

My Brother...Just Doesn't Fit In

No. 52, December 2012

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My brother David is 42. He was diagnosed with Type 1-Juvenile diabetes when he was 2 or 3. Later on in his childhood he was diagnosed as “moderately retarded”, sorry for the non-pc term (this was the terminology of the time).

David has limited problem solving and decision making abilities and due to his health problems and autism he cannot live independently. He lived at home with our mom for all his life.

David has many lovely and positive qualities. He is very sociable, a sweetheart and has an enormous laugh. He loves cars and will remember what car you drove back in 1978 and all the cars after that. He also loves movies, Wii games, and Singstar. So, although he lacks important basic life skills; he can and will beat you in Wii bowling.

David is well known for his strict schedule. Trust me, you will be informed when it is breakfast, lunch, dinnertime and all snack times like clockwork. Briefly, when I was really little, I did not realize my brother was different. I thought everybody had a detailed list of instructions on how to use the toilet. Who knew the order of those steps was so important...! My mom would tell me that I would help direct David. I think that was code word for bossy! It really wasn't until I was 9 or 10 going to summer camp that I realized how different he was. I hated summer sports camp. Instead of learning the fine art of T-ball I was fending off some serious bullies. I got my first taste of my role as the protector and really just how cruel kids can be.

So, as I progressed onto a lovely, thoughtful teenager, I dreaded family outings. I would try and hide if we all went to the grocery store. My brother was and still is quite loud, singing and yelling as we went down the grocery store aisles. I could not crouch low enough. That just wasn't cool! I went to your stereotypical high school and my brother attended a vocational high school in

a different city; which was great for him. He was still an outsider; but he graduated and went onto a work placement at a garage, which has turned into a permanent full-time position for 20 years.

Our parents divorced in the 1980's. My mother continued as my brother's primary care giver for all of his life. My mom took care of everything, from the mundane stuff such as balanced meals and hair cuts to outings with the group from Woodview Manor (for a respite weekend). My mother was the driving force behind my brother's successes. She taught him as many life skills as he could absorb. My mother fought hard for many years for any opportunities David could have. She had the most patience of anyone I ever met. She unfortunately passed away suddenly in 2010. I was left with some very big shoes, which I could not fill.

I had to make many decisions. This was not the life I had envisioned. I thought one husband was enough to fill that criterion of 1.7 children! So, what were we going to do as a family? A lot changed for me when my mom died. I had to turn into a caregiver overnight; from sister to mother. I tried hard to keep my brother's routine going; but I was slowly falling into a big dark hole.

One of my first concerns was to not kill my brother. This may sound like an obvious necessity but we had some issues with his insulin injections and poor David ended up in the hospital a few times. My mom knew how to tweak his diet and insulin just by looking at him. I did not possess these skills. So, after many painful finger pricks and swabs we got his glucose numbers under control. During this process I had been lost as a sister and became the primary care giver. My brother would try to communicate his needs but it always felt like an order. Some days I resented him; felt like his maid. I finally came to the conclusion I could not handle being a full time caregiver to my brother. I felt a lot of frustration,

sadness and guilt. In the end we had to look into other living arrangements.

That is when we started our journey through Contact Hamilton (Children's and Developmental services). There was hardly any paper trail. My mom was last in contact with them 10 years earlier.

We finally went for an intake evaluation, and even went through the painfully long new Developmental Services Intake Assessment. I thought I could take a breath. These people can finally help me.

However after many tears and begging, we were still left with very few options. They were unable to place David at that time. He didn't fit in.

We were instructed to look at nursing, retirement homes and secondary lodging homes. Nursing and retirement were out of the question; he was 40 and still working.

My husband and I viewed several lodging homes in Hamilton but these were not a good fit either. Most weren't willing to take on someone with his diabetes, unless he was independent with his injections. During this time, my brother had to learn a lot of new skills. He now had mastered loading his insulin pens, delivering the correct insulin, and checking his blood glucose. These skills were all coming along but not enough for most of these facilities. And besides, I wouldn't live in most of the places we looked at so there was no way I was going to let my brother live there!

