No Surprises, Please: A Mother’s Story of Betrayal and the Fragility of Inclusion

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As the parent of a child qualified for special education services under the Individuals With Disabilities Education Act (IDEA), I have often felt a lingering sense of apprehension when encountering some of the school personnel. At the same time I align myself with educational professionals because I, too, have worked in schools as both a general and special educator. Perplexed by this apparent contradiction, I sought a deeper understanding by re-examining my own experiences while exploring the question, “What circumstances might be contributing to this disconnected feeling I have from other adults who have significant influence over my son’s life?” Thus, in this paper I attempt to shed light on the often unintended consequences of school personnel’s comments and actions as told from the perspective of someone who is both the mother of a young child with disabilities and an experienced teacher, sensitive to the particular conditions and constraints of the special education system.

The importance of building relationships, especially between parents of students with disabilities and the school personnel who work with these children, cannot be overstated. In-services for teachers, therapists, and administrators offer Tips for Better IEP (Individual Education Plan) meetings (Spectrum Training Systems, 2005). Strategies for Communicating effectively in difficult situations (Keystone Area Education Agency, 2005) are also offered to school personnel. Preservice textbooks for teachers nearly always include a section about the importance of developing a positive parent–professional relationship (A. Turnbull, Turnbull, Erwin, & Soodak, 2006). The Reauthorization of the Individuals With Disabilities Education Act of 1997 emphasized the role that parents of children with disabilities should play in the development of a child’s Individual Education Program (IEP). Furthermore, states and school districts are increasingly adopting more inclusive practices where children with IEPs spend more time in the general education classrooms, thus increasing the numbers of school personnel who need to share information. Considering this, it seems of increasing importance that positive parent–professional relationships develop.

Regardless of the available information and opportunities for school personnel to learn more about strengthening relationships with parents as partners, I continue to experience situations that distance me from school personnel. Here, I share some of these experiences, although I do so cautiously, ever-conscious of the misunderstandings that often occur between parents of children with disabilities and school personnel (Biklen, 1985; Erwin & Soodak, 1995; Ginsberg, 2002; Soodak & Erwin, 1995; Wickham-Searl, 1992) to the possible detriment of the child. My efforts to share these stories are not meant to offend or put blame upon school professionals. Rather, I offer an examination of these situations as part of an effort to encourage discussion among my special education colleagues about ways we might improve our relationships with parents.

The 2004–2005 school year was a time fraught with uncertainty as I found myself constantly having to justify my son’s inclusive placement and services during his first grade. “No surprises, please” captures the idea of this uncertainty as I began to recognize the fragility of inclusion, how educational services and supports can change at any moment, without apparent warning. Such tenuous circumstances serve only to add to the sense of tension and distrust that emerged as a result of instances of betrayal I felt when interacting with some school personnel.

The Fragility of Occupational Therapy Services

I had worked in my son’s school supervising a student teacher and volunteering in his classroom for much of his kindergarten year. I regularly read and wrote in the communication notebook we had agreed to use to help with our communication, and I felt I was part of the IEP team. However, in a meeting during my son’s first grade, the school personnel who were on the team appeared to have already made decisions prior to the meeting. My husband and I entered the meeting thinking we were
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finally going to get direct occupational therapy services for our son after more than 4 years of requesting them, but instead we were told “Your son will benefit from consult services,” and presumably nothing more. Consult services, I knew, meant there would not be a goal for the occupational therapist to work on with my son and, therefore, no accountability for his progress in this area. For us, consult services, which had been written on the IEP for the previous 4 years, meant that we would rarely if ever see the occupational therapist in meetings, and she might not see our son at all. She insisted, though, that she would respond to teacher questions if they asked. The meeting was nothing more than the occupational therapist sharing with us a report and a decision that was already made.

I know meetings without parents happen. Colleagues of mine from years ago used to justify these prior, private meetings without parents as part of “getting ready.” They argued that it would “save time” for the parents as well if the school personnel presented themselves as being “on the same page.” I can recall at least three times where my husband or I was told, “We’ve already talked and decided . . . or something similar, all of which eroded any sense of partnership.

