

## Stop Playing the Victim - Become an Effective Advocate

### A Success Story by Susan Bruce

#### Difficult Beginnings

My twin boys, Alex and Blake, were about 7 weeks premature. Alex cried all the time. When Blake began to talk, he pronounced the letter "r" like the letter "w."

Little did I know I would soon begin the journey of my life.

I would cry oceans of tears for my children before I began a path of discovery that would forever change my life.

#### Why Can't My Children Read?

When Alex entered kindergarten, his teacher noticed he was having difficulties. He could not pass the school readiness test. His pediatrician determined he had [ADHD](#). No one told me he might also have learning disabilities.

Blake passed the readiness test and seemed to be doing fine until second grade. In third grade, he began to slip in reading and other subjects that required him to read.

I read to my kids. We did homework and extra work together. I made flash cards and bought computer programs to help them. Why couldn't my children read?

#### The School's Response

The school did several "screenings" and said the twins did not qualify for special education. I did not know that the [Individuals with Disabilities Education Act \(IDEA\)](#) requires schools to complete comprehensive evaluations, including [psychological and educational evaluations](#), before deciding if a child is eligible for special education.

Finally, the school completed comprehensive psycho educational evaluations on the twins. The results indicated that the boys qualified for special education services under the category of "learning disabled." Blake had problems in [reading](#). Alex had problems in math.

After a year of special education, Blake's reading skills had not improved at all. The school told me it took about three years to see any progress for children in resource classes.

I bought this, hook, line, and sinker.

The twins repeated the 4th grade to "catch up."

My daughter, Haley, began Kindergarten at this time. The teacher was concerned about her letter-word identification skills.

#### An Education for Me

A parent told me about the book, [Overcoming Dyslexia](#), by Sally Shaywitz.

After reading the book, I was convinced that Blake was [dyslexic](#). Did Alex and Haley also have dyslexia?

I requested an IEP meeting. I took the Shaywitz book with me. I highlighted everything that applied to Blake. The school said they had only seen one true dyslexic child in 15 years, so they dismissed my concerns.

Two statements made at that meeting would fuel the automobile I was about to drive on this special education journey for the

next several years...probably the rest of my life.

- The school psychologist recommended [Recordings for the Blind and Dyslexic \(RFB&D\)](#).
- The principal said that my boys might benefit from this, but it would be very expensive for me.

This should have been a dead giveaway.

Why? Because even though something did not seem quite right, I did not know to ask for [prior written notice](#)!

I read my school district's special education handbook. I found the important phone number for my [state Parent Training and Information Center](#). A PTI is an invaluable resource for the parents of a child with a disability.

A member of the PTI staff told me that if the psychologist recommended RFB&D in my child's IEP meeting, the school should provide it and pay for it.

I began researching dyslexia. I learned that, according to studies done by the [National Institutes of Health](#), one in five children is dyslexic.

I attended workshops on [IDEA](#) offered by my state PTI.

As I learned more, the school began the assassination of my character.

As I continued to learn, I became angrier and felt more betrayed. I trusted these people. They were supposed to be the experts, not me! I depended on them to do what they were educated and paid to do.

## Special Education 101

I decided what I must do.

- **First**, I had to find a way to get [independent evaluations](#). I had to put a name on the face of my enemy.
- **Second**, I needed to become an expert on the [IDEA](#) and my children's disabilities. Either the school lied to me, or they were ignorant about the law too.
- **Third**, I realized I needed to [document everything](#), including telephone conversations.

I borrowed the money for private evaluations.

I heard about a website that had a world of information concerning IDEA – [www.wrightslaw.com](http://www.wrightslaw.com), and it did. I bought two of their books, *From Emotions to Advocacy* and *Special Education Law*.

I read *Special Education Law*.

*Special Education Law* included much of the same information I had learned from my PTI. This further infuriated me. The school told me there was no such thing as dyslexia. But, IDEA specifically includes “dyslexia” as a specific learning disability! Pete Wright is actually dyslexic!

