

# *Planning a Good School Experience for Children with Autism: A Family's Story*

Ling-Ling Tsao, Ph. D. & Dena Krueger

University of Idaho

## *Abstract*

The purpose of this article is to present a parent's perspective on collaborating with the general education of their son with autism. It is a story of how both sides worked for the educational benefit of a child with autism.

## *Planning a Good School Experience for Children with Autism: A Family Story*

Autism occurs more often today than ever. A recent study reported the prevalence to be 1 in 150 children (Centers for Disease Control, 2007). As a result, there has been a surge in the attention given to instructional considerations for children with autism at school. However, the availability of well trained and knowledgeable personnel to organize programs for the preschool and school age children with Autism Spectrum Disorder (ASD) is highly variable (O'Brien & Daggett, 2006). One of the clear needs in the field of autism is to increase the number of well trained professionals to work with children and their families (National Research Council, 2001). Meanwhile, when parents first learn that their child has autism; most of them do not know anything about it. Some parents quickly begin their learning journey into the world of autism spectrum disorders; many parents become immersed in reading and studying everything they can find about ASD. Later as they meet with professionals at school, they sometimes find they have more to say than the professionals because they have been developing their own kind of expertise about autism (Hodge & Runswick-Cole, 2008). Yet, it is unrealistic to expect all classroom teachers to be autism experts; a more practical approach is to support parent-professional collaboration on behalf of children with autism.

To date, the value of parental input has gained increasing recognition when it comes to providing services to children with disabilities (Prezant & Marshak, 2006; Spann, Kohler, & Soenksen, 2003). As a result, more and more professional training programs are preparing professionals to understand the importance of parent involvement and collaboration. Professionals who understand that past experiences influence current attitudes about services and/or service providers can respond to negativity with empathy and support. Moreover, professionals who are willing to help parents learn about and negotiate the world of special education services somehow contribute a great deal to parent involvement, a sense of collaboration and trust in professionals (O'Brien & Daggett, 2006).

## *Parent Teacher Collaboration*

Collaboration is regarded as "a style for direct interaction between at least two co-equal parties voluntarily engaged in shared decision making as they work toward a common goal" (Friend &

Cook, 2003, p. 5). It characterizes collaboration as voluntary, sharing mutual goals, responsibility for decision-making, resources shared, and accountability. Somehow, speaking of “collaboration” seems easier than actually implementing it. Parents often see their child in a lifelong context and their future; professionals sometimes see the child who needs services within limited resources provided by school systems. For parents and professionals to come together on behalf of the child, they must be able to share their sources of information and their perspectives (O’Brien & Daggett, 2006). To identify the perspective differences between parents and professional might actually help each other to find a common ground to support children with autism as their utmost goal.

In fact, many training programs at universities and colleges provide a class or two to help pre-service teachers understand the importance of collaboration with families of school age children. There are also many printed materials available to support teachers’ professional development. However, there is a dearth of materials or information regarding families of children with special needs on how to collaborate with professionals on behalf of the child. Most literature studies have addressed how school teachers can support and collaborate with parents of children with ASD but few have pointed out how parents might become an active part of building collaboration with school teachers particularly when they may not get adequate support or training in teaching children with ASD. Therefore, the purpose of this article is to share a family’s story of how Tyler<sup>3</sup>’s parents initiated and worked with general education teachers to support Tyler’s education at an elementary school.

### *Tyler’s Story*

Tyler is a very smart, active, and sensitive boy diagnosed with autism when he is three and a half years old. He enjoys activities including Thomas the Tank Engine and Friends, coloring, reading, playing on the computer, and playing trains with his father. At school he enjoys playing with his friends, recess time, and loves math classes. Tyler also has participated in an early intervention applied behavior analysis (ABA) program for three years before he becomes a kindergartener at a faith based private school.

