

A young boy with light brown hair, wearing a green t-shirt with two white stripes across the chest and dark pants, stands in a school hallway. He is leaning against a grey locker on the left, looking upwards and to the right with a thoughtful expression. He has a dark backpack on and is holding several books, including a prominent green one. The hallway is brightly lit, with a set of double doors visible in the background.

Enough is

It's your child's first day of school. Teary-eyed parents watch and wave, hearts swelling with pride as their little ones step into a new phase of life. The picture for parents of children with autism is often not as rosy, but rather filled with trepidation. They may begin the trip feeling supported by a promising host of acronyms – IDEA, FAPE, NCLB – but they frequently find the journey a constantly changing experience, a road cluttered with speed bumps arising from red tape, school policies and budget constraints, all running contrary to their expectations.

Conflicting attitudes surface about accommodations and services for the child. Parents find themselves shouldering unanticipated external pressures, such as obtaining accurate evaluations and finding (and funding!) necessary services. The lack of even a foundational understanding about autism is an eye-opening shock, with ripples of discord and miscommunications making it difficult for IEP team members and parents to maintain a collaborative balance.

This is hard work for everyone involved: parents, teachers, and

Enough:

Stop Fighting, Start Looking for a New School

By Sandi Busch

administrators. In the end, whether the path has been defined by cooperation or confrontation, many of our children with autism still will not have the needed and appropriate supports and services at school for emotional, behavioral and academic progress. At some point every parent wonders: is this the right school for my child?

The Long Hard Road

What some parents endure as they strive to create the best program for their child is almost unimaginable, even to those deep in the special education trenches. Four moms shared their stories and the challenges that caused them to consider different educational placement. These moms were devoted to overseeing their children's education. Some of them quit satisfying and successful jobs to meet commitments for meetings, interventions, communication and therapy. In hindsight, they see everything was part of the road leading them toward the decision to switch schools.

Amy's son loved pre-school and kindergarten. He talked up a storm in classic Asperger's style. But everything changed one month into first grade. He

stopped talking except to say he didn't like school, he didn't want to go, and then the comment that would break any parent's heart: "Can you keep me safe, Mom?" Amy immediately expressed her concern. His teacher replied, "Everything here is fine." Then one day a note came from school saying there were problems; that her son refused to work and had meltdowns. A meeting was called and during that meeting Amy learned her son was being put into a room every time he had a meltdown. The "calm room" was nothing more than a closet with no windows, with a rug and a therapy ball. The school did not perform a functional behavior analysis. The IEP team did not create a plan for positive behavioral supports. Even worse, they did not contact Amy first to discuss their choice of action. They just closed her son in a room alone, sometimes for as long as 30 minutes, until his screaming stopped. Amy considered whether to invest time and money in a legal battle or put her efforts into something that would help her son. The decision to opt out of that public school was easy, especially after her son was diagnosed with post-traumatic stress disorder as a result of the inappropriate restraints.

Kathy's autistic son was enrolled in a public school that only offered regular education or life skills classrooms. The team recommended private placement but upon review, the approved private schools were all clearly inappropriate for her son. The school agreed to include him in the regular education classroom with full time support from the county's behavioral health wraparound program. But, before the support person was allowed into the school she had to sign a contract, one that stipulated she was prohibited to discuss with Kathy (or any parent) anything that happened during the school day. Feeling caught in the middle and unable to do her job properly, it wasn't long before the aide quit and Kathy's son was left without one-on-one assistance. Without that critical support, her son's behavior disintegrated and frequent behavioral outbursts followed. Whenever that happened, he was sent to the life skills classroom, little more than a babysitting stop, where he received neither appropriate support nor academic education.

Carol's son survived in public school through 9th grade even though their district offered no autism-specific

support programs. A good year was when the teachers tried their best in spite of no training on autism. Most years were marked by lack of communication and a failure to implement plans agreed upon in the IEP. In 8th grade her son was physically attacked by students. The school did nothing. In 9th grade he was harassed in the gym. For several years he had been blatantly bullied by not just students, but teachers also. In spite of Carol's best efforts – and they were many - no one at the school intervened. Every day he came home incapacitated from the stress endured at school. "Year after year I thought it would get better," she said. "I hung on too long to the ideal that they would do something."