Next, I read *From Emotions to Advocacy*. The first chapter said not to take what had happened personally. I got angry and put the book down. I ranted about what I considered the school's blatant disregard for the law. I sent an email to the Wrights.

## A Mighty Force

I sent an email to Wrightslaw. Pam Wright's answer surprised me. “I can see you know what you're doing, but you are going about it the wrong way. **Stop playing the victim and being the overly-emotional parent,**” she said.

I picked the book up, finished it, and followed the advice. From the Wrights, I learned about the system and how it works.

I got accurate, independent test results from the private evaluation. I requested my children's records and put them together in chronological order. I saw trends. For the first time, I understood what was happening.

Both Blake and Haley were dyslexic. In the school's Special Ed program, Blake made no progress in reading. Alex had auditory processing disorder.

I also learned how to turn things around. I turned my anger into something else - [ADVOCACY](#).

At Blake's [IEP](#) annual review, I invited my school district's compliance officer and the special education coordinator to the meeting.

Although I felt the school had attempted to assassinate my character, I had no proof. I learned from the Wrights to focus only on issues that can be proven. I was determined to get the help my children needed. I would use my emotions as a source of energy. I would become a mighty force.

I walked into this IEP meeting bearing a smile, food, and an arsenal of information. I left my emotions in the parking lot. I focused on the most important issue: my son could not read.

I made charts that showed Blake's lack of progress. I learned from the Wright's book that numbers from tests do NOT lie. When the school said Blake was "making progress," I brought out the charts of test scores that documented his lack of progress. I asked the team to explain these test scores.

The numbers didn't lie. The IEP team agreed with me. They offered Blake one on one [ESY services](#) over the summer.

Since that day, my district began to monitor Blake's progress. They brought in their reading specialist who used [AIMSWeb](#) to monitor all three children. AIMSWeb is similar to [DIBELS](#).

The specialist monitored Blake every month. When he showed little progress, she monitored his progress every week. As we tracked the numbers, we saw that the school's program was not working. Blake was not making progress.

The school called an IEP meeting to discuss Blake's IEP goals. When I asked for more information, the school acknowledged that they did not implement the [Wilson Reading Program](#) correctly. They used an uncertified teacher.

I had expressed concerns about the teacher training issue earlier. I did research on the website for the [Florida Center for Reading Research](#). For a reading program to be effective, the teacher must have "[extensive professional development](#)."

I read a study where 200 students received 62 one-on-one tutoring sessions with a certified Wilson teacher. Their progress was incredible. These kids made nearly four times the gains Blake had in half the sessions. For monitoring, the researchers used standardized assessments so they had accurate baseline information on these kids.

Although the IEP team increased Blake's resource time to two periods a day and he had received at least 130 one-on-one Wilson lessons, he was still not learning to read.

I had to convince my district and his IEP team that to receive a free and appropriate public education, Blake needed a certified Wilson teacher.

## Charting the Numbers

I followed what the Wright's book said about monitoring progress with test scores. I had good baseline data for Blake. I also had the AIMSWeb scores that the school was using to monitor his progress.

- I got my [documentation](#) together.
- I made graphs of every assessment Blake had over the past year.
- I made [Power Point charts](#) mapping his progress since he entered special education.

When the annual IEP review time came, I was ready. I did not feel angry or intimidated. I was informed. **One word**

**describes how I felt - EMPOWERED.**

Again, I entered the meeting bearing a smile, food, and an arsenal of information.

The principal produced a benchmark that showed Blake was reading on nearly the 6th grade level – 3 grade levels higher than the standardized assessments showed.

From my research, I knew that AIMSWeb was 90% effective in predicting scores on [high-stakes reading tests](#). I asked if this assessment was [scientifically research based](#).

The school produced documentation from the publisher that it was research based. I asked the IEP team what education journal documented it as [peer reviewed](#). The principal stated it was in the material she handed me.

