

# Navigating the Storm: Advocating for your Special Needs Child

by Amie Borst

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<http://www.iser.com/resources/advocate-mom.html>

**Turbulent:** 1. causing unrest or disturbance 2. characterized by agitation or tumult. This word is the one that has come to describe my experience advocating for my child in the special education system. I wish however, the word had been something more flowery or hopeful or even simply, happy. But, advocating for a child's needs in today's education system is not an easy one. While it may not cause agitation for everyone, it certainly is a time of great unrest.

I entered the system optimistic and completely ignorant. I returned feeling distraught and defeated but very educated. Initially, I believed that the school would always have my child's best interest in mind, but that ideal was quickly put to rest as we experienced nine months (and counting) of opposition. While my story is not unique, nor not unlike many who advocate for their children, there are things I have learned along the way that have changed my perspective. I cannot justify keeping my experience, and what I have learned from it, to myself. Not sharing it would be an injustice to every parent or guardian struggling to fight for their child's rights. Do we not have challenges so that we can gain knowledge and in sharing it, others might benefit?

As a mother, my greatest desire was to aide in my child's education and learning. If I could also provide support to teachers, then I was willing to do that. When called upon by faculty, my response was without delay or hesitation. I actively engaged myself as an involved parent, happily assisting teachers with classroom responsibilities, throwing class parties as room mom and as an active member of the PTO (Parent Teacher Organization). However, when I noticed my child was struggling and falling terribly short of her potential, the school was not as eager to respond.

Although my child's disability does not confine her to a wheelchair or render her unable to communicate, she still very much suffers from disabilities which prevent her from achieving her best. Her disabilities may not be devastatingly severe, but I have learned that, the existence of any disability can be severely devastating.

My heart broke when I learned of my child's auditory processing disorders, short term memory deficiencies, speech and language shortcomings and her ADHD. I wondered what it must have felt like for her to drown daily in a classroom full of noise, commotion and activity. To try to focus her attention despite the background clamor that incapacitated her ability to listen effectively. To try to sit still and be obedient when her body and brain were screaming to move. To try to remember the lesson discussed but the information seemed just beyond grasp. I wondered how she managed to pass through four years of school with these distractions. I wondered how these disabilities went completely undetected by the school system. I wondered why, when I brought them to the attention of the school staff, they offered only band-aid solutions instead of services designed specifically for her needs.

The school seemed, to put it kindly, reluctant to offer special education services, even going so far as to say family history and the private evaluations were insignificant and insufficient information. But, despite their insistence and lack of interest, I followed my gut instinct. The one thing I knew: they were wrong. The one thing I didn't know: how very wrong they were. Thankfully, we had resources from the very beginning that aided us. I believe everyone advocating for a child should have these same tools.

### **#1 Know your rights**

Your greatest weapon of defense in dealing with the school system is being familiar with the special education law; Individuals with Disabilities Education Act (IDEA). [www.IDEA.ED.Gov](http://www.IDEA.ED.Gov) Each state has their own set of special education rights, but ultimately they have to follow and implement the laws outlined in IDEA. To obtain a copy of the special education guidelines for your state, or for more information, check your local school or your state's Department of Education. Schools are unprepared for parents who have taken the time to educate themselves. While initially, they may feel threatened by your comprehension and knowledge of the rights entitled to your child, in the end it will demand their respect.

### **#2 Hire an advocate**

While not every family is in a financial position to afford this, every family should at least have a parent advocate at their disposal. A terrific link about advocates is found here [www.wrightslaw.com/#advocacy](http://www.wrightslaw.com/#advocacy). Our advocate, Dr. Judith Greenberg, PhD at [www.schoolfinders.net](http://www.schoolfinders.net) was an invaluable resource to my husband and me. She provided information and instruction that otherwise would have been unknown to us. Her wisdom and emotional support were limitless and a precious reserve when our tanks were empty. She gave us hope and direction to navigate through the system.

