

H: Parent Stories

“Just a Parent” – I Think NOT!!

By Rhonda Jacobson

As the parent of a child with special needs, you get used to telling professionals, Well, I am just a mom, but I think...” “I think...”, discredits everything I am about to say? “I think...”, do not listen to my words? “I think...” NOT!!” Your words are setting the stage for the relationship with the person or people that are providers of services for your child.

When my daughter turned two, I realized that she was different than her peers and her siblings. When consulting with professionals, not many were concerned, advising me to “give it time”.

Instead, following my gut, I started to scour the internet, and picked the brains of professionals, looking for information and answers. I became an ‘expert’, reading all I could about children who were like my daughter, about what their parents did, about what interventions helped, and what research was out there. I subscribed to group lists and discussion lists and attended any and all workshops that I could.

At the time, I was something of a rarity: a parent wanting to attend professional seminars so that I could gather more information about my child’s condition. I will never forget the time that, once “granted permission” to attend a professional session, I was asked to sit at the back of the room and not ask any questions. It is funny now, but I wasn’t amused at the time.

As time went by, I began to realize that sometimes, I had more information about my daughter’s condition than some that were on her treatment team. So I shared what I knew and lent out books that I bought or copied articles or forwarded reports. As a result, and in hindsight, I think this served to establish my position as a full member of the team involved with the treatment and care of my child.

YOU are your child’s only advocate. You need to understand her diagnosis, her strengths and weaknesses, and you need to ask questions when you are not sure, or you don’t understand.

Information is power. Never underestimate the power of an informed parent. And never, ever refer to yourself as “just a parent”!