



Complex Child E-Magazine

www.ComplexChild.com

The Other Side of Learning: Coming Together for a Common Goal

by Jennifer A. Peterson

My son Thomas is currently in full-day Kindergarten. He enjoys art, music, computers and gym class. He is reading and comprehending at a level equivalent to the end of First Grade. Thomas looks forward to seeing his classmates each day. After school, he likes to unwind for some time and then transitions to our family's usual homework and bedtime routine. As with any child his age, Thomas is somewhat reluctant to engage in his homework. Sounds like any typical kid, right? What you don't know is the work that it took to get him to this point of success.

Early Intervention and Preschool Programs

As a family, we had recently moved from another state and received the first diagnosis of Thomas' GI condition, an eosinophilic disorder, months before. Our world was still reeling and he was missing more developmental milestones, in addition to his medical circumstances. Thomas was referred to the Early On program through our intermediate school district, a program based on Part C of the Individuals with Disabilities Education Act (IDEA), a federally mandated directive that guarantees a free and appropriate education to school-age students. Therapies were coordinated through Early On at no cost to us. During the summer after Thomas turned two, he received twice weekly Speech and Occupational Therapy sessions in our home.

One of the goals behind Part C of IDEA is to provide services in the child's most natural environment for his age, typically the home. We also participated in a playgroup run through our local Great Parents/Great Start group. At first, I was unaware of what to look for when trying to note subtle skill improvements. For example, one of the first things the playgroups teach is *attending*, or sitting still and paying attention during story time. Thomas wasn't having any of that. For the first few sessions, he instead flitted around the room from one area to the next. After a month had passed, one of the employees pulled me aside and whispered happily, "He's making smaller circles!" What she meant was that he was starting to gain the skill of attending. In no time, he was ready to sit for story and circle time.

After Early On, Thomas began preschool, primarily in an Early Childhood Developmental Disabilities classroom. Thomas did make initial gains in his social and academic skills in this classroom during his first year of special education preschool.

However, his gains leveled off once he was included in a classroom with typical students four afternoons a week. We thought he would benefit from spending Fridays in the separate classroom when the typical class was not in session. It turned out that although he was familiar and friendly with the staff, their time that year was spent more on classroom management due to the magnitude of needs within the classroom. This is why having my son in a classroom all day with students who have severe emotional or cognitive impairments would not be an appropriate placement for him.

Mastering the IEP

When we were preparing to schedule the Individualized Education Plan (IEP) team meeting for his first year in a regular elementary school, I often dreamed of holding it in my living room. It was sheer coincidence that we lived directly across the street from the school Thomas would attend. If anything, we could emphasize the point of getting him from here (home) to over there (school). For what it's worth, maybe some of the other members of the team are visual learners. The intent of this meeting was to develop a special education plan that would support Thomas' learning in a regular kindergarten classroom.

As a mother, part of me felt as though we were throwing Thomas to the wolves. He had too many health issues to be without an aide, yet he also had social deficits that could make him an easy target for teasing. Enrolling Thomas in public school was necessary to receive the federally mandated supports *and* for him to grow as a student. Although there are self-contained classrooms, special education is supposed to be regarded as a SERVICE, not a PLACE. There is no such thing as a "special education curriculum." The goal of special education is to assist the student with gaining access to the general curriculum and this is what the fundamental idea of inclusion is all about.

I often think of the process of developing an IEP as being like Finals Week in college for every member of the IEP team. The difference is that the success of everyone's efforts is not immediately known. It doesn't always matter how many hours are poured into testing, evaluating, sharing and negotiating. The success of the team's combined effort is manifested in how well the student performs academically, emotionally and socially during the time the contract is in effect.

