"YOU GOTTA KNOW THE RULES IF YOU'RE GONNA PLAY THE GAME"

by Graciela Tiscareño-Sato



From the Editor: A San Francisco-based mother of three, Graciela Tiscareño-Sato is an advocate for kids with special needs. She is also a global technology marketing professional, a published author, and a US Air Force veteran aviator. With her husband, Genro, she created the presentation and DVD "Letting Your Child's Wild Side Out: Raising the Confident Blind Baby, Toddler, and Preschooler." She can be reached at grace@babymilagro.org and through the web at <www.babymilagro.org>.

Our firstborn child, Milagro, entered the world one hundred days ahead of schedule. Her severely premature birth occurred at twenty-five weeks gestation.

She weighed just one pound two ounces, about as much as a package of butter and a muffin. After nearly five months in the NICU, four hospitals, nine ambulance rides, and five surgeries, she came home with mostly-detached retinas.

When Milagro was a toddler, before her transition to preschool, my husband, Genro, and I determined to get the knowledge we needed to be her advocates. As a couple we had accumulated years of professional experience in the areas of information technology, software and web development, marketing, public relations, and military aviation. However, our knowledge of state and federal special education laws was nonexistent. Instead of approaching the special education process with fear and uncertainty, we decided to take control and fill in our knowledge gaps. In this article I suggest three steps toward empowerment for parents, based upon our own learning and experience.

Step One: Attend a Wrightslaw Special Education Law Boot Camp.

I highly recommend this program to parents of children who are in the special education system. Live training costs \$175 per couple or \$100 for one person. You can also obtain a CD, "Special Education Law and Advocacy Training," for \$49.95.

We attended a Wrightslaw Special Education Law Boot Camp when Milagro was about two and a half years old, just after her first assessment for preschool services. Our entire family attended the workshop. My husband and I took turns taking notes and holding Milagro's two-month-old sister, Kotomi. Milagro entertained herself with toys on the hotel's ballroom floor. The knowledge we gained in this workshop launched us on our journey of advocacy and enabled us to keep learning.

Wrightslaw training is conducted by Peter Wright, a renowned special education attorney. Wright grew up with dyslexia and learning disabilities. He openly shares his dismissive kindergarten report card and other personal stories of low expectations. Later he describes how he won a case before the US Supreme Court on behalf of a disabled student. His wife Pamela is his coauthor and business partner. Together they raised a son with special needs. The Wrights have an immense body of knowledge and they make an outstanding teaching team.

The workshop taught us that we would be the special education law experts on the Individualized Education Program (IEP) team. Nobody would ever be able to misinform us, accidentally or intentionally, about what program elements were available or possible. Try asking these questions at your next IEP meeting. "Has anyone in the room been to law school?" "Has anyone present taken a course on special education federal law, IDEA 2004, or state education law?" You'll probably see that somewhere around zero people in the room have this knowledge. The people on your child's team are highly educated teachers, administrators,

educational psychologists, and speech therapists, but they are not knowledgeable in the specifics of federal and state law. This is your critical role. If you can convince a teacher on the team to attend a training workshop, it will be doubly beneficial to your child. Imagine an education team with several members versed in the legal requirements, all working toward your child's IEP goals and supporting services.

The Wrightslaw Boot Camp focuses on two critical elements: the federal law called IDEA and the culture of the education system. You don't merely read through a book of laws. You read the law with Peter Wright's explanations in plain English. He tells you what key parts of the law mean for your child's IEP. You also gain insight into the personality types and motivations of the program administrators, teachers, specialists, and aides you'll encounter in the education system. You'll learn to recognize these personality types and use your knowledge to your child's advantage.



You'll also learn the meaning and requirements of state and federal law. You'll learn how parts of the law are commonly interpreted by school

districts, and how to determine whether or not the interpretations are correct. You'll hear about specific court cases and learn their implications for your own situation. You'll learn to interpret test scores and will become comfortable with the all-important bell curve. By the end of the training you'll know why an IEP goal based on teacher observation instead of a quantitative standard usually isn't worth the paper it's written on.

There is simply no substitute for this foundational knowledge. Get it live or via CD-ROM, but get it.

Step Two: Start an in-home library on special education law and best practices.



If you attend the Boot Camp training live, you'll receive two essential books as part of the workshop package. You can get the books plus the Boot Camp training on CD-ROM for \$89.95. The books alone are also available for purchase.

The first book is called *Wrightslaw: Special Education Law, Second Edition.* It is available in print or print/ e-book combination at <www.wrightslaw.com>. This book includes the texts of IDEA 2004, Section 504 of the Rehabilitation Act, the Family Educational Records and Privacy Act, and several US Supreme Court decisions, along with

analysis and interpretation. I find the electronic version of the book especially valuable. It is in Adobe PDF format and is quickly searchable with keywords when you need a reference. For example, suppose your program administrator says, "We've had to cut the transportation budget for your child this year. We can only reimburse you for mileage for one round trip a day." With a quick text search you find transportation directly addressed in Appendix A to Part 300. "... A public agency must provide transportation as a related service if

it is required to assist the disabled child to benefit from special education ... at public expense and at no cost to the parents, and that the child's IEP describes the transportation arrangement." You can print out the page and show the administrator what federal law requires. Ask her to show you the written authority that trumps federal law and allows the implementation the district wants to use to save money. Watch how fast transportation services get written into the IEP.

The second critical book is *From Emotions to Advocacy*. I call it "my special education how-to manual." This book demystifies the organizational culture of school districts and the educational bureaucracy. Have you ever wondered, "Why can't they just do what's right for my child? Why does everything have to be so hard? Why doesn't the teacher stick up more forcefully for my child in the IEP meetings?" This book answers these questions and many others.

