



Getting to Yes: Confessions of a Reluctant Advocate

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Even just the word “advocacy” used to make my heart beat faster, my palms sweat, and fill me with dread. This word and I are polar opposites. Even when I was a young child, if someone wanted something bad enough-- be it my brother or opponents on the sports field, all anyone had to do was assert themselves against me and I handed over whatever they wanted.

Thus, it is no wonder I felt completely inept when I had my first conversation with another parent following our children’s diagnosis who said, “You are your child’s best advocate.” I imagined Uncle Sam pointing right at me. I really had no idea how to take up this role suddenly bestowed upon me. So began my own journey to find out what advocacy was all about.

Talking Possibilities

Growing up, I knew IEPs meant one thing: frustration. Not only did my brother need specially designed instruction, but my mother was a high school Special Education teacher and talked openly at home about the challenges of writing IEPs and complaining about how my brother’s teachers just didn’t understand. (Sound familiar?) From this early exposure, I knew I was not cut out to deal with IEPs, or so I thought.

I can’t say our first experience in an IEP meeting was comfortable or successful. There we sat; my husband and I doe-eyed and fighting the urge to run. I hated the very thought of being there. Who were all these people, and why was I even sitting in an IEP meeting?

After all, I thought I had made my wishes specifically clear about how our children’s lives would play out before they were even born. *Let them be who they want to be, but whatever happens, please oh please let them never ever need an IEP.* Isn’t it funny how life happens? The very thing we are most afraid of turns up in our lives as if to say, “Here you go; you asked for it.”

I disliked that first meeting’s experience so much. I knew that if IEPs were going to be our lot in life that I needed to create a new perspective on the whole process. I needed to learn how to get to “yes” at these meetings.

First, I began to read through the pages and pages of evaluations and data collected by strangers about my kids in order to form choices for their Free and Appropriate Public Education or FAPE for you rookies. These pages soon became chapters and volumes housed in two separate three inch binders. One day, as I was thumbing my way through the pages, it occurred to me these documents represent everything that was wrong with my child. How did we get to feeling and being so *WRONG* in such a short time? It broke my heart. I placed some pictures in the front of the binder to remind me who my son really was. After all, I may not have known about the importance of bell curves, but I could talk in depth about my son and how he loved flying kites and riding his bike. It was only by accident that these pictures caught the attention of other team members –realizing that they too appreciated knowing who our son was beyond their narrowed and limited versions. This interaction was by far the most important in defining our relationship as a team. No longer were we talking percentiles. We talked possibilities and asked questions of one another to match services to the child on the front cover of that thick binder.

Tricks of the Trade: Always be Prepared

A few years back, Tony Attwood, one of the world's renowned authorities in Asperger's syndrome, came to our tiny burg in Bellingham, WA. As a coordinator for our county's Parent to Parent program I couldn't pass up the chance to see him and learn what I could do to help other families.

The one thing that stood out for me from his presentation was how important it is to have "tools" when you are in any circumstance. Eventually, this concept got me thinking about my own challenging circumstances with IEPs and my need for helpful tools that would assist me in getting started.

Talking to team members requires both preparation and tact. I found this form I keep close at hand for any occasion: the little black dress of IEPs as I call it. "Preparing for Your Child's IEP" is a basic list I create prior to each child's meeting that helps me sum up where we need to focus. I type it out, make copies and present it to our team and they always welcome this information.

Preparing for Your Child's IEP

- My child is best at:
- My child needs the most help with:
- My child enjoys:
- My child least enjoys:
- My child compares to other children his/her age in these ways:
- My child differs from other children his/her age in these ways:
- When I play or work with my child we usually:
- Help my child has received in the past include:
- Ways I have worked to help my child with behavior or school work that worked are:
- Ways I have worked with my child with behavior or school work that did not work are:
- Special concerns I have about my child
- Questions I have about my child's education are:
- Suggestions I have about working with my child are:

Taking it on the road:

Shortly after our children were first diagnosed, I went through advocacy training. When the time came to check the box to become an advocate for a local agency, I declined. I still didn't feel ready. However, just recently a parent called asking for my help. Her daughter was transitioning and she desperately needed someone's supportive hand to guide her. With just a week to prepare, we met and I handed her resource after resource from the Hands & Voices website. I knew it was bordering on overwhelming her, but there wasn't any time for a slower pace. I instructed her to inform the school team she would be bringing a friend telling her I would be there taking notes. At the meeting the school was VERY curious to know who I was, since H&V was just becoming known in Washington state.

During the meeting it was so clear how determined this mother was to get her child's unique needs met, but as all of us do especially on a first meeting, she often fought to find the right words that would make an impact on the team. I volleyed a few questions to get the team focused and responding to this student's particular situation. When the reception cooled and the parent answers began, I backed off. I knew this meeting wasn't going to conclude well, and the parent would need to reply by letter to this team the way it was proceeding. I kept taking notes. Standing in the parking lot afterwards, with this exhausted mom who was near tears and holding onto her daughter, I recognized that feeling of helplessness and failure I had felt myself at these meetings. This meeting had only been a first step and it killed me to see her doubting herself and asking me "Why didn't you say more?" I gave her a hug and told her we would meet next week to begin her reply. Meanwhile, with her permission, I contacted the professionals servicing her child outside of school asking for back-up. All declined my plea to attend a meeting for various reasons. It was then that I realized just how valuable a parent run organization like

Hands & Voices could be in the day to day lives of families and their children in our state, whose sole allegiance is to the parent and their child.

When the parent and I met again, I had tapped into every resource I knew, both locally and through the Hands & Voices network. We went over the notes from the previous meeting, pulling out useful quotes she could use in her response. It was then that she declared to me she wanted to go for out of district placement over an hour's drive from their home. My only response was to ground myself in the resources I had gathered doing what was asked of me and pushing through my own self-doubt knowing anything is possible. We crafted a detailed letter stating the child's case and sent it off.

Upon receiving the parent's letter the school district responded by requesting another meeting. I came prepared with reading glasses, pen and response form in hand ready to take copious notes, when the Special Education director said he was just going to cut to the chase and agree to transfer this child! Stunned, I managed to write on my form just one fabulous word: "YES!"

Advocacy did not come naturally to me, but the alternative of not raising my voice for others (including my own children!) was simply not an option. I've realized through this journey there is so much work to do in our legislation and education in order for systems to recognize the unique needs of each child.

After all, none of us dwell in silos, but rather each of our actions, small or large, matters in the bigger picture. To "advocate" just means to speak up on behalf of another. With the support from the H&V network, I have continued to find my own voice, and was honored to help another parent find hers.