The IEP we developed last May was the most important one to date since Thomas was transitioning into a new school and into a regular, full-day Kindergarten classroom. As parents, we had to more or less teach the teachers everything there was to know about the multiple health, neurological and academic issues that come with having Thomas as a student. He can be considered *twice exceptional*, as he has health issues that affect his ability to learn, yet he is highly intelligent in some academic areas. About a week before school started, I prepared a PowerPoint presentation for a handful of school staff. We also thought it would be a good idea to do a hands-on live Epi-Pen demonstration with some day-old grapefruit. The staff was also familiarized with the enteral feeding pump supplies they would have to use.

One of the most important things I have learned is that communication is vital. Any medical reports we receive are almost immediately forwarded to the school in the case they may affect his performance. I don't mind the numerous daily telephone calls with the school or medical personnel to coordinate appointments and services. After all, it all comes together and has an impact on Thomas' education. A valuable tool we have used is to hold a monthly staffing with most of the members of the IEP team. By doing this, we can share information as it comes along and nip issues in the bud before they become full-blown problems that interfere with Thomas' ability to learn and participate.

As was our experience, a great number of IEP teams meet during the month of May. Unless summer services are arranged as part of the discussion, most of the accommodations, modifications and other supports will not be utilized until the Fall. Another fact to consider is that the IEP team has most likely had enough meetings regarding other students qualifying under IDEA that they are starting to see double. If your meeting happens to be scheduled for a one to two-hour block after school, be prepared! Bringing food works great. Not only does it raise morale but everyone's blood sugar will be on par in order to concentrate on the task at hand. In addition, the IEP can always be adjourned to a later date and the team can pick up where they left off (whether it is due to a stalemate in the dialogue or if additional information about the child is to be sought). Just as special education is a service and not a place, an IEP is a *process*, not an event.

Problem Solving

Most of my problem-solving strategies are out of the pages of the many books written by Peter and Pamela Wright, the co-founders of Wrightslaw.com. As I am also a former paralegal, they drive home the point of documenting every phone call, piece of mail (delivered or electronic), medical record and conversation. Preparation for meetings and appointments is mandatory if you want to get the results you desire for your child.

There have been occasions when we have had to back up a request for services with proper information and research. We have also learned the hard way that if we want to find the answer to a question, most often we must do the necessary legal or medical research to get the correct answer. At best, general education and teachers certified in special education only have a couple hours of training in special education law.

It is my personal philosophy that, as with any democratic system of government, no leader wakes up wanting to completely mess with the lives of the people they are responsible for. The same goes for school employees and officials. Unless they are true sociopaths, these people really want what they think is best for your child. The will to help the child is there; it is their approach that may be different.

During the first six months of our journey into special education, my husband and I had the deer-in-the-headlights look during meetings with school staff and administrators. We

had to hand over control of our child's education to them and hope that what they did for Thomas was going to turn out fine in the end. We have no doubt that our son has had very positive outcomes in his experience with special education services and supports. There are many families who do not fare as well or do not have the adequate effort or support from their school system. It is my hope that as parents we continue to share information with each other so navigating the path to appropriate education for our children is not as lonely and frightening as it may sometimes be.

I must remember at times that we have been at this for only four years. We started out by treading water and slowly venturing out to the deep end of the pool. There is no lifeguard on duty because *we* are the lifeguards for our child's education. In the end, we must also learn to trust the other swimmers who want to lend a hand and help him along.

For more information, see these resources:

- Wrightslaw.com
- "Do You Hear What I Hear?" by Janice Fialka http://www.amazon.com/Parents-Professionals-Working-Together-Children/dp/1882792858/ref=sr_1_1?ie=UTF8&s=books&qid=1233025369&sr=1-1
- Mito Action: <http://www.mitoaction.org>
- Food Allergy Information: <http://www.foodallergy.org>

Jennifer Peterson is an at-home parent and uses her experience as a Paralegal to ensure the medical and educational needs for her children. Her son Thomas is a delightfully complex child with the diagnoses of multiple food allergies, Eosinophilic Gastroenteritis with a GJ tube for enteral feedings, High Functioning Autism, and most recently Mitochondrial Disease (Complex II and IV). Despite everything he has been through, Thomas remains a chipper, smart and cute little kiddo with an infectious smile.