

My name is Kristy Kazian. I am a speech pathologist who works with children with special needs; specifically, children in the age range of birth to three who have communication and/or feeding difficulties. I am also a mom of a child who was born with a severe brain injury due to a lack of oxygen during delivery. Little did I know 9 years ago when I began working in the IL Early Intervention Program treating infants and children with special needs, that I too would someday be the parent of a child with special needs. I had already been a practicing speech pathologist for 8 years before I began working in the early intervention program. Previously I worked with adults with brain injuries, most often due to stroke. My switch from adult rehab to early intervention was a big decision and one made mostly due to financial reasons, at least that is what I thought at the time. Now I believe it was a twist of fate that was meant to be; a guiding light from an angel up above. I began working in the early intervention program in 2001 supervising new graduate students.

About a year later I found out I was pregnant. During that year I gradually learned more and more about the EI system and was amazed at how many children in the Chicago land area were in need of therapy services due to developmental delays. These delays were caused by a variety of reasons but often the delays were undiagnosed. I received desperate cries from parents who wanted help trying to figure out what was wrong with their child. When I started working as a speech pathologist, I knew very little about sensory processing disorders. In fact, I don't remember learning a thing about SPD when I was in college, even in graduate school or during my internships. Yet time after time I would be called into evaluate a toddler with the same complaints from the parents: something is wrong with my child, he won't sit still, he has miserable temper tantrums, he doesn't sleep well, doesn't eat well, he isn't talking, he won't answer me when I call his name, he bites, he bangs his head, he hates getting his hair cut, he hates to wear socks, etc. etc. Parents would say "my pediatrician just said it is the terrible two's" or "my mom said I'm not a strict enough parent" or "my sister thinks he might be autistic!" Parents would look at me with a painful shadow in their eyes; a look I did not understand or recognize until I had a child of my own with developmental delays. Even I, with a graduate degree in communication disorders, thought that many of these children, upon evaluation, were on the autism spectrum. It wasn't until the correct team of therapies began (occupational, developmental and speech therapy) and a home program put into place, that all of a sudden these children began to bloom and developmental milestones were beginning to be met! Low and behold these children were not Autistic!

As the years went on, I learned from occupational therapists who specialized in sensory processing disorders and took as many continuing education classes as possible; soon enough I was able to differentiate between a child who was showing early signs of autism vs. a child showing early signs of SPD. A skill, I think, should've been taught to me in graduate school. Unfortunately, I also learned that most pediatricians know little to nothing about SPD and

therefore they are chalking up the parents' complaints to the "terrible two's" and children are losing valuable therapy time because they are not being referred for therapy; time that is invaluable in allowing these children to meet their developmental milestones and catch up to their peers. I found out children who were referred to the EI program before they turned two had a much better chance at catching up to their peers before preschool than children who were referred to the EI program after they turned 2 ½.

Two years after I began working in the early intervention program, my first child was born. After a long drawn out labor, my child was born with brain damage due to a lack of oxygen during delivery. My daughter, Lexi, spent the first month of her life in the NICU hooked up to machines and tubes and underwent test after test to determine how bad her brain damage actually was. About a week after her birth, the doctors gave us, what we thought at that time was, the worst news of our life; she had severe brain damage across her entire cerebral cortex. As my own brain tried to process that information, I remembered sitting in my neuro-anatomy class in college and as if I was having a test that day, my brain knew exactly what the doctor was saying and it felt like I had just been kicked in the stomach. I knew that the cerebral cortex is the most highly developed part of the human brain. I knew that it was responsible for thinking, perceiving, producing and understanding language. I knew that the cerebral cortex was responsible for our vision, hearing, touch, movement and smell. I knew exactly what the doctor was saying. But as the wind was getting knocked out of me, I looked over at my panic stricken husband as he asked the question I didn't want him to ask because I already knew the answer: "Will she ever be able to walk or talk?" I wanted to put my hand over his mouth or scream "don't say it!" but it was too late and right then and there I saw a familiar look in his eyes...one that I had seen before in other parents eyes, but not my husbands. It was the look with the painful shadow; the look of panic, fear and desperation that I see from the parents of the children I evaluate and at that very moment I felt my life crumbling and I had no way to stop it. As if it happened in slow motion, I saw the doctor's mouth say the word "No, she will never be able to walk, talk or eat like a regular child" and everything after that was a blur. That was the day our lives changed forever and as the doctor walked away, we were left standing alone in the hallway of the hospital...trying to figure out how we were going to pick up the pieces of our crumbled life.