### **#3 Learn the Lingo**

RTI, SERT, IEE, IEP – What? This is only a portion of the jargon and lingo that you will quickly become accustomed to hearing. While the acronyms may be different in each state, typically the process, and what they accomplish, will be similar. I've outlined a few for you.

Because of the recent changes made to IDEA, schools now have the option to try Response to Intervention (RTI) before anything else. RTI may work well for some children, particularly children who struggle in the classroom that do not have a learning disability (LD). RTI's might include, but are not limited to: preferential desk placement, desk "buddies" and positive reinforcement and feedback from teachers.

Special Education Referral Team (SERT) is the step that follows RTI. This is a meeting to discuss the needs of the child if the RTI has been unsuccessful. A team of individuals will meet with you, the parent or guardian, and your advocate. Typically the team will consist of your child's teacher, the principal, the Special Education teacher, a social worker, an Educational Diagnostician and school psychologist. The team will address concerns about your child, if further information is warranted or required for a clearer picture, grades, classroom performance, teacher feedback and any testing or evaluations that have been done.

The school may then decide to do a "battery" [www.jstor.org/pss/1510945](http://www.jstor.org/pss/1510945) of tests, to confirm or deny the existence of a learning disability. Once these tests are completed, the

team will meet again for an Eligibility Meeting. The intent of this meeting is exactly as its name identifies; to determine if your child, according to the school's criteria and guidelines, is eligible for services and can be classified as having a specific learning disability.

If your child is found eligible then there will be another meeting to implement an Independent Educational Plan (IEP). This meeting will discuss what they intend to do for your child's specific learning disability. This is a great opportunity for your advocate to use their expertise. Many times, the plans the school intends to put in place, fall short of the child's needs, or merely address it for only a short time (ie: speech mastery of a sound in 2 sessions as opposed to 8 sessions).

If your child is not found eligible, then they will deny special education services. If this happens, and you still feel as though something is blocking or interfering with your child's ability to learn, do not be discouraged. There are options.

Get an Independent Educational Evaluation (IEE). If you disagree with the school's findings in their testing, then the law entitles you to receive an evaluation by an independent consultant, not employed by the school district. The IEE is completed at the school district's expense (no cost to you). Use this tool. It can be to your greatest benefit.

#### **#4 Retaliation is Illegal**

If you have advocated for your child and action was taken against you, the child you advocated for, or any other member of your family, which made you feel threatened or otherwise unwelcome in the school setting, this is retaliation. Do not take it lightly, brush it off as coincidence, or give hopeful anticipation that it will end. If the school personal believes they can get away with these actions, they will. Report retaliation to the Office of Civil Rights (OCR) at the web address listed here:

[www.ed.gov/about/offices/list/ocr/docs/howto.html?src=rt](http://www.ed.gov/about/offices/list/ocr/docs/howto.html?src=rt) You should know that there is a statute of limitations on these disputes. The Office of Civil Rights requires that the alleged discrimination is reported within 180 days. Otherwise, an investigation will not occur. Although the OCR does have options for retroactive cases, these accommodations are usually for extenuating circumstances only (ie: coma).

#### **#5 Get Everything in Writing**

Documents, paperwork, report cards, your child's school file or record and anything that might have your signature on it should be something that you have a copy of and keep in a folder. While asking for copies of everything might annoy school personal, it is your right to have these items. Keep them organized and filed. Should you need to refer to them for any reason, they will be at your disposal. One tricky tactic that school personal like to perform is the phone call. If your case were to go to Due Process the he said/she said of phone conversations would be difficult to prove. Instead, inform the school that you would prefer not to communicate via the telephone. Suggest email or snail mail. There are times when phone calls are inevitable and in these cases follow-up with an email. Be sure to include date, time, person you spoke with and something that says, "As per our conversation today." Forward or CC the email to anyone involved in advocating for your child (spouse, advocate, etc). Print off the email and save it for your records. Typically the school will not respond to these kinds of emails, but nonetheless, you have created a paper trail of evidence should you need it.