A brief history about the years leading up to this meeting with the occupational therapist might help explain why I felt betrayed. She worked with our son for his first 2 years in our home as part of an early intervention program. On a number of occasions when I asked for direct occupational therapist services to continue into preschool, the occupational therapist told me, “Don’t worry. He’s doing very well. We can talk about services when he begins writing in school.” I reviewed the occupational therapist’s reports. When my son was nearly 3 years old, the same occupational therapist had written “Muscle tone is characteristically low,” yet she concluded, “It is not felt John needs or qualifies for educational occupational therapist services at this time.” A year later, handwritten on the back of John’s IEP, the occupational therapist wrote “Janet & Chris, The team told me that you would like John to receive an occupational therapist & physical therapist evaluation.” Then she described a number of suggestions for what we might do at home to help him. She concluded, “I did write up a report that you will be getting a copy of. Only a short report since I really didn’t have much involvement with John this year. Have a nice summer.”

The next year, the occupational therapist wrote, “John does not need the expertise of an occupational therapist; he just needs the daily practice and repetition to improve his skills” (7/8/2002). After another year of trying to collaborate with the school on integrating fine- and gross-motor skills into the regular school activities without the expertise of an occupational therapist, my husband took our son to Iowa City Hospital clinic to get another opinion. Their hospital occupational therapist wrote “At a chronological age of 6.1 years, John obtained an age equivalence of 36 months (significant delay)” (6/23/2003). Although her recommendations did not specify the magic words direct services, I asked the special education teacher and local area consultant for involvement from the school occupational therapist based on the discrepancy between the scores and my son’s age.

Six months later the “team” put Iowa’s intervention process into action in January of my 6-year-old son’s kindergarten school year. According to the Iowa Department of Education (2005) special education eligibility standards, the process of determining eligibility for special education or related services requires an intervention with integrity. Without any in-person communication with me or my husband, the occupational therapist developed an intervention plan based on John’s poor results during her own assessment. After 6 weeks of intervention with an assistant occupational therapist (who incidentally did not know my son and whom I never met), the occupational therapist determined, “Although John made some improvement, it is the opinion of this therapist that the improvement was not significant enough to continue” (5/17/2004). When the occupational therapist shared her results in a meeting, I wondered why others on the team did not ask any questions. “It is the team’s responsibility to determine the integrity of intervention implementation” states the Department of Education document (emphasis in original, p. 21).

In contrast to Iowa’s Department of Education document, in our situation the opinion of one person, that John did not “improve enough” (who determines what “enough” is anyway?), determined his lack of eligibility. I felt betrayed by the occupational therapist whom I had trusted to have my son’s best interest in mind, who had promised her help years before. I also felt betrayed by other team members who did not ask any questions about the interpretation of the intervention or her recommendations. I believe that if we expect a team to develop, then team members need to explain their reasoning behind decisions or recommendations and openly invite alternatives.
At the beginning of first grade, we asked the school for a second opinion about our son. The occupational therapist from a nearby school district contacted us and spent a significant amount of time observing and interviewing our son and those who interacted with him. This was the first time a thorough and contextualized assessment took place. I asked this occupational therapist to talk with us prior to the sharing of her report with the school team. I told her, “I don’t want to be surprised.” She called a few nights before the meeting was scheduled, and we talked for about an hour. She said, “I noticed how hard handwriting was for him and the method the school uses is particularly difficult for many children to learn. Poor little guy.” I had the distinct impression that she was recommending direct services, and I put my trust in yet another occupational therapist.

So, when my husband and I sat through the first part of the meeting in the spring of 2005, we were fairly relaxed. After all the evaluation results were reviewed, the occupational therapist made a list of recommendations and said, “If the team implements these suggestions, occupational therapist consult services would be adequate.” We sat, confused, and without further discussion until the meeting ended. Months later as I put this story to paper, I have not been asked how I feel about the decision nor have I seen or heard from our school occupation therapist. In fact, she did not attend our son’s annual IEP meeting 2 months later when we planned for second grade.

