

Capabilities vs. Deficits

The Journey with My Son

Early Childhood to Adulthood

Trent is a 33 years old autistic man. He is a wonderful example of how someone with autism can grow and overcome challenges to live a full complete life with a positive self-image and a community member. Yes Trent has autism, but I say autism does not have control over him. He has grown personally, matured, and reached living life beyond anyone's previous predictions. Today he is employed part time at Meijer (with supports) and has been for 8 years. He lives independently with a friend who is his roommate. He is a brother, a son, a nephew, a cousin, a neighbor, and is an artist who has friends in the art community.

Painting has positively changed who Trent is. He is an expressionistic artist who paints what he cannot say. Today Trent travels to art shows, has won art awards, and exhibits at national disability conferences.

The Unknown Path

Trent is a middle child, with a brother Todd three years older and Travis his brother three years younger. Trent was born in 1977 just a few years after P.L. 94-142 was passed which entitled children with disabilities a right to have public education. At the time, I didn't know how important the passage of that law was to him.

When I first held him in my arms, I heard a voice in my heart say, this baby is a special gift to you, 'you will care for him the rest of your life'. I recall thinking abruptly, why would I think such a thing, 'care for him the rest of my life'. The following months, I remember people saying, how beautiful a baby he was, yet very quiet.

When he was 10 months old, Trent smiled, said a few words (ice cream, moma), and imitated his oldest brother Todd. Trent made the rmmmmm.... sound of his matchbox cars on the sofa while looking up to his brother Todd as the leader to show him how. Then around 18 months of age, everything changed. Trent began to get out of his bed and sit in the dark alone, rocking on the sofa. When I turned on the light, he just kept rocking as if he ignored that I was there to comfort and hold him.

Trent was diagnosed as autistic-like at the age of 3. Thereafter his doctors labeled him autistic. During the school years, he was placed in a self-contained classroom while being mainstreamed (a term used in the 80s) into regular education classes, mostly music and art. During the 80s there was not much information about alternative therapies except for behavioral interventions. Trent did however attend the Louisville

School for Autistic Children providing him behavioral therapy.

With limited receptive and expressive language abilities, he had tantrums daily. I kept a journal and one day I wrote, Trent is having his 7th temper tantrum today. There are many memories of struggling to be a mother to his brothers and involving Trent into everyday family activities, one was eating at the table with his family. Outings were most difficult with my three small sons. Some scenarios I recall:

- 1) When Trent was three years old, he was terrified of the sliding doors at the entrance to most grocery stores. I remember practicing with him over and over again when I was able to leave his brothers with their dad or their grandmother. With gentle supports and consistent practice, he eventually learned to walk through the sliding doors with ease. I recall how incredible the relief became as it was important for me, a mother with three small children to manage grocery shopping.
- 2) When my oldest son Todd was in cub scouts. I became a Den Mother, so all the scouts could come to our home after school. I had my mother's help during those meetings with the wild hungry boys. I recall going to award ceremonies and other scout outings. When Trent was with us, I sometimes missed seeing the part of the show or ceremony in order to leave with Trent to support his needs. I realize how embarrassing and difficult this was on his brothers.
- 3) I recall many experiences of rude and cruel people whom I encountered in public. One summer day I found the courage and enjoyment to take my three sons along with two of their friends to a nearby amusement park. Trent was 8 years old then, and was not able to manage the full day outing as he was miserable and began to tantrum. I remember that a woman from the amusement park approached me and questioned me. She thought I had been abusing him. She asked Trent questions, and when he could not answer effectively, she walked away. I remember how humiliating it was to be judged and not understood.

I was Trent's advocate at a time when there were few children labeled with autism. I faced an uphill battle during his early school years, advocating for speech therapy, appropriate goals and objectives for his IEP, as well as inclusion with nondisabled students for participation and socialization.

Fortunately high school became a positive experience for Trent. He sang in the high school chorus. I remember attending a performance where he was the only one singing

and rocking in perfect time to the beat. His body language gloriously shined indicating his enjoyment in performing. He had the opportunity to have a paid job in a grocery store with a job coach who went with him for support and training. These examples were some of the positive highlights of Trent's high school experience.

I believe that transition from school to adulthood was incredibly the most difficult phase for Trent and our family. For the first two years after Trent left high school he had few resources that connected him to others or the community. He regressed into severe withdrawal and obsessive behaviors. Without opportunities to participate, be included, and grow, people with autism often regress.

I networked and advocated for Trent a life of his own. In Trent's behalf numerous persons became part of the process helping him get the life he has today, a life that is personally satisfying to him. With the broad creative supports i.e., a live-in assistant friend, a job coach, and coworker supports on his job, Trent was capable of working. At the age of 24, Trent worked at K-Mart. placing security tags on clothes. For 8 years thereafter, Trent worked at Meijer Retail and where he continues to work today. We (the job coach and I) negotiated in 2002 that Trent and Jason (his live-in roommate) be hired as a team so Trent would have the supports he needed on the job. Throughout the years his jobs have been in lawn and garden and the Pets Dept., cleaning the bird and gerbil cages.

The Discovery of Trent Artistic Gift

One year after Trent had been living in his own house with a roommate for support, I thought that he would benefit from new community exposure and experiences. I recalled that his teachers through out the years commented that Trent loved working with his hands, crafts etc. I explored crafty art activities in the community. Yet when I found art classes, they were mainly for adults who were advanced, or children. So I approached an art store and asked if anyone would be interested in coming to Trent's house and doing art work two days a week. I placed an ad on their bulletin board, and the next day a University of Louisville art student responded. Teresa worked with Trent on different kinds of art activities, but painting was his favorite. After 6 months he began producing some very unique artistic pieces. That is how it all started. Trent's work has evolved over the past five years. Moreover, he has grown in his capability to create his artwork. He has since had several art facilitators, Elaine and Lori. Trent still has challenges in expressive communication yet with people supports he experiences social belonging. With certain broad creative supports, along with exposure and participation in different community settings, he exhibits a positive self-image and increased adaptive capability.

Since Trent was a small child, I dreamt of him living as an adult in a quality of life with

his needs met. That dream unfolded: Trent's own home, a job he likes, a life as an artist with friends. I never dreamt he would have an artistic talent nor that he would become an award-winning artist. He has become a contributing member of society. I suppose Trent and I both got 'icing on our cake.'

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