The book promotes the philosophy that you should always act as if some day you're going to litigate. That way you'll never have to do so. Document every exchange. Record every IEP meeting and keep a phone log of conversations. The book presents a step-by-step plan for organizing documents, setting the tone at meetings, writing post-IEP meeting thank-you letters, and writing letters to object to decisions.

Another invaluable law-based tool is the Pop-Up IEP, available at

<www.unco.edu/ncssd/bviIEP/INDEX.SHTML>. It is a sixteen-square matrix of conversation stoppers that parents sometimes hear when advocating for their children. Each statement is followed by possible responses and the passages in the law that back them up. It's a brilliant tool, one you should bookmark and use frequently.

Step Three: Keep the knowledge coming.

Now that you've graduated from Boot Camp and have the first two essential books in your library, the last step is super easy. Just visit <www.wrightslaw.com> and sign up for continuing education and information through the awesome free weekly newsletter, *Special Education Advocate*. It will inform you of new court cases that may have a direct impact on your child's IEP and delivery of services. At the beginning of each school year an article will remind you how to read a bell curve. You can also see the upcoming Boot Camp schedule or get the training on a CD-ROM.

The Results

Because we began to educate ourselves when our daughter was two years old, my husband and I have established reputations as powerful, professional, informed advocates. We never attend an IEP meeting solo; both of us prioritize the meeting as more important than work events. If we're not both available on a proposed meeting date we make sure that the date is changed.

We treat the IEP meeting as the business meeting it is, and we present as business people do. We open the meeting with our own tone-setting PowerPoint presentation. We show a slide called "Our Vision as Milagro's Parents." The slide keeps everyone focused on the ultimate goal, ensuring that Milagro becomes an independent, literate, employable, self-fulfilled adult some day. Our presentation is sprinkled with photos of our child so that nobody forgets why we're all there. If you're not into PowerPoint software, bring a framed 8x10 photo of your child and place it in the middle of the table. It accomplishes the same thing; it keeps the meeting focused on your child. If you want the meeting to be child-centric, you will need to guide the team.

We make the point that the meeting is about Milagro and her FAPE (free and appropriate education). We state up front, "We are her project managers. You, the professionals, are temporarily on our team. We thank you for being here." We state this because it's likely that only the parents will be on the IEP team from preschool until high school graduation. Along the way, other team members will move, retire, or change jobs. The parent project managers will provide the only continuity.

In our presentation we celebrate our daughter's progress and thank each team member for his/her hard work and dedication. The expression of thanks sets a positive tone and helps everyone feel good. We then move to the challenges ahead and present the areas of focus for Milagro's upcoming year. We cover specific, measurable goals we want included in the IEP. After our presentation we provide handouts to everyone in the room. Our presentation becomes part of the official record. We are equal partners on the team.

When a meeting is very tight on time, we provide a "parent agenda." This strategy ensures that we cover the points we want to discuss instead of following only an administrative agenda. We bring our laptop and make an audio recording of every meeting, as is our legal right. We burn a CD copy of the audio file at the meeting's conclusion and give it to the administrator.

We own this process. We are the experts on our child. The professionals ensure that her age-appropriate goals and objectives are on track and update us on her progress. Together, we make course corrections on this journey. We request, in writing, additional IEP meetings when we feel they are necessary.

My husband and I subscribe to the mantra "Trust, but verify." We don't stay away from the school, assuming that things are going swimmingly. We take turns doing parent observations about once a quarter, and more often if needed. We take notes just as the professionals do when they observe a child in a school setting. IEP non-compliance is hard to hide when a parent is present.

You may encounter resistance when you want to do an observation at your child's school. If this happens, ask to see the federal or state laws that prohibit or limit your ability to do observations. I haven't seen any. You may be presented with a district-specific policy on observations or with nothing at all. Chances are good that you'll be free to observe and get a sense of whether the IEP is being executed in a compliant manner.

When things go wrong, as they sometimes do, we call a team meeting to fix them. Once we had an IEP meeting with two elementary school principals in the room, two general education teachers, two TVI's, two speech therapists, two APE teachers, two O&M instructors, and several other team members. Twenty people were needed that day to transition our daughter from a school whose culture proved inappropriate to the school where she is now thriving. We will forever be grateful to the TVI (Yardley Hoffman), the O&M teacher (Lori Cassels), and the program administrator (Sandra Nevin) who suggested the change, and to Sandra for orchestrating the process.

We have a solid, effective, efficient, and mutually respectful relationship with our IEP team and administrators. We don't dread IEP meetings. Instead we look forward to them. The meetings give us a chance to help construct goals to start our daughter on her next steps toward success.

Above all, we preserve the relationship with our IEP team members. Pete Wright reminds us to treat this relationship as "a marriage without possibility of divorce." We nurture it, keep it professional at all times, and always, always keep control of the big picture. We will never relinquish that control. Milagro is our child.

Please consider spending the money on the training and reference materials I have described here. You can spend as little as \$90 for the essential training and reference materials, or you can spend a few hundred dollars and travel to do the live Boot Camp training. The full schedule of live training events is here: <<www.wrightslaw.com/speak/schedule.htm>.

If you make this investment in yourself and in your child's future, you'll be ready to start the special education process without fear. You will be full of knowledge, knowing how to look up what the law requires. If you don't take these steps to educate yourself, you may be susceptible to the folklore perpetuated throughout bureaucratic organizations. You may believe erroneous statements made by professionals who have neither studied the law nor gathered the information recommended here. As Air Force Captain Cuomo once said to me in a former life of mine, "You gotta know the rules if you're gonna play the game."