

Justin's story

One family's journey to find the right place for their special needs child

By SHARON MACGREGOR

Away from family, Greg Maxwell stationed at Fort Stills, Oklahoma and his wife Sherri started a family of their own. Born 11 weeks prematurely in Oklahoma City with a variety of health issues, Justin Maxwell was in and out of the hospital requiring medical care.

As a baby and then as a toddler, he truly seemed to not sleep enough and as he grew a little older he would exhibit some unusual behaviors like running back and forth and simply staring at walls for hours or obsessing over particular songs.

Mom was prepared for battle after getting the best advice

Justin's mom, Sherri Maxwell of Pine Bush explains, "Justin is autistic with a manic diagnosis and some medical problems as well. He can get really excited and easily over stimulated and may act out." The pediatrician gave this advice: "The biggest fight you are going to have is with the school districts so don't ever give up. If you think Justin doesn't have what he needs you keep fighting!"

At the time, Maxwell thought the comments were a bit odd, but years later after returning to New York, they proved to be the best advice she ever received. As forewarned, Justin's educational journey was rocky.

Originally enrolled for kindergarten in the Port Jervis school district in an inclusion classroom with an aide, the parents expressed concern over the arrangement due



Born 11 weeks early, Justin was in and out of hospitals.

photo courtesy Sherri Maxwell

to their son's issues related to ulcerative colitis and potential bowel movement problems. After just one day, the faculty, administration and the Maxwells all confirmed the setting was not suitable.

Justin's BOCES experience

Transferred to BOCES for the school year, the next step was for Justin to begin a BOCES STRIVE (Structured Teaching in Reinforced Visual Environment) program in Goshen designed for students within the Autistic spectrum with a one on one aide.

By just first grade, Justin had been in 3 different schools and the following year he was enrolled in regular BOCES due to the improvements in his verbal and social skills. At age 9, Justin's one-on-one aide who had been able to help with the various transitions up to this point by following him from school to school, was now no longer available and his behavior declined.

As a result of her son acting out

(and sometimes due to bowel movement issues and sanitary reasons), Sherri was called fairly frequently to pick her son up, many times by 10 am. Over the next two years, annual reviews, parent-teacher conferences and after countless district meetings, Justin's school schedule was reduced by the administration first to half days on site then one hour of tutoring until eventually the family was told that home schooling may be a better option.

They were also told no spots were currently available for Justin's needs. However, the Maxwells did not view home schooling as a solution since Justin had developed a strong attachment to his mother and seemed to suffer a separation anxiety when he had lost his one on one aide, they felt their home environment would be too limited for social skills. Following a number of discussions with a parent advocate, and despite a number of caring and nurturing teachers, the limited environment outside of the home



Justin and his buddy, Jody. Says mom, "I always try to stay positive."

photo provided by Sherri Maxwell

available to their son simply wasn't working and the Maxwells retained a lawyer.

Reviewing the best options for their child with administrators was difficult as suggestions were made to place Justin in other institutions that were not suitable for his diagnosis including McQuade's Childrens Services or institutionalizing him in a psychiatric hospital.

A place at last

By the age of 12, the couple were able to transfer their son, now 13, to the Center for Discovery, a private school in Harris. And it's at this new school that Justin has been thriving. "He is learning to read, write, do math and understand money while becoming more independent." Sherri explains that students will "work in 15 minute intervals, and then do other activities. They may take a walk or a hike, or go swimming. They also have animals that they take care of and jobs that they do every day."

Justin has a variety of jobs at the school including cleaning the animal stall, cooking and cleaning in the kitchen and delivering supplies to other classrooms.

For those who are starting the journey with a special needs child, Sherri shares, "If you don't think something is right, fight for what you think is right."

Keeping a positive attitude as Sherri does can also be key. Maxwell admits, "I always try to stay positive because I am happy Justin is here."

Sharon MacGregor is a freelance writer and columnist living in the Bloomingburg area with her husband and two sons.

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