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CPD LEGACY STORY: SCOTT PEHRSON

October 17, 2011 by cpehrson

This CPD Legacy Story is written by Connie Pehrson, the mother of Scott Pehrson who attends the CPD's Developmental Skills Laboratory, an adult day program.

"He's just perfect!" My pediatrician and I shared a moment of awe while he examined my newborn son at his two-week checkup. I couldn’t have agreed with him more. Scott was our second child, just rounding out our little family with one beautiful little three-year old daughter, and now a strong, healthy little son. Our family was perfect.

Several months later, I would remember those words with sadness.

Scott developed typically, reaching his developmental milestones right on time; sitting up, crawling, walking, saying mama and dada and two-three word phrases, pointing to his eyes, nose, and ears when asked to, playing peek-a-boo.

But that all stopped the day that he had a grand mal (tonic-clonic) seizure at 18 months old.

The life that we had known up to then stopped, also, and we began our journey down a path that we had never anticipated nor wanted. It took the neurologist at Primary Children's Hospital another year and a half to give us a diagnosis of, not just epilepsy, but a severe form of epilepsy called Lennox-Gastaut Syndrome (LGS), a rare and severe form that involves frequent seizures of multiple types and moderate to severe cognitive impairment.

At age three, we took Scott to the CPD, then known as the Exceptional Child Center (ECC), for a complete developmental evaluation. The news was devastating; Scott’s development was essentially at the level of a 12-month old, at best. Already he had lost some of the skills that he had acquired and had not moved forward in any of his developmental areas in the last year and a half.

As my husband and I tried to process what that would mean to our son’s life and the life of our now, not-so-perfect family, we again turned to the ECC and enrolled Scott in the preschool that was held there. I remember watching him through the one-way mirror and thinking that he really didn’t belong there. But, my background in special education (I had taught Special Ed classes for 5 years) told me that, yes, he needed the help that the teachers could give him here. We were so thankful that there was someone who could help him.

Not only did the staff at the ECC give Scott what he needed, they gave me the emotional support that all parents of children who are newly diagnosed with disabilities need to help them through that first grieving process. Just being able to talk with other parents whose children were enrolled in the preschool was a great help.

As time went on and the severity of Scott’s condition was revealed, he continued to attend one of the self-contained classrooms offered at the Center as the name changed from the ECC to the Developmental Center for Handicapped Persons (DCHP). When he turned eight years old, Scott was moved to a classroom in the Logan School District, although at that time we lived in Smithfield. There was not a self-contained classroom in his home district. He attended many different schools in both districts during the next years.

When Scott turned 22 years old, he began to attend the Developmental Skills Laboratory, an adult day program housed on the USU campus. To my surprise, we discovered that the DSL was yet another program coordinated by the CPD! Though the name was changed (the DCHP was changed to the Center for Persons with Disabilities in 1991), the services answered the great need we had then, just as it had done when he was a little boy.
He has been at the DSL now for the past nine years, and is still going strong. They have been through many ups and downs with him; broken bones, sprained ankles, black eyes, cuts, and bruises caused by his many seizures, and last year, a near-deadly illness that sent him to the ICU for ten days. The staff there are more like friends than providers. How many providers would bring up a bucket of Kentucky Fried Chicken, balloons, and his favorite Sesame Street books to the ICU and share tears and hugs with us as he struggled for his life?

We are so lucky to have a program like the DSL to send Scott to during the day so that his dad and I can go to work and not worry about what might happen to him. His safety is their first concern; finding activities to do that will help build his skills is an important part of his day; taking him out into the community to go see a movie or visit a museum is a frequent part of the DSL. They recently took the whole crew to the Clark Planetarium in Salt Lake City -- what brave people they are!

Another long time friend of Scott's and CPD occupational therapist extraordinaire, Amy Henningsen, took on a project for Scott this year. Calling for help from some USU students, Amy and her team built an activity board for Scott to use during those long winter months when he can't be outside. Not only did they ask what Scott's interests were, but they went over to DSL to see him and paid a visit to our home to find out more about him so they could make sure that the activities on the board would engage him. They even made it so we could interchange activities and add new ones later. We look forward to Scott spending many hours with his activity board this winter!

The CPD truly supports people with disabilities throughout their life span; from birth to adulthood, their services are so valuable and life-changing. Our family thanks you for being there to support our perfect... well, almost perfect... son.

Be watching for a follow up blog on Scott soon, as I share his story through the eyes of his three sisters.