



Guest Editorial

Liam Bowie

A Journey Through Disability: A Sibling's Perspective

Editor's Note: *With the holiday season upon us, my mind, like those of many others', turns to family. Pediatric nurses know that there are all kinds of families – large ones, small ones, multigenerational ones, and so on. As a holiday gift to our readers, I turn this issue's editorial space over to Liam Bowie, the 13-year-old brother of a child with "special powers" from Berwick, Maine. He will tell you the inspiring story of his family. Happy holidays!*

– Judy Rollins, PhD, RN

Ever since I was little, people have told me Aidan was "different." To me, even from the first moment I laid eyes on him, he seemed normal. He was born when I was 2 years old, and at the time, I was really excited to be getting a baby brother. However, when he was born, he was taken away to another hospital where he stayed for three months while they tried to diagnose what was wrong with him. I, being 2 years old, had no idea what was happening. I stayed with my grandparents during this time, so I didn't really get a chance to see Aidan. When Aidan did get out of the hospital, the news was far from good. The doctors said he would never be able to walk or talk. They diagnosed him as developmentally delayed. He had to be put on an IV and needed a G-tube for the first year or two of his life. One of my earliest memories is of helping my mom feed him through the G-tube.

As a toddler, Aidan was also diagnosed with hypotonia, which means that his muscles were not strong enough to fully support himself, making walking and feeding very difficult. For the first five or six years of his life, the house was full of therapists; some helping him start to use a walker, others helping him learn how to hold simple things, like a fork, and still others helping him to use sounds to ask for things,

like more food. For me, this meant that there were lots of strangers in *my* house and invading *my* space while they played with *my* brother. When the therapist came, it made the house feel chaotic, and I felt like there was less time being spent with me. When Aidan turned 5 years old, they stopped coming to our house, and we went to see them at their office or he had therapy at school. This was a relief because it meant I didn't have to hide away in my room while Aidan had a therapist seeing him.

As a toddler, Aidan couldn't walk at all. He needed to be driven around in a stroller or held by my parents or me; Aidan would be propped on me as I sat on the couch or elsewhere. Our home was not very accessible, and multiple steps were required to get into the house. This was a challenge that we faced everyday because Aidan could not climb stairs and was growing and getting heavier. We knew that we needed an easier way to get Aidan in and out of the house, so my parents decided that we would get an outdoor lift. This was a big project. My dad had to move the stairs, put down cement, and get rid of some of the railing. Once we had the lift, though, it was a lot easier to get Aidan in and out of the house. Two years ago, our community came together and raised money for a wheelchair-accessible van for Aidan, and we even had an interview by the town paper (<http://www.youtube.com/watch?v=DS9eyEBNT48>). My mom started a blog (teamaidan.wordpress.com) with the dual purpose to raise money for Aidan's van and to meet other parents who had children with "special powers" (as my mom calls them). Aidan's disabilities have made my mom learn many things about disabilities, health care access, and education for children with disabilities. I've learned a lot also.

When most kids were learning to talk, Aidan was making a lot of noise.

He couldn't form the words, signaling to my parents he needed something. He reacted a lot when he heard loud noises, like someone mowing their lawn or an airplane overhead, mostly by crying. He had no way to communicate with us, and this made life very difficult. The first time Aidan learned to verbally communicate with us was by making an "Mmm" sound when he wanted more of something. Aidan mostly does this when he is eating because we have to feed him with small bites, and boy, does he like to eat!

Soon, Aidan started school. This was one of the most stressful times in my mom's life. For the first month, my mom had to meet with the special education team and set up an Individualized Educational Plan (IEP) for Aidan. Although this time was exhausting for my parents, Aidan's first year in school was not very stressful for me. Being only 7, what responsibility I did have in helping with Aidan was somewhat lightened by him not being around as much. I was also finally able to spend *slightly* more time with my parents than ever before. Life with Aidan for the first few years he was in school did not seem too hard.

This was about the time I really started to realize that Aidan wasn't the same as all the other boys in second grade; they didn't visit the doctor every other month. I started to wonder if the other kids knew what they were missing. At my age, having Aidan as a brother seemed awesome. He was giggly most of the time, and I would never fight with him. It also seemed pretty cool to go on doctor visits and get stickers all the time. To most kids, the hospital may seem scary, but when I first went to the emergency room to get a splinter removed, they had free drinks and a cool goldfish tank. What was not to love about the hospital? However, whenever Aidan goes to the doctor for something besides his regular check

ups, I get really worried. What if they find something else wrong with him? One time, Aidan had fallen and knocked out a tooth and was bleeding. My dad decided that he should go to the emergency room and get Aidan checked out. I went to my friend's house and waited. I was playing and having fun, but underneath all that I was worried. I knew Aidan would probably be fine, but what if he had hit his head and now had a brain injury. Those thoughts worried me until Aidan came home. Aidan was fine and just needed a tooth pulled that was damaged when he fell.

Some people in public have what I call "Excessive Staring Syndrome (ESS)." People affected by this affliction can show these symptoms: staring at people in wheelchairs because they are different, staring at anyone who is different, and quickly looking away if someone sees them staring. When I was a kid, this never really bothered me, partially because I never knew that people were looking at him and partially because I didn't realize that they weren't staring at him because he was so handsome. When I got older, though, I realized that they were staring at him because he was different. Now I understand why they stare, but it really kind of makes me a little bit frustrated. Also, when people see him, some of them say, "What happened to him?" Most of these people are kids, but when an adult asks this, I wonder if they grasp the concept that some people are born different.

