

CSH Support Corner – Parent & Caregiver Blog

April 2023



Happy Spring to all families! I love springtime because it reminds me of new beginnings, and the possibilities of being able to start over – each day, each moment is a chance to start over. As a parent of a child with special needs, we learn to start over. Constantly. We learn patience. We learn to let go of our expectations because perhaps they were too much for our child with special needs. We learn how to care and love for our child in different ways. We learn that the general advice given to new parents does not work for us.

This education started for me days before my child was born. I was admitted to the hospital on Christmas Eve when I was 28 weeks pregnant. Pretty soon, the doctors and staff tried to get me prepared to have my child within a few days. Having read all the books about what was best for our baby, I refused to accept it. I refused to tour the NICU. I told them that I would agree to having him at 32 weeks, because that would be better for our child. Of course, I could not negotiate this. It was my life they were trying to save at that moment. I had to start over. Accept that things were going to be different than what I had planned.

With a preemie, we had to make lots of changes for our newborn's care after we brought him home from the hospital a couple months later. Once we tackled that transition (with the help of family), we had specialist appointments – the pediatric eye doctor, the neurologist, the brain scans, ear specialists, etc. It seemed endless. After a year and half, we thought that we had succeeded against the odds, and graduated from the specialist visits. Only then, the pediatrician recommended early intervention due to our child's delayed speech development. We started anew learning about the special needs of our child.

Fast forward thirteen years, we have been through speech therapy, occupational therapy, physical therapy, psychology and neuropsychology evaluations for our child. We learned about special needs without a diagnosis. We learned to not focus so much on the diagnosis, but rather to focus on the aids and therapies that would help our child to develop and thrive.

We learned about IEPs and how to advocate for our child's special needs. We learned to work with the school district. We learned and advocated for our child with the professionals in school and outside of school, to ensure our child's special needs were not an obstacle for his development or socialization, but rather a stepping stone for him. We approached his special needs as his unique blessing to learn to appreciate the world in a new way, for all it has to offer him.

We have learned how to help our child to succeed with his special needs (not in spite of them). You see, special needs are a wonderful blessing. It opened my eyes to the world of special needs that I had only observed with compassion prior to this experience. I became part of a small group of parents with special needs children. We shared a culture of giving, of tolerance, of acceptance, understanding and love.

Much of our experiences are not only 'trial and error' but 'trial and success,' as we come to understand the special needs of our child. Despite the moments of loneliness, and the moments of feeling different, all individuals with special needs, and families and friends who support them, are blessed with each other. Each present moment is an opportunity to thrive, just as the new growth of springtime!

