



Daniel's Story

When Daniel was born in 1994, he was immediately whisked away to the intensive care unit because he was having trouble breathing. After several months of appointments and tests, Daniel was diagnosed with CHARGE syndrome. CHARGE Syndrome is a rare and complicated genetic disorder that affects many areas of the entire body. Birth defects from CHARGE Syndrome can affect the eyes, central nervous system, heart, sense of smell, and nasal passage (which makes it difficult to breathe), as well as cause ear anomalies and deafness, difficulty swallowing and feeding, genital and urinary defects, and developmental delays. Along with his diagnosis, it was discovered that Daniel was deaf and legally blind.

Daniel was able to get a cochlear implant as a child that along with ASL opened him to a new way to communicate. But, his parents were struggling with balancing his medical appointments and maintaining their jobs; and as he got older and it came time for Daniel to start going to school, his parents discovered there was an entire new complicated system to try to learn and navigate. They needed help.

Daniel's mother Sue, who at the time was overwhelmed by her young son's 25-page long education plan, admits now that there were times she would nod her head in agreement without truly understanding what it was she was agreeing to or if it was benefiting her son. Around this time Sue (and Daniel) met CPARC.

A CPARC Special Education Advocate began attending school meetings with Sue and Daniel, explaining terminology and informing the family of Daniel's rights under educational law. The CPARC Special Education Advocate worked collaboratively with Daniel's entire education team providing solutions and compromises, especially when Daniel's parents and the school district had disagreements, on how to best meet Daniel's needs in the school setting.

As Daniel began to approach adulthood, his family started to get concerned about what life after high school would look like for him. The family's relationship with CPARC evolved with an Adult Services Advocate who would be by their side as they once again learned to understand an entire new system of adult services. Daniel's CPARC Special Education and Adult Services Advocates worked together to develop a plan that would help Daniel and his family smoothly transition into the next stage of his life and prepare for his future before he left the school system.

Today Daniel lives happily in the community! He loves any chance he gets to go swimming, getting monthly massages, and Hershey Park! Daniel and his housemate also have a pet cat that they take care of together. With the support of CPARC Staff, Daniel enjoys an everyday life.

Daniel's story is just one of many examples of CPARC's dedication to its mission to *empower, inspire, and educate* people with intellectual disabilities, their families, and the community. With your help CPARC is able to continue providing support, training, and opportunities to those in need. ***Your gift today ensures Daniel's tomorrow.***