#### **#6 Take Notes**

At each meeting you attend, you should be prepared with pen and paper. Label the paper with the date and type of meeting, and then have everyone sign in. Take notes in the

meeting, also. This will give you a point of reference when the school begins to forget promises or gets off topic. Better yet, if the school will allow it, bring a tape recorder. Assure them that you will gladly make a copy for their records. This may ease their apprehension of having such a device in the room. A tape recorder will allow you to listen more intently and can be a great tool to help aid your memory in reviewing the meeting.

### **#7 Dissenting Opinion**

You have the right to disagree with the school pertaining to any determination regarding your child. If a test result seems off, tell them. If a proposed program is not appropriate, speak up. If the team agrees on something, but you don't, just because you are a part of that team doesn't mean you have to silently suffer, or sign the paperwork according to their terms. Instead, in most cases, you will fill out a form with your dissenting opinion. Don't be afraid to make your voice known, get a second opinion or even approach other professionals on the matter. When you stand strong, rest assured, you are doing everything in your power to help your child.

### **#8 Mediation and Due Process**

In the end, if you find that the school hasn't fulfilled your expectations for your learning disabled child, or that a mutual agreement cannot be met, then it is in your best interest to pursue mediation. Unlike due process, mediation is free to you, the parent, and will provide an opportunity for you to caucus with the neutral school appointed mediator. Both sides have a chance to present their case, and help the other understand what it is you hope to achieve for your child. While you may not get everything you hope for, mediation, in most circumstances, will result in a plan that both parties can be happy with. However, if your case isn't settled at mediation, due process would be the next step.

[school.familyeducation.com/special-education/ada/38427.html](http://school.familyeducation.com/special-education/ada/38427.html)

### **#9 It's not over**

If your child receives an IEP through the school, don't expect this to be the end or ultimate solution to your child's learning disabilities. While the services at school can be extremely helpful in providing them with much needed coping mechanisms, and even assist in addressing aspects of the LD, helping your child does not end here. You must consider outside services, counseling and therapy, and other treatments. The school's specialists have very limited time to work with your child, and although they will honor every commitment made in the IEP, there is only so much that can be completed in the course of a school day. There will also be additional meetings to attend and monitoring of the progress to ensure both parties are upholding their commitment as outlined in the IEP.

If your child does not receive an IEP or the school still refuses to provide services that you feel satisfied about, there are other options. Private school, Homeschool, Co-ops, Online programs, the list is endless [www.kidsource.com/kidsource/content/learningdis.html](http://www.kidsource.com/kidsource/content/learningdis.html). Most advocates and doctors will have lists of resources to help you. For some children, the school environment is too stressful and despite everyone's best attempts, the child is better served elsewhere. Don't be afraid to investigate other options. Remember, you are your child's first teacher.

While this certainly isn't everything you need to know about advocating for your child in the special education system, it is a start. Had I known any of these things from the beginning, I would have been better prepared. I figured it was simple; point out a problem, school performs tests and finds problem, IEP in place. Now, I know better. I know that it is a long road and a stressful journey. I know that at times, hope seems something we only dream about. I know that the anxiety can flood into our homes and bring undesired effects into this

most sacred of establishments. But I also know that my child is worth every single tear-filled moment.

For us, despite all we've gone through, we see progress. Not only with the school, but with our child. However, our journey does not end here. It continues onward in the storm of life, a continuous cycle of ups and downs as we persist in advocating for our child. Being an activist for your learning-disabled child never ends. It is a process that will continue for years, not only in the school system but in many aspects of life. Stand strong and unwavering and the benefits to your child will prove worthy of your effort.

I hope your voyage with your child is rich, filled with excitement and discovery. We are all individuals in this journey of life, and what we may see as a great weakness, may be your child's greatest strength someday. Be encouraging, uplifting and hopeful. With your guidance and love, your child will know, beyond measure, the limitless possibilities in their life.

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