Patty was satisfied with the effort her school team put into helping her son with Asperger's overcome his emotional and sensory issues, although she also encountered the "everything is fine" syndrome. She talked with his special education teacher every afternoon and was almost always told it had been a great day. In preparation for an IEP meeting she asked the teacher to document any behavioral issues that needed a better plan. Even knowing that his "great days" must have had some difficult moments, she was stunned to read details about serious meltdowns that had never been communicated to her. Patty said it sometimes felt like teachers were blindly programmed to squeeze her son into the same mold as all the other students. In the middle of an emotional crisis so severe that hospitalization for her son seemed imminent, she called a team meeting and asked them to drop all expectations for a few weeks. The principal, who was usually extraordinarily supportive, said, "We can't do that because we have to prepare him to move up to middle school." It was a complete disconnect between individual needs and institutional

requirements. Her son's energy was consumed by the effort required to maintain control at school, leaving him with no emotional reserves and unable to participate in any activity outside of school. When he got home he either withdrew or had meltdowns for hours. "Where's the quality of life in that?" Patty asked.

Mapping a New Direction

When you're in the middle of a struggle with a school system it's easy to get caught up in emotions and hard to take a step back for a fresh perspective. Amy, Kathy, Carol and Patty kept their focus on six principles as they searched for the right course of action.

1. Know your child ... well.

It all comes down to thoroughly knowing your child because that's the only way to confidently pursue their needs. Along this path, when you're faced with choices about accommodations and programs, you will need that conviction. It also provides courage when teachers, administrators, health professionals, family, friends and society in general are all saying you should be doing something different. Know your child. Stand your ground.

2. Dig deep to discover what's happening at school.

Realize that even under the best circumstances you may be way outside the communication loop. This simple awareness works to your advantage. Ask questions like a pit bull while maintaining a calm exterior. Don't assume anything.

3. Don't settle for business as usual.

Some education standards are spouted like billboards along a crowded highway. One of the most

common regards socialization: "how will they learn socialization if not in this school?" If your child spends most of his time in an inappropriate environment or his free time being bullied and called names ... what kind of socialization is that? Challenge the team to think outside the box.

4. Research your options.

What approved private schools are on your school district's list? Are any of them appropriate for your child? Are other public options available? Would cyberschooling, homeschooling or an in-home tutor work for your family? Are you willing to move to a different school district? Does your state offer special funding for different school options?

5. What are you fighting for?

What outcome can you expect if you continue to fight with the school? What are the chances the school will agree to the accommodations? And even if they do, how long will it take them to implement the program? Are you certain they will even do that? Agreement and action are not the same.

6. Don't let the fight become the focus.

What's happening to your child while you fight the school? Don't take too much time negotiating if your child suffers in the meantime. If your child is increasingly frustrated, anxious, withdrawn, acting out or melting down ... take action. *All the parents adamantly agreed: Don't wait too long.*

Finding True North

Making the decision to switch schools – usually done standing alone against

the majority opinion – was the best thing that ever happened for these parents and their children. It was never viewed as a failure or made with doubt. Their challenges were channeled into the needed fuel for taking action. And, for these families, it was quite simply the right choice. Their children have thrived since different arrangements were made.

How do parents embroiled in difficulties with their school know when they've come to that fork in the road and it's time for a new school placement? The four moms shared this from their experiences:

- When the emotional, physical and financial toll becomes such that your child is losing *you* as the best parent you can be.

- When the resolution to the problem is not on the immediate horizon.
- When you've given the school every opportunity but things haven't improved. It's a world of difference to have your child in the hands of people who don't have to be pushed or sued to do the right thing.
- When quality of life is diminished and your child fails to progress or is simply falling apart.

Realigning Your Compass

Let's consider one of those acronyms – NCLB (No Child Left Behind). Would it surprise you to learn that one of the hallmarks of NCLB is “expanding educational opportunities”? NCLB seeks to enlarge school choice by encouraging a variety of public options such as

charter, virtual and magnet schools and by providing tuition assistance. Check it out.

Finding a truly individualized strengths-based program is an attainable goal. If your child's current educational placement is falling short then maybe it's time to consider changing schools.

As Carol said, “Every family has to decide what will be right for their child ... and thank goodness we can!” 🙌

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