**Preparation for the journey.** When the time came for Tyler to attend kindergarten, Tyler’s parents, July and Sam, sent a letter of introduction to school administration, the principal, and his future teacher several months before the school term started. They wrote a letter (see appendix A) to introduce Tyler and autism to school personnel. In the first letter to the school, they addressed their intentions for Tyler’s education, what they were looking for, and what they were willing to contribute to the classroom to support teachers in teaching Tyler. The letter aimed to help the school know them not only as parents of a child with autism but also as a partner to share responsibilities for teaching their child. July and Sam also made appointments and met with school administrators and staff to discuss what the roles and expectations of all involved. The first letter to the school was an early, clear commitment to collaboration, which is the key to successful working relationships with school and teachers (Daven, 2004; Stivers, Francis-Cropper, Straus, 2008).

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<sup>1</sup> Tyler and all other personal names in this article are pseudonyms.

Although July and Sam initiated the conversation and seemed confident on how to best educate Tyler, they went to school and talked to staff and teachers to learn how to create the best possible education environment. Sharing leadership is another key when teachers, administrative staff, and parents come to build a successful collaborative relationship (Hines, 2008). On one hand, general education teachers have considerably more knowledge and experiences with his/her content area. The parents of children with disabilities have an understanding of their child's learning styles and how to make modifications to support their child's learning needs. By the same token, the administrative staff also makes an effort to understand each member's point of view and encourage teachers to share ideas about lesson plans, classroom management, and assessment with parents before beginning the school year to ensure the success of collaboration (Wolery & Odom, 2000).

July and Sam then went to school and met with the staff and the principal; they talked about what they thought were Tyler's educational needs, expressed their willingness to work with school, and answered questions that the school had. Three weeks later, they received a call from school about welcoming Tyler to his new school in the fall.

It should be a given that each individual engaged in a collaborative activity has resources to contribute that are valuable to reaching the shared goal (Friend & Cook, 2003). After the meeting, July began preparing a binder for Tyler's teacher based on the conversations they had at school. It included information that was necessary for the school to support students with autism in their learning needs. July hoped the binder would provide enough information for teachers on teaching children with autism. This binder would be delivered to the teachers four months before school began.

**Autism binder.** There were four sections in the binder that included general information about autism, Applied Behavior Analysis (ABA), learning styles and educational resources that focus on autism. The first part provided information regarding what autism is and the features and characteristics of autism spectrum disorder. July printed few pages from Autism Society of America website and handouts that she had from the conferences, workshops, and meetings that she went to. The second part was about ABA. Tyler had received ABA training since he was about four years old so July thought it might be helpful for teachers to know what training methods had been used with Tyler. The third part of the binder was regarding learning styles. July put some fact sheets or handout of modifications and accommodations to support students with autism in class. July provided a sheet of few techniques on how to calm Tyler down, keep him focused, and so forth. The last part included resources that July used to help prepare teachers to work with children with autism. Among the resources were different aspects such as how to inform classmates and others about autism. Sometimes, she included a few videos that covered Tyler's performances in communication and social interactions with other children at home for the teacher to learn more about Tyler.

A follow up letter with additional information on Tyler would be sent to his new teacher, Ms. Freed, about three months before the school term started in fall. July used this chance to offer parental involvement (e.g., classroom aid) and support as needed. Communication was the main focus of the letter, such as the discussion of how teacher/parents communicate during the year and scheduled meetings between teacher/parents. A communication folder with lined paper would be utilized on a day-to-day basis.

Two weeks before the start of the school term, July called and set up meetings with Ms. Freed and Tyler in her classroom. This allowed Ms. Freed and Tyler to get to know each other and for Tyler to become comfortable in the classroom he would be in. In their first meeting, July asked if Ms. Freed could do an activity with Tyler so that Tyler had an actual experience of interacting with his teacher. After the meeting, July spent time talking with Tyler about his experiences in class and helped him get ready for the school term. This visit also allowed Ms. Freed to establish rapport with Tyler and observed his behaviors and performances in a direct and personal manner. This type of activity would really establish the trust, openness, and reciprocity relationship between parents and school teachers (Dunst, Trivette, & Deal, 1988).

