You Are an Important Part of the Solution In the Autism Diagnosis

By Kate FOLEY



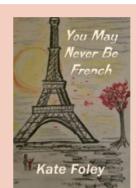
hree years ago, my husband and I were facing very difficult questions. Those questions often didn't have simple answers, and worse, the professional responses we received didn't always mesh with other professional responses. How would I navigate this?

I can tell you my pediatrician felt my son was "just a boy." Had I listened to that professional opinion, a very well regarded one, where would we be? I was lucky enough to have another opinion from a mother herself. Her guidance was simple: what can it hurt to check? Early intervention can do nothing but help. In fact, the earlier it's started, the stronger the impact. At that moment, I learned something valuable, and that was to listen to myself! Listen to everyone else, too, and filter out what you don't need. Go with your gut and err on the side of 'why the heck not?' This is my child. In the end, I'm his advocate, and that means I push myself out of the equation. It doesn't matter what other people say. If he continues to struggle with symptoms, then I need to address those symptoms.

My Brady has always presented well. He is social and conversational. He has been involved in speech and occupational therapy (OT) since he was two and a half years old. He was brought up with theater games and has been read to since before his birth. However, he internalizes a lot. Much of what he does comes out when he has held all he can in. He is sensitive and will become hurt very easily. I never like to talk about Brady's behavior because it is simply a symptom of his autism that he struggles with and not who he is. I never want him to think that is our focus. However, in a doctor's office, you must.

We have gone to some tremendous treatment facilities, and I am always grateful, but there has been more than once the strong opinion that what you are saying is wrong. They might not see a change in behavior when removing this or implementing that, but I can tell you, I have seen my child react to different foods and have noticed enormous gains when he is working on OT regularly. I know I've seen it, but depending on who I told among his doctors, there was either an emphatic nod or a disenchanted "meh." I did eventually change pediatricians and am very happy with her. I also feel my old pediatrician has done great things for many, and I don't disregard his achievements, but he wasn't for us. I always left feeling bad about myself and my decisions. I can even remember going home and crying. You have to feel supported, and there are a lot of educated opinions on OT, art therapy, and equine therapy that clash. Who do you trust? In the end, you trust yourself because you have to be okay with it, so it's always best if you follow your own gut and decisions while parsing through all the advice.

Currently, I am lucky enough to belong to a committee that is looking at changing the medical profession from the inside. The organization is called CHATID and is working on teaching medical professionals to change the way they interact with people who have disabilities. Our focus is on creating positive experiences for people with special needs and their families and helping create an environment where they feel comfortable and heard. Often, that is a complaint I hear most from people. The truth is we can disagree and perhaps rightly so, but it's important to feel heard, and it's extremely important to recognize your value in the treatment of your child. It's essential to understand what their needs are. We had to cut back on many of Brady's therapies because it was so overwhelming for him and was causing more harm than good. There is no cookie-cutter answer to what everyone can agree is not a cookie-cutter diagnosis. Each child is different. Each family has different needs and circumstances. It is important to remember that regardless of whether or not you carry many doctorates, you are still an essential part of treating your child and you are both unique with unique circumstances that require your involvement to properly address.



Kate Foley is an author/illustrator with a background in communication, education, and theater, whose personal experience in parenting a child with autism as well as one without has led her to create stories to help children navigate their complex emotions while teaching them to celebrate the uniqueness of themselves. Kate has a degree from Keystone College in communications as well as an elementary education certification for K-6. She studied theater at Mansfield University and for her professional de-



velopment was grateful to have received training in effective leadership and communication skills from some of the best in their fields at Lehigh University's lacocca Institute. In college, she and some friends ran a nonprofit theater group, the Footlights Players, which earned money for local charities. She also heads up a local group for parents with children on the spectrum, teaches a small, inclusive preschool class based in drama and play therapy for children both on and off the spectrum, and is a committee member of CHATID, a local advocacy group for all people with disabilities.

Kate lives for both the quiet moments and those filled with wild, raucous laughter. She has been known to indulge in too much coffee and even more chocolate while living in Carbondale, Pennsylvania, with her husband, two beautiful children, and her cat, Mrs. Norris.

Website: www.katefoleyauthor.com

CHATID: chatidnepa.org