

A Letter of Thanks

My name is Janice Smith. Many of you know my son, Sean. He is a 33 year old young man with Autism. I have been an advocate for individuals with disabilities and their families for many years. Over 20 years ago I started a small support group, The Family Voice, with a friend who also had a child with Autism. We started in the basement of our church and within a year we out grew that space and moved to a larger office space in Ashland. That support group has now grown into one of the largest Autism Resource Centers in the state, Autism Alliance of MetroWest.

Sean lived at home with me and his younger sister, Cassandra, until he was about 18 years old.

At 18, Sean's behaviors were getting more challenging. It became too difficult to keep Sean home. I had no choice but to place Sean in a residential school. That was the hardest decision of my life. His first residential placement lasted less than a year and was not an appropriate placement.

He then moved to a very well-known and respected school for children with Autism. This was an intensely structured, behavioral program. It may have been a wonderful program for some however it was not the right program for Sean. By the time Sean was 22 he was on a 7-minute reinforcement schedule. He would get an edible reinforcer every 7 minutes that he was not aggressive or self abusive.

At 22, Sean's behaviors were even more difficult than when he first went to the residential school. He was aggressive and extremely self abusive. There were times he would wear a helmet during episodes of agitation to prevent injury from him banging his head. There were episodes of aggression, and at times he bit others as well as himself. These behaviors made it very difficult to find an appropriate group home. I did look at a few group homes and many of them seemed run down. There was one I looked at where all of the residents were very overweight and when I mentioned that I was concerned about Sean's weight they said that if the individual wanted to eat something in the house they could not stop them. "It was their home". They didn't seem to have many healthy

activities and the residents just didn't look happy. Ultimately though there were no group homes that would take Sean.

On his 22nd birthday he was moved to the Glavin Regional Center, a state run Institution for Developmentally Disabled Adults. This was a very traumatic time for me. Sean handled it much better than I did.

When Sean transitioned to Glavin he was considerably overweight and on psychotropic medication that contributed to liver damage.

There were both good and bad things at the Glavin Center.

- At the Glavin Center, Sean did calm down considerably.
- The nursing staff at Glavin was able to put him on a very limited calorie diet and monitor his medication so that we were able to wean him off of the psychotropic meds all together.
- The Glavin Center did away with the re-enforcer program.
- Sean quickly learned that if he did any mock aggression or loud outburst he would be removed from the activity and put in his room. He preferred being in his room and he would spend most of his time sleeping.
- There was not an awful lot of interaction with staff or the other residents.
- It was an institution and not a home.
- This was not necessarily the healthiest thing for Sean.

After 18 months in the Glavin Center, Sally Mueller, the Area Director of DDS approached me with the idea that Life-Skills was creating a new group home for young men with Autism. Sean would be the first person to move into the house. I was very nervous about making the switch to the unknown. I remembered the few group homes that I looked at and the residential programs that he had been in and I was so afraid that Sean's agitation and negative behaviors would return but I knew that Sean needed more than he was getting at Glavin.

Sean moved in to the house on Chestnut Hill Drive in 2006. Again, Sean handled the move so much better than I did. The management team, Cathy and Nancy, did everything they could to ease my concerns and made sure that Sean had everything that he needed. During the transition Lori, Sean's new one-to-one, would spend time at the Glavin Center to get to know Sean and make sure that he was comfortable with her.

Over the next few months the 3 other guys moved in. The four men have very different personalities and function at very different levels. They have all stayed together ever since. Although there have been some changes in staff over the years, the training has always been consistent. Consistency is so important for all of the guys.

There have been many dedicated people that have been there from the beginning for Sean. As one of the day staff just told me, these folks are the back bone of the program.

- Lori was Sean's first one-to-one and quickly moved up to the House Manager.
- Eric joined the house shortly thereafter. When Lori moved up to become the Residential Coordinator Eric assumed the role as House Manager.
- The over-night staff, Annie, Shem, Lorraine and Chris or (Christ as Sean would say) have all been there from the start as well.

The day shifts have also been very consistent; Andrew, Adam, Courtney, Angela, Andrea, Tanner as well as the many relief staff that pitch in. (I hope I haven't left anyone out.)

Sean has been very lucky to have such dedicated people working with him over the years.

It is clear that all of the staff really care about the guys and make sure that they have opportunities to do the things that they enjoy, that they get out into the community and they are safe, healthy and happy.

Sean now lives in a warm, safe, comfortable and beautiful home environment.

There is the right balance of structure and a level of freedom for Sean as well as the others.

Sean has thrived in this environment and it is all thanks to the wonderful staff that chosen to work at Life-Skills.

I visit Sean often and although he does enjoy my visits (especially the pizza or Chinese food) he is ready for me to leave when he is done with his lunch. Although it does tug at my heart every time he says "Mama's going home" I leave knowing that he is happy in his home and is very well taken care of.

I have always been so impressed with the caliber of the staff that Life-Skills hires. I have been a member of the board of Directors for several years now and I see that same caliber of employee through-out the agency. I have come to many of these recognition dinners and have always been impressed with the number of employees that have stayed with the agency and continue to dedicate their lives to this important work.

On behalf of the board of directors, and I'm sure I speak for many family members; I want to thank all of you for choosing this line of work. It is hard work and I know this field does not always get the recognition that you deserve. Your dedication and caring truly makes a difference in the lives of the individuals that you care for.

Thank you ALL for the work that you do!

Sincerely,
Janice Smith