

**A Sibling's Perspective**  
**Thoughts on a life with Jordy**  
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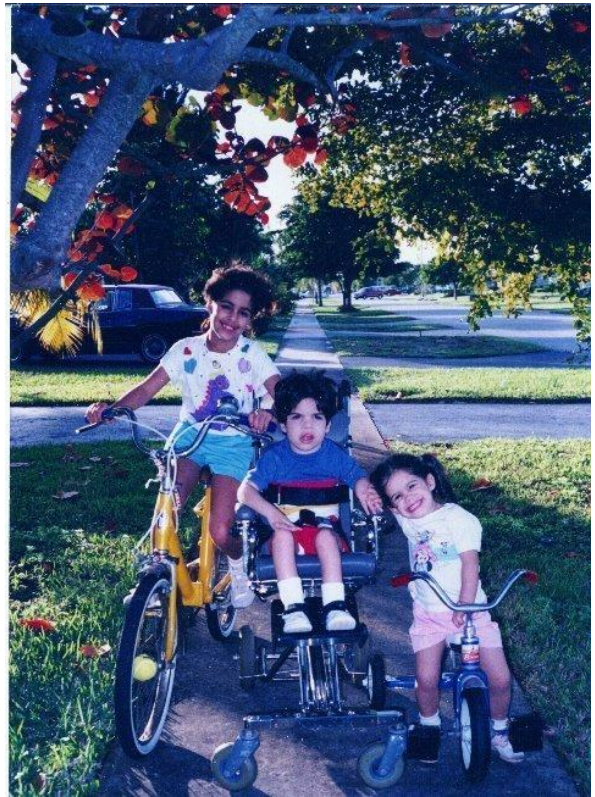
Every parent believes their children are special. Whether they are exceptionally cute, smart, funny, talented in something like music or math, every parent strives to be proud of their children for their accomplishments and their character.

However, what do you do when your child is not any of these things? What do you say about a child who is not capable of achieving anything in life and whose biggest success is merely continuing to exist? This is what my family has faced.

I may have only been three years old when I became a big sister, but I understood right away that something was not right when my brother was born. There was not the great feeling of joy I expected to feel or see throughout my family. I knew something was very wrong. Instead of coming home with him, my parents instead disappeared from my life. They took him all over trying to figure out why this happened, what happened exactly and what could be done to help him.

Luckily, I had a strong family support system so I stayed with both sets of grandparents and everyone tried to make my life as easy as possible. When someone finally explained to me that my brother was profoundly retarded and severely handicapped, I knew that no one in my family's life would ever be the same.

I remember a lot of crying. I remember a lot of people coming through our home to care for my brother. I remember the day my parents realized it would be impossible to for him to live at home and he would need to reside at a facility where there were other people like him. And, I remember the day he moved there and all the times I would leave school early so we could drive the three hours to see him.



**Carly, Jordy, and Marlo Engels, 1989**

I knew that in my life, this was not enough. Selfish as it was, I wanted a sibling, a real sibling. Someone I could play with and talk to. Even though I was only 4, then 5, I passionately argued for my parent's to try again, completely unaware of how they must have felt and the risks that might be involved.

When my sister was born, loud and healthy, I knew there was a big feeling of relief. It was palpable. Yet, this is where things became difficult for me. My sister always viewed my brother as a normal part of our family. She had no problem interacting with him or visiting him. She was born into the situation and when she was very little, she assumed everyone had a brother like ours.

When I was in grade school I was teased about my brother, like being a kid isn't hard enough and kids don't already have a plethora of things to pick on someone about already. The word retarded was thrown around in every conceivable hurtful context. At that age, no one understands that sometimes bad things happen to good people for no reason. My parents did not deserve this. It was not G-d punishing them and it was not the result of anything they did or did not do.

Even when I got older, unconsciously, I did not bring up the subject of my brother. It was not as if the topic came up often either. There were many times when people who had known me a long time did not even know I had a brother. I was not ashamed, but merely did not think to make it something to be known for.

Subconsciously, watching my parents fight for funds to keep my brother alive and issues related to his care propelled me to study health law in law school. When my brother passed away the year after I graduated law school, I will not lie, I felt a weight had been lifted off. As much as I loved my brother for who he was, I admit I did not like what he was. Again, I know he could not help it, but I felt little connection to him and so when he passed I felt like he was probably more at peace in that moment than he probably had ever been, though I am sure he was not ever conscious of it.

I do realize that after he died I was more adept at talking about him. I did bring up the subject of him more voluntarily and my tribute to him has been to continue the activism work my parents advocated for and carried through while he was alive. I honor his memory by trying to make sure other families have access to the same quality of care my brother had during his short lifetime.

Many people applaud my efforts because I have continued to do this after he died. The truth is, it became easier after his passing because I am no longer as connected to it; I have some distance. Since I am a more rational than emotional person, I sometimes still have trouble justifying the argument of allocating money to people who do not really actively benefit society, but then I remind myself that they did not wish this upon themselves and therefore should be not penalized for their disposition. It is society's obligation to take care of everyone including the sick, the weak, the infirm and the imperfect – a categorical imperative if you will.

I would not say I am stronger because of my experience. I would say my parents are the stronger souls. I would not say I am a better person because of the work I do. I would leave that title to the caregivers who work with retarded and handicapped

every day. I would not call myself lucky because I learned tolerance or empathy or understanding. I may have learned these things, but I learned them the hard way.

In the end, I am just another person who was faced with an extraordinary experience, not of the good kind. I am sure if you ask my sister, she will have a very different account of life with Jordy. The same can be said for my parent's perspective or people who know us. I can only speak for myself. My voice is the one that rings clearest in my head and this is the experience I take with me when I face the world and the future.