I think that inclusion of children with "special powers" in regular classrooms at school is good. I can see why parents might worry that "normal" kids might bully their "special" child, but I see it quite differently. If you keep someone locked away from society, when people do see them, they will stay away from them like they have a contagious disease. However, when you let children and adults talk to the special child and get to know them, suddenly you have an accepted child. If all the kids in school have seen "the special child," in this case, Aidan, and gotten to know him because he was in their classrooms since kindergarten, they will be able to accept Aidan. Aidan has a friend who has been his friend since second grade.

Now would seem to be an appropriate time to bring up a very touchy subject: the word "retard." The word means to delay or hold back in terms of development or progress. Some people have a disability called Mental

Retardation (MR), which means they have an IQ under 70. However, the word retard has slowly become a word that kids use on the playground to make fun of other kids. Lots of kids don't even know what the word means. If you don't know what it means, you shouldn't say it. The best way to use the word retard is as a medical term. I am lucky to have had an experience when one of my schoolmates used the word in the correct manner. I was on my bus and he said, "I don't mean to be rude, but is your brother retarded?" Boom! Right on the mark! That is the way the word should be used. Now we don't know if Aidan is retarded or not, but his developmental delay is both physical and mental, but that is not the point here. The boy was using the only medical term that he knew to ask about Aidan's disability. He had just seen me with my brother a few times and had noticed Aidan was in a wheelchair. He knew this wasn't the most polite question to ask, so he made sure that I understood that he wasn't making fun of Aidan, but was genuinely curious about Aidan's disability.

Aidan is now 11 years old, and he has learned many things. He is off his G-tube and can feed himself with some help and drink from a sports water bottle. Against all odds, he is now able to walk with someone helping him keep his balance. He got a motorized wheelchair this year and has learned to drive it all around, giving him independence in movement for the first time. He can answer simple questions using his iPad or communication board at school but still does not talk. I am proud of Aidan for accomplishing these tasks. Some of the best parts about being his brother are that I get to be close to him and support him through everything he does.

There are still many challenges ahead. Two years ago, Aidan was diagnosed with epilepsy and went through a series of drugs that were supposed to help control his seizures. These drugs barely altered his seizures and only made Aidan tired. The seizures that he has last no more than five seconds, but he can have more than 40 in one day. My parents and Aidan's neurologist decided to take him off the drugs as they felt the drugs did more harm than good at the time. His seizures were usually harmless. The greatest threat was that he would hit his head or fall from his chair (both of which have happened). Aidan is now back on seizure medications because the seizures were get-

ting stronger, but he doesn't seem so sleepy and groggy this time.

My parents have just been told that Aidan needs hip surgery in a few months. It will be really hard to have him in the hospital, and I will worry. The other hard part is that the doctors have told my parents that Aidan will not be able to stand or walk for six weeks after his surgery. He is getting big, so it will be hard to care for him at home, and he has worked so hard to learn to walk with assistance; we don't want him to stop walking. Aidan also needs back surgery sometime in 2014. His spine has been growing in a curve. You don't notice it if you are looking at Aidan sitting up in a chair, but if you feel his spine, it is very curvy. The surgery could mean that Aidan has to go into the hospital for more than a week, and I will be very worried about him.

Family time is definitely more limited, but it is not serious. When I was younger, all of the therapists in the house seemed to prevent family time from happening, but now it is actually quite easy to hang out together. The hardest part is to find places out of the house that are accessible and enjoyable. The things we can do together as a family are mostly limited to our house and somewhere that has a relatively flat surface so Aidan can drive his wheelchair. I don't feel like this takes away from our being a happy family; all you need for that is time together.

My parents do a fairly good job of letting me help make decisions about Aidan. Obviously, there is some stuff I don't understand, but for a lot of things, they listen to me. For instance, this year my parents had to choose to either keep Aidan in his current elementary school that had a special education program or to move up to the middle school with his classmates. When they asked me what the special-education program was like at the middle school I attend, I told them they should definitely keep Aidan at his current elementary school because the elementary school has a decent program while the program at the middle school was just for kids with learning disabilities. When we were choosing Aidan's wheelchair, they wouldn't even listen to my opinion of getting the one that goes the fastest and having it painted neon green. Seriously though, for the most part, my parents are very good at listening to my opinion.

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Everyone has treated Aidan differently, but I am happy to say none of those ways include discrimination or making fun of him. For people in my family, it is easy to interact with Aidan, and he loves the attention. Some of the people in my family have worked with other kids who have disabilities, so they are accepting of Aidan's behavior.

Being Aidan's brother has affected my outlook on life. I have not known life without having Aidan as a brother. I am used to frequent crying fits and know that I'm going to have to live with them. I am also asked to hang out with Aidan a lot when my parents have to do something. I think that it has taught me more responsibility than some other kids have because I have to do things that parents would usually do while my parents deal with Aidan. If I could give any advice to other kids that have a sibling with a disability, it would be to be patient. A lot of the time, it may seem that your parents aren't paying attention to you, but that's because they are dealing with a lot of stress and confusion, but they will eventually get over it.

Aidan being my brother seems like the best thing that has happened me. He may have challenges that hold him back, but I still love him. ■