feels good about herself. My parents feel good about themselves for having accomplished such an amazing feat. [Inclusive education services] have been overwhelmingly positive for everybody. Exciting and fulfilling. It's been unbelievable to see Stephanie improve.

## Discussion

There are two main limitations of this study that warrant discussion. First, the scope of this phenomenological case study was limited to the experiences of one family. Case study research is time intensive work that involves data collection, analysis, and debriefing with participants. In this case, the reader is limited to the story of how Stephanie's family members conceptualized, enacted, experienced, and made sense of the change of Stephanie's educational services from more restrictive to less restrictive educational settings. When interpreting case study research the responsibility is on each reader to determine the extent to which the case is applicable to his/her particular experiences. Second, the findings of this study are contextually bound and particular to Stephanie's family. Specific descriptions of how Stephanie's family experienced the agreement for and implementation of special education services could, however, prove valuable to other families, teachers, administrators, researchers, and advocates as they attempt to traverse the complex landscape of effective services for students with significant disabilities in inclusive general education classes. Though this study does discuss the experiences of one family as they advocated on behalf of their family member, these experiences may not be applicable to other families who have a different educational philosophy or education background, or who face different challenges associated with different schools and districts. Therefore, as noted by Patton (2002), the reader must judge for himself the transferability of the findings.

Family systems theory suggests that families play a crucial role in the development and educational outcomes for their children with disabilities (Dunst, Trivette, Hamby, & Pollock, 1990). In fact, Dunst, et al., found that child outcomes were a function of social support for parents. Consistent with this Stephanie's family members indicated that they relied on both personal support from family members, and social support from community members, friends, and professionals to sustain their efforts to advocate for Stephanie to receive effective educational services and move from more restrictive to less restrictive educational settings. Consistent with the literature this study supports the need of parents who have children with significant disabilities obtaining social support from other family members (Gray, 2006), as well as from friends, other families who face similar struggles, and formal professional agencies and programs (Twy, Connolly, & Novack, 2007).

This study also is consistent with other studies that suggest the need for families to have a variety of supports to help them deal with the complexities related to developing and implementing effective educational services for their children with significant disabilities in inclusive general education settings (Kluth, et al., 2007; Soodak & Erwin, 2000). For example, parents may need to seek: (a) external supports,

such as professionals to assist with the negotiation of the educational system; (b) emotional supports, such as other families; or (c) information and advocacy agencies, such as Sibling Support Project, and National Parent Center Network (i.e., PACER/ALLIANCE). Having an extended network of support may relieve spouses and other children in the family of bearing the entire burden of supporting the family's lead advocate.

It could be argued, however, that families' extensive need for social support could be decreased if more structured opportunities were provided for families to acquire the knowledge and support they need to effectively advocate for their children. While IDEA mandates that legal information be provided to families by school districts, this study is consistent with other studies that indicate the information currently provided by them may not be sufficient for all families, and the activities used to provide that information may not be effective. For example, 147 parents who had children with disabilities from several geographic regions of the United States reported the lowest levels of satisfaction with school and support personnel as their children grew older (e.g., parents who had children 3-5 years old and 6-12 years old were less satisfied with services as compared to services received for their children from birth-3 years of age) (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005). It is evident that schools need to become more responsible for providing parental support once a child enters school-age services. Unfortunately, this often is not the case and parents find themselves unnecessarily at odds with school and district personnel (Kluth et al., 2007; Soodak & Erwin, 2000). Further research is needed to determine the degree to which districts are able to provide sufficient information for families in an effective manner, as well as whether this information dissemination role constitutes a conflict of interest for districts. It might be necessary for information also to be provided to families through agencies, organizations, universities, and funded projects, addressing not only legal mandates, but also effective (a) services in inclusive general education contexts, (b) strategies to advocate for such services, and (c) strategies to maneuver the political realities faced in today's school systems. An alternative approach might include placing families *within* the structures established in schools, districts, and state departments of education to ensure that their voices are heard consistently and loudly when policies and procedures are developed, implemented, and evaluated. Perhaps then families' perspectives would have a more wide-reaching influence on services provided for all students with disabilities, including those with significant disabilities. Parents also need opportunities to obtain information about the effects on, and outcomes achieved for, students with significant disabilities who receive services and supports in various educational contexts (i.e., self-contained special education classes; inclusive general education classes). If parents are expected to advocate for effective services in the least restrictive settings for their children with significant disabilities across the country, then they must be privy to research that describes both the various types of services and their historic outcomes.

Consistent with Wang et al. (2004), this study indicates that in addition to the stress and frustration they felt while advocating for changes in educational services, the family reported continued experience with school-related stress and frustration after

obtaining services for their family member in inclusive general education classes. This family's stress and frustration, however, was related directly to teachers' lack of professional preparation on multi-level curriculum and instruction in inclusive general education classes, as well as school and district administrators' resistance to changing the services they provided for students with significant disabilities. It is unreasonable for districts to rely on family members either to develop curriculum and instruction adaptations for students with significant disabilities over multiple years, or to provide professional development support to school professionals. Such expectations are antithetical to the concept of collaborative teaming embedded within IDEA, and erode the family-school relationships on which effective special education services for students with significant disabilities are reliant.

Unfortunately most teachers still consistently report being unprepared to teach students with significant disabilities (Bennett, Deluca, & Bruns, 1997; Davern, 1999). To remedy this effective and targeted strategies for preparing *all* teachers to effectively collaborate and meet the needs of diverse students, including the needs of students with significant disabilities, in inclusive general educational classes are necessary (Browder, Trela, & Jimenez, 2007; Ryndak, Clark, Conroy, & Stuart, 2001; Ryndak et al., in press). Furthermore, focused efforts need to address pre-service and in-service teachers' attitudes about students with significant disabilities, knowledge of effective practices, and skills related to effective adaptations for students with significant disabilities.

Although the process of obtaining services in inclusive general education classes for Stephanie was an arduous task, it is compelling that the overarching theme throughout her family members' interviews suggests hopefulness and optimism for her participation as a self-sufficient contributing member of her local community, because of her new educational placements. This is consistent with findings of other studies that reported families having more positive feelings and hopefulness for the future of their family members with significant disabilities after experiencing services in inclusive general education classes (Hanline & Halvorsen, 1989; McDonnell, 1987; Ryndak et al, 1995; Ryndak et al., 1999).

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