The short story is that our precious angel lived for 2 years and 3 months and struggled every day of her life. My husband got a crash course in therapy and unfortunately was able to use his paramedic training at home as our daughter had seizures, cerebral palsy, and a feeding tube. She was hospitalized multiple times over her short life and during that time we struggled to find a balance between giving our daughter the opportunity at living the most normal of a life as possible and grieving the loss of the child we thought we were going to have; the one who would do ballet instead of physical therapy, the one who would learn to ride a bike instead

of getting fitted for a wheelchair. We felt as if we were the only people in the world who had a child with special needs, who feared for our child's future. I longed for another mom to cry with and laugh with and enjoy our children together. I felt isolated in my own neighborhood as all the other new moms complained of spit up and not getting enough sleep, I just could not relate to them and seeing their babies just made it more obvious how delayed my child actually was. My husband and I coasted during the time she was alive; we needed a support group but nothing was offered to us, nothing that we knew of was out there for parents like us to network with other parents and gain comfort from those who have walked in our shoes. Every doctor who saw our daughter told us a different story, a different outcome, a different way to interpret the same test results. I sought out comfort from my clients; they became my support system as we were in the same boat, we shared the same painful shadows in our eyes. Who were we to believe? Who were we to trust in? The bills piled up, we worked two jobs, and we did what we needed to survive.

The day we were told our daughter was dying, we soon enough realized, was actually the worst day of our life; as opposed to the day we were told our daughter had severe brain damage. Again, little did we know 27 months before? Shortly after our daughter passed away, we decided to channel our grief in the only way we knew how; by helping other people who were dealing with the same challenges we dealt with as parents of a child with special needs. Today we run a not for profit organization (The Lexi Kazian Foundation-Helping from Heaven) with the mission to improve the comfort and quality of life for children with special needs. We try to accomplish this mission by hosting multiple family networking events every year. These networking events are planned to be fun, free and family oriented in a low stress environment. We invite children with special needs of any nature or severity (can range from a typical speech delay to a syndrome, SPD or cerebral palsy), their immediate and extended family, therapists, social workers and doctors. We take this opportunity to introduce families who have children with same or similar diagnoses so that they can share their successes and challenges, fears and joys. These parties also allow for siblings of children with special needs to be able to go to a fun outing with their brother or sister that does not require sitting in a waiting room of a doctor's office or therapy clinic. At these networking events, our foundation, in memory of our daughter, has created relationships that will last a lifetime. We have also organized support groups that meet on a monthly basis for parents to have an emotional outlet in a safe and caring environment, so that parents realize they are not alone in their battle and crusade to give their child with special needs the best life they know how, yet still keep their sanity, marriage and other children as healthy and cared for as possible.

Our foundation has recently sought out and connected families who have children with SPD, as this disorder has been coined the "invisible" special need. Not only is sensory processing disorders not visible on a child, unless the child is in "melt down" mode, but SPD is

not well known about, if know at all, by many medical experts and teachers let alone people in the general public. With that said, I am a mother and a speech pathologist who is on a mission; a mission to educate the world on sensory processing disorders so that there will be less parents on this earth will painful shadows in their eyes and more parents with joy knowing that there is support and hope out there for them and their children! Please help me and join my crusade to spread the word and educate others on SPD so we can help improve the comfort and quality of life for children with special needs and their families!

Sincerely,

Kristy Kazian

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