The Fragility of Inclusion

Earlier in the year, I received a phone call from my son’s first grade teacher about dinner time. I saw her nearly every morning when I dropped off my son, and I communicated daily with her or the associate in our communication notebook. She told me that she and the special education teacher had discussed it (His performance? His placement? I didn’t know what it was). “He should go down to the resource room, for math at least,” she suggested. This time, I found my voice and said, “We need a meeting before changing John’s placement.” I hung up the phone wondering when the school personnel had decided this and why we had not first tried intervention strategies and/or other supports. Although this was a legal issue, and it was possible that the teacher just did not realize she had not followed the correct process, I was more bothered by the feeling that they had discussed and made decisions without me and my husband. We made it clear from the start how important it was to us to have our son included (it was our vision statement in the IEP) with his classmates, even if his goals might differ from theirs. I had also shared articles with the team in which the authors described the benefits of inclusion. Now it felt as if our opinions were being disregarded with an unexpected phone call.

For me, it has become ever more apparent how John’s teachers’ attitudes toward him and toward disability affect their expectations. Their expectations then play a part in how “appropriate” his placement is. Since my son’s transition from a fully inclusive preschool to a local public kindergarten class, I have been asking myself the following questions: “Why isn’t inclusion the assumed placement for my son? Why do I feel an awkward tension between myself and my child’s educational team? Is my situation unique?”

Thirty years after parents succeeded in their advocacy for a free and appropriate public education of children with disabilities, inclusive placements and services remains tentative (see Gaskin et al. v. Commonwealth of Pennsylvania Department of Education the IDEA, 2005). Two related principles continue to challenge both families and professionals, in particular the emphasis on the least restrictive environment and the principle of parent and student involvement in the IEP process. Recent court cases and statistics from the U.S. Department of Education demonstrate how dismal the situations are for families and professionals advocating for inclusive education, particularly for children labeled with developmental disabilities, such as mental retardation and/or autism. Parents, like me, continue to face circumstances where placement and services for our children might be decided without or in spite of our input. On the occasion when we think we have succeeded in securing an inclusive placement, we are quick to learn that the situation could change overnight. This uncertainty seems to contribute to the apprehension I feel when discussing my child’s particular needs with school personnel. Kliewer (1998) wrote, “Strict segregation of children with Down syndrome remains the predominant educational practice in today’s schools” (p. 42). Reports to Congress under IDEA show numbers confirming such practice. A child labeled with mental retardation is more likely than any other label to be segregated. He or she is likely to be removed from the regular classroom more than 60% of the time in almost any state.

Only in New Hampshire and Vermont are children labeled with mental retardation more likely to be taught among their typical peers at least 80% of
During the time of John's level of service, this time a reduction in speech and language support. My husband sat up in his chair. "Excuse me. Are there not other children in addition to John whom you help with speech and language?" "Yes," he replied. Turning to the general education teacher, he asked, "And aren't you working on sound and letter relationships in your phonics program?" Both my husband and I are teachers, and we had been helping our children with phonics homework for 2 years now and had become familiar with the school curriculum. He turned his gaze back to the speech–language pathologist and asked, "Couldn't you be working with a small group of children in the classroom on speech goals while also working on regular reading?" In the absence of anyone else commenting, I pleaded, "Please, would you reconsider and think about it?" We spent the remaining meeting time trying to convince her that John needed her expertise. It seemed that services were being removed because our son was fully included.

The Fragility of Speech and Language Services

My husband and I sat in our then 7-year-old son's annual year-end IEP meeting, surrounded by several school personnel, including the principal, the general and special education teachers, the paraprofessional, the local area education agency special education consultant, and the speech–language pathologist. I assured my husband that I did not anticipate a stressful meeting. "We only need to discuss extended school year service." Instead, shortly into the meeting, the speech–language pathologist said something like, "I'm not really doing anything in John's first grade classroom, so next year I think I should just serve as a consultant to the team." As I described previously, we had been unsuccessful in getting direct occupational therapy services for our son for years, and the occupational therapist was noticeably absent at this meeting.