Luckily, we were told about Dromore house. It is a special place in Dundas, Ontario that is a lodging home which is home to 6-7 other men with various disabilities. Most of the residents are dealing with mental health problems rather than autism disorders. They were willing to take on his diabetes and autism and work with me to find ways to help David continue some sort of routine, go to work and try to be happy again. We finally found a place where David fits in!

Now, this was a huge adjustment for him; he was leaving his home of 40 years. He would get angry, he would get quiet, he would slam his arms, slam doors at times, I think to express himself.

I begged for psychological counseling. The experts were all telling me due to his level of functioning it would be of no help. I was told it would really only benefit me. So, there was no help for helping my brother deal

with his grief and coping with change. If he was higher functioning there might be a couple of programs but once again, he just didn't fit in. I brainstormed with several other intelligent people and we tried a few things. One thing that helped was a photo album. We took pictures of the house, all the parts he liked and he could look at them whenever he wanted.

We had to pack up and downsize his things. This was a painfully slow process. We sat down and went through every car book, magazine, comb, and penny collection. I am no counsellor but I think it helped him have some sense of control and in the end we sorted it all.

One of the toughest situations was saying goodbye to his home he had known for 40 years. I started him off by walking around the inside of the house. We then followed it by pacing straight up and down the lawn saying goodbye to important items, e.g., "Good bye tree." When David was done his ritual he came back to me, gave me a hug and asked why I was crying. He was perfectly okay; that process of letting go worked for him. I tried to follow his lead several weeks later but it did not work as well for me.

ODSP (Ontario Disability Support Program) and DARTS (Disabled and Aged Regional Transit) were other important issues that needed to be addressed. ODSP provides additional funding for David's housing, diet, medication and transportation. Without this support the family is responsible for making up the difference or finding alternate funding. This process was pretty straightforward once I knew about the monthly paperwork and responsibilities. DARTS is the transportation service out of Hamilton. David had been using this service for almost the entire 20 years he had been working. This is what enabled him to go to work. We were warned that changing his route to work might be difficult. Luck was on my side and they were able to change his route with little disruption in his schedule.

David did not possess a bank account. He is not a good money manager as my mom managed all his money. The bank eventually came back with an acceptable solution: a joint bank account. I now manage his money and his bills.

Ultimately my brother ended up with some support structures again. He was involved with Contact Hamilton again, social services, even had a bank account. He had more structures in place then he had had for over 10 years. Even though I had family and friend support, I felt really relieved that I wasn't doing this alone as our mother

did. Because, a lot of the time you do feel like you are alone and no one is listening. And if they are, they can only do so much.

I think my mom had given up on the system. I think she was still a fighter for his cause in the end; but did not know how to use what energy she had left. My biggest issue at the moment is working on my brother's guardianship. Officially he does not have one. Originally a lawyer told me that this could be an expensive and long process. But since talking and listening to presentations at an autism conference I feel I can tackle this challenge. This designation will help me address his future healthcare needs. His diabetes will be an ongoing, progressive issue that I want to fully be a part of. I also cannot start an RDSP (Registered Disability Savings Plan) without this title. I want to secure funds for his future needs.

So, I guess the issues I would suggest to parents, caregivers, and others to think about are: what will be the future needs of your adult children be? How are you going to meet those needs? Where will they live? Are they going to be able to manage independently or dependently? Are their enough supports available and in place?

In my opinion, there are not enough appropriate living options for adults with autism and not enough social workers to go around either.

How to make it better? How to see those issues change? I am not sure. I think it starts with communicating. Discuss with the other adult siblings what your future wishes are and start to make plans. Set-up the infrastructure - continue to work on those important life skills, organize bank accounts, prepare your wills and prepare yours and your children's Power of Attorney or guardianship.

I continue to be inspired by all the people who have helped me and continue to help me; friends, family and people who were strangers a year ago. People like Robin who works at Woodview, believes in everybody's abilities and strives to see change happen and people like Josephine & Michael at Dromore House, who continue to monitor my brother's day-to-day welfare. All these people continue to see people's abilities and truly want to help.

As for my awesome brother, who didn't fit in most places; now he is fitting in. I am so proud and amazed at how well he is adapting and coping and also of all the new skills he acquired. He may never be able to fully cope with all his losses but he continues to go to work, enjoy his new routine and be my brother again.

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