I continued to look for this information but it was not there. I asked again.

The principal said assessments do not have to be peer reviewed to be [scientifically research based](#).

The compliance officer leaned over and told the principal that I was correct.

This challenged the validity of the assessment.

The next topic was my concern that Blake's lack of progress was because his teacher did not have the knowledge and skills she needed. She was not certified to teach the Wilson Reading Program.

I really liked the teacher. I felt that without training, she would not be able to implement the program correctly.

A district level employee stated that IDEA did not require a special education teacher to be certified. I agreed that she was correct.

Then, I produced the charts that showed Blake's regression over the past four years and the study of students who were taught by Wilson certified teachers. Blake made some progress but his percentile rank was dropping. He was falling further behind his peers. At this rate, he would never catch up. The numbers did not lie.

I asked if the team thought it was appropriate for a child who received special education for four years to show this level of regression.

The IEP team agreed to contract with the regional trainer for the Wilson Reading System for [ESY services](#). The Wilson trainer gave Blake a battery of assessments before and after ESY. After 22 sessions with this trained teacher, Blake's reading improved by 1.6 grade levels!

The IEP team met before school began to discuss Blake's progress in ESY. During this meeting, I requested compensatory services for the school's failure to provide him with a [free, appropriate public education](#) for the last four years.

I am still awaiting their response. I am not worried. The school failed to provide FAPE and they know it. Better yet, they know that I know it.

## **A Parent's Journey**

If you learn what I learned, you can be an effective advocate for you child.

I now have an excellent relationship with my school district. There is a mutual respect – a vital component of advocacy. You must build [positive parent-school relationships](#). To be an effective and equal member of your child's IEP team, you must gain and maintain credibility.

Make yourself an expert on your child's disability and IDEA. Focus on the issue that needs to be resolved. Thanks to my state Parent Training Information Center and [From Emotions to Advocacy](#) by Pam and Pete Wright, I was able to do this.

The Wrights correctly named their book, [From Emotions to Advocacy](#). There is no other way to describe it.

Here is the question you must answer: Are you willing to take the emotions you feel and turn them into something positive? Are you willing to use your emotions as motivation to learn [advocacy skills](#)?

I knew I was taking a big chance in doing what I did. I was afraid. I felt intimidated and angry. The more I learned, the less I felt these negative emotions. Your emotions can be the driving force in acquiring special education services for your child. Harness them and use them! I did it! You can do it too!

Is my journey over? No. I will have to continue until my children graduate from school.

In 30 years, special education has come a long way. Before the special education law was enacted, many children with physical impairments and emotional or behavior problems like autism were not allowed to attend school. Many school personnel viewed children like mine as dumb, lazy, or as discipline problems.

We still have a long way to go. But, if we parents educate ourselves, work with the schools, and apply pressure in positive ways, special education advocacy will grow and evolve to a new level.

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### **Susan Bruce**

Susan is the mother of three children with learning disabilities.

After spending years researching and learning about IDEA and about her children's disabilities, Susan has spent the last two years applying all she has learned. She's now a "force to be reckoned with" when advocating for children.

She is currently working for her state Parent and Training Information Center. She is the Region 3 Regional Education Coordinator for [PRO\\*Parents of South Carolina, Inc.](#)

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### **Do You Have a Success Story?**

Do you have a success story or advocacy strategy that you want to share?

We are collecting stories about successful advocacy from parents and other advocates. We will post some of these stories on the Wrightslaw site and others on a new parent advocacy site.

If you are interested in submitting a success story or strategy, please send an email to: [success@wrightslaw.com](mailto:success@wrightslaw.com)

In the Subject line of your email, type **SUCCESS STORY** in caps.

You will receive an autoresponder email that contains details about our submissions policy.

Please do not send an article until **after you read and review the Submissions Policy**.

Send your success story or strategy by email to: [success@wrightslaw.com](mailto:success@wrightslaw.com)

In the subject line of your email, type **SUCCESS**.

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