**Beginning the journey.** During the school year, open communication between parents and the school administration, principal, teacher, and therapists was vital. July usually wrote a note to school regarding things that came up during the school year, such as picture day or field trip (see Appendix B for an example). July also offered assistance in the beginning of the school term to transition Tyler into the classroom. She stayed in or outside of classroom to conduct brief observations on Tyler's behaviors and performances and helped both Tyler and his teacher to a successful transition in the classroom.

For example, on the first day of school, July's observation notes to Ms. Freed included:

*T's a huge water drinker—may need to think how we could meet his need for water at school. Will monitor and observe further.*

*T had difficulty drinking out of milk carton at lunch; I will send straw with lunch.*

*Plan for tomorrow: mom present till first recess, then leaves and returns at lunch recess for rest of the day.*

When things did not go well, July would use notes more often with Ms. Freed and other specialists at school. For example:

*July: T did not want to go to school today.*

*Ms. Freed: T having some minor difficulties in the classroom. "weepy" today.*

*July: T did not sleep well last night. Seems to be doing OK this morning.*

*Ms. Freed: T don't want to put thumb on an ink pad to make a thumb print today (sensory issue)*

*July: T verbally acting out over the weekend.*

*Ms. Freed: T upset over a game during recess today.*

*July: T is expressing some anxiety. Just to give you a heads up*

*Ms. Freed: T had a good day.*

During the semester, Tyler's speech pathologist (SP) could not hold a regular therapy time with Tyler and a problem arose.

*Ms. Freed: T had a meltdown at school today.*

*July: Let's get together for a parent conference and discuss this.*

*Ms. Freed: SP at school today but did not get T for therapy.*

*July: Just to bring you up to speed on my meeting with SP. The plan is to see T between 8 to 9 am on Mondays. Feel free to discuss further with me if needed....I tried to "lock" her in on a time as this will help T to know when to expect speech therapy during the week. If*

*her Monday schedule gets changed, I have asked her to give us a heads up for your and T's benefit.*

Few weeks later....

*Ms. Freed: SP is still inconsistency with time of therapy and this is disrupting my classroom and putting T on the negative for going to SP.*

*July: I contacted SP regarding her scheduling inconsistency. She states 11:00am on Thursdays will work for her.*

*Ms. Freed: T refusing to go to SP.*

*July: since picking T up from school, he has been VERY confrontational and weepy. This includes shouting/screaming verbal "tantrums"...this is not like him.....he is probably trying to "gain" some control over his environment...refusing to complete homework tonight.....stemming and patterning a lot.....don't hesitate to call me....I can be there to help keep him focused today...*

*Ms. Freed: T received a hugged from me for reassurance today.*

*July: we have an emergency IEP meeting with T's team to discuss inconsistency with SP and how to resolve this matter. Until then, do not send T to SP.*

*Ms. Freed: I am available whenever you need me for the meeting.*

July and Ms. Freed used their daily notebooks through the school year; information from parents at home gives an ongoing picture of behaviors and progress. Frequently, family members have developed ways of assisting at home that can be included at school. For example, July and Ms. Freed used it for information sharing, such as what happened in the child's day or night, what activities the child participated, special events, instructional themes in class, and opportunities to do troubleshooting which were also mentioned as benefits by Davern (2004).

**Continual journey.** In late winter of school team, July wrote an introduction letter to the next teacher in line for Tyler. This letter was to introduce Tyler to the next teacher so the teacher might have an opportunity to observe Tyler at his current classroom and/or talk to his current teacher. A follow up letter would also be sent out in March or April to the next year teacher, including the bag with the binder of information and other resources. Tyler's current teacher kept the information most of the school year; then July retrieved it back during late spring time to make adjustments for the next teacher. Again, July would set up one to two meetings with the next teacher during the summer months to see how she is doing with the preparation work and if she has any questions, concerns, or need assistance. Again, before school begins, July, Tyler, and his new teacher will have a meeting to allow the teacher and Tyler to get to know each other and for Tyler to become comfortable in the classroom that he will be in. During the school year, a folder containing brief information, such as a quick reference guide is given to the teacher for the school year. It is kept by the teacher and retrieved at the end of the school year so July can revise it for the upcoming school year.