Suddenly, on the table was another change in John's level of service, this time a reduction in speech and language support. My husband sat up in his chair. "Excuse me. Are there not other children in addition to John whom you help with speech and language?" "Yes," he replied. Turning to the general education teacher, he asked, "And aren't you working on sound and letter relationships in your phonics program?" Both my husband and I are teachers, and we had been helping our children with phonics homework for 2 years now and had become familiar with the school curriculum. He turned his gaze back to the speech–language pathologist and asked, "Couldn't you be working with a small group of children in the classroom on speech goals while also working on regular reading?" In the absence of anyone else commenting, I pleaded, "Please, would you reconsider and think about it?" We spent the remaining meeting time trying to convince her that John needed her expertise. It seemed that services were being removed because our son was fully included.

Conclusion

When my child was determined to have trisomy 21, I did not anticipate the tension between myself and some of my educational colleagues because I had identified myself as a special educator and presumed we would all be advocating for my child to be taught and provided support services among his typically developing peers. The preference for educating children with disabilities in general education is part of the original language of the law and has been supported by policies and guidelines of organizations since the 1970s (Taylor, 1988). Thus, my expectation at the beginning of my child's public schooling was that we were to start in general education and that his placement would not change unless the team had agreed to its "failure." I will admit to never having truly considered the idea that we would fail in developing an adequate system of support services for John. For me, the concept, value, and benefits of inclusion have taken precedence over the codified practice of relying upon a continuum of placements. I learned over the course of the past year, however, that others on my son's team did not characterize the removal of a child from general education as a "failure." To the contrary, some members of my team might have agreed with those who "take the position that the continuum permissible under the federal statues includes regular and special classes, with variations, in regular school buildings in which nondisabled students are educated" (Taylor, 1988, p. 50).

Parents of children with special needs have long felt alone or relegated to the "outside" of the education system when it comes to advocating for their child's right to an inclusive education (R. Turnbull & Turnbull, 1985). One parent who was also a teacher put it this way:

I found that suggestions I would make regarding my own child would be totally dismissed by some professionals, while these same suggestions that I would make as a professional concerned about other children would be cherished by my colleagues as professional pearls of wisdom (Roos, 1985, p. 246).

I would like to think that the revelation that this continues today, despite all that we know about the importance of developing positive parent–school relationships, upsets parents and school personnel alike. As A. Turnbull et al. (2006) wrote: "The principle of parent and student participation challenges educators and parents to cast off the outdated role of parents as recipients of educators' decisions" and our newly defined roles as partners requires us to look more closely into the reasons behind our
tensions. My hope is that school personnel follow suggestions like those of Biklen (1992), who called for professionals to consider looking to parents for ways to adapt and include students. He pointed out how membership in families for children with severe disabilities was not conditional or earned based upon skill level nor should it be for full membership in a general education classroom.

In order to eliminate situations where parents like me feel betrayed by school personnel, perhaps those of us who work with children entitled to special education or support services will more seriously reflect upon our own attitudes and beliefs about special education and children with disabilities and how those beliefs are reflected in the way we communicate in and out of meetings with and about families. In a recent article Dabkowski (2004) asked school personnel, “Do you actively invite parents to participate?” (p. 34). She and others offer several useful suggestions for building “team culture.” Implementing such efforts is long overdue. Imagine what we can do together, when we refocus our energies from distancing parents to addressing more meaningful questions such as, “How can we make this work?”

Postscript
Since writing this paper, our relationship with school personnel has significantly improved, in part, due to monthly team meetings and, in part, due to general and special education teachers, with the support of administration, having time for team planning and team teaching. Special thanks to Professor Christopher Kliewer for his encouragement and helpful suggestions.

References


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