Now, Tyler is a happy second grade child and very successful in the classroom. He still has good days and bad days, but he loves school. The school has also taken on three to four more students on the autism spectrum this past year because of good experiences of teaching and working with children with ASD. July and her husband are very pleased and continue to be supportive to these teachers, the school administration, and other families of children with autism.

## July's experiences

*As a parent of a special needs child, I would like to share not to be afraid of the school systems you are a part of. Don't be afraid to ask straight forward questions and offer what you are willing to do to help them and your child to succeed in learning. Be an advocate for your child and don't give up. This would include any classroom modifications that may be needed. My husband and I are willing to offer financial assistance to the teachers to attend workshops and seminars that focus on teaching strategies for the autism spectrum. This includes a paid teacher sub, seminar/workshop fees, gas, meals and lodging. We also offer to pay for a classroom aide for our child, even though at this time he does not require one.*

July's experience in working with families and teachers is that not everyone has all the information on how to help the child to learn. They need to listen to each other and have open communications with each other is the key to success. For example, a teacher may want to try a teaching technique that parents may not be familiar with in working with their child. On the other hand, teachers need to listen to the concerns of parents who know their child very well. It's the mixture between the two that helps build open and working relationships for the benefit of the child.

*July: We have been blessed to have teachers willing to listen and work with us as team members. I also have seen techniques that worked with my son that I was not familiar with.*

## Conclusions

**A word for families.** School professionals may not have extensive experiences providing accommodations for children with autism. Yet, they might feel it is their responsibility to know how to meet students' learning needs. Indeed, many do. However, teaching students with autism is very challenging because each student's learning patterns are different and finding an effective teaching strategy for individual students takes time. Won't it be easier to get a positive response from school if a parent says "my child has different learning patterns from most of other children so how are we going to address this" than another parent demanding specialized instructional services for his/her child with disabilities because they are required by law? Open communication is the beginning to build a positive relationship between parents and school teachers. Till then, parents can share all of their research and information with school educational teams and why it is beneficial for their child. As July often said, it is a matter of putting all ideas together and seeing what makes the most sense for school teachers.

When July was asked about how to help students with autism at school, she said,

*"When it comes to working with children on the spectrum, many of these kids are motivated to learn when given short goals to achieve and are rewarded for reaching those goals or responses. Rewards are usually more in the beginning until a trusting relationship has formed and then these rewards are slowly backed off over time. Rewards should be something the child enjoys and is willing to work for."*

**A word for school teachers.** Parents are seen as collaborators and equal partners with school teachers these days. Studies also indicated that the characteristics of effective collaboration identified by parents as being open mindedness, free thinking, and a willingness to take on board new perspectives (Hodges & Runswick-Cole, 2008). Since more and more general education

teachers who include children with special needs in their classrooms now need to work closely with parents of all children with and without disabilities, teachers now must work with parents together to help children with autism to develop the skills that they need.

Parents may know what works for their child but may not know where to start a conversation with school teachers. The building of positive school/home partnerships requires that the family be viewed as a key partner in the education of a child with a disability. Successful school experiences require the involvement of parents. Turnbull and Turnbull (1997) speculated that some parents may not have the motivation to assume a more active role or may lack of the requisite knowledge and skills to become active participants in their children's education. As a result, parent empowerment and family centered services should be emphasized while building collaborative parent professional relationships. Collaboration involves sharing of information and resources as well as expertise and a commitment to jointly reaching decisions (Friend & Cook, 2003). Collaboration means that professionals no longer have power over families but rather achieve power with families. In view of practical limitations of programs that provide specialized training for teachers that work with families of children with disabilities, it is the hope of this article to demonstrate that parental efforts at collaboration can support the educational needs of children with autism.

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