

I would first like to thank each and every one of you for being here today. I know all of you have a full agenda ahead of you but know that there are several people in this building right now that appreciate your efforts.

I would like to give you a parent's, mainly a fathers, perspective on what it is like to find out your kid has Autism. I must begin on January 25, 2011, this is the day my son, Maverick was born. You see, Maverick was not my first child, in fact I had three girls prior to him. So Maverick was my first son. I never told myself I wanted a boy over a girl. In fact when I was preparing to have my girls and someone would ask me what we were having, I would always answer, "I don't care as long as they are healthy". That was all that mattered to me.

As a father of three girls, I saw myself as the protector of my three princesses. I knew what my job was, to work hard to raise them to be ladies and to protect them against the evils in this world. I always hoped they would look at me as their Superman. So when I found out I was having a boy, I could immediately see my role and responsibility was going to change for him. What I am about to tell you, I have not even told my wife. I feel it necessary to relay a personal story, shared between me and my newborn son.

On January 25, 2011, I was sitting in the hospital room holding my son. He had jaundice and we were instructed to try and get him as much sunlight as possible. So I was sitting in the window seal and I was holding my new son in my arms. I had stripped him down to his diaper so the sunshine would shine on him and help with his jaundice. My beautiful wife was lying in bed and taking a nap for the first time since her C-section. I felt, as a father, it was my time to have a talk to my son. I knew he was less than a day old but I was always told that kids retain information better at a young age. And we all know you can't tell a teenager what to do so I figured this was as good a chance as any.

I remember holding Maverick in my arms. He was looking up at me and I began to tell him about how a man is supposed to act. I explained to him the importance of being polite to everyone, and the importance of always holding a door for a lady. I told him that when he sees people being picked on, that he won't join them but rather stand up for them and when he sees someone's life is in danger, he will act selflessly and do what he can to help others in need. To me, those were some of the main characteristics of a man and that is what I wanted him to be when he was grown up.

In reality though, I was wanting him to live the life I was living and always wanted to live. As a police officer, firefighter, and medic, I devoted my life to helping others and seeing the rewards that these careers gave me and the people I was involved with. So I had a conversation with him on how to fight fires and how to fly a helicopter, something I always wanted to do. So I had laid out his future but he didn't know it yet. This was my plan for Maverick. These were the goals I had laid out for my son.

All that changed in August of 2012.

You see, Maverick was born a healthy boy. For each of his monthly visits to the doctor, he exceeded his milestones. We had no concerns for Maverick's developmental status. In August of 2011, at about 8 months Maverick started making "dada" sounds. Although he never associated the sounds with me, I

knew, having prior children that the word "dad" was coming. Any of you in this room who are parents, know that moment well and can probably still recall the first time you heard it. Whether it was Mom or Dad. It was a sound that melted your heart and reminded you of the blessing that was in front of you and calling out to you. However, Maverick's vocabulary did not expand much beyond the occasional "dada" or him trying to sing a song with me. As time went on, Maverick started to lose his vocabulary. My wife researched the causes for this and mainly got a response of "kids will talk when they are ready to". It sounded like no big deal.

Before long though, Maverick was showing other unusual signs such as flapping his hands, spinning in circles, walking on his tippie toes and he was not making eye contact with us anymore. I can still recall the night I had had enough. I sat down at the computer and typed in "Toddler Walks on Tippiie Toes. This is the first time a whole list of searches came back with the word Autism. I opened one up and it had a list of 20 warning signs your child might be Autistic. As I went down the list, my heart sank. Maverick did not have 1 or 2 of the signs. By the time I was done, he had 17 of the 20 signs. My next and most difficult thing I had to do was show this to his mother. I should be remembering Maverick's first steps, or the first time he rolled over or sat up. However, I can't remember those. But I can still remember that night when I knew my son was Autistic.

As the next week or so dragged on, it was hard to get someone to return our phone calls. Thankfully Maverick had two parents that were stubborn and didn't take "leave a message" very well. Sometimes being forceful is a good thing. We began the multiple questionnaires over Maverick and the 1 hour of therapy a month Maverick was receiving. 1 hour a month compared to the 30 hours a week that is recommended for a child with Autism. But this is all we had so we took advantage of every minute.

As a city employee, I felt blessed that we had the state insurance plan and it covered Autism. After seeing the bills come through, I wondered how someone with a child with Autism or another disability could ever afford to get their child services without insurance. I came to the conclusion, after going through all of this that the parents will do whatever they can for their child, but the child suffers in the end by not getting the care they should have had at the early onset of the symptoms.

We tried to get Maverick into KU Med or Children's Mercy for a diagnosis so we could begin treatment. However, the earliest we could get an appointment was January of 2013, 5 months out. So we plugged along at the 1 hour a month sessions, and did a lot of research online and read books to try and help as much as possible, and in January of 2013, Maverick received his diagnosis that he had Autism.

Here comes that punch in the gut feeling. The one that tells you your son is not going to be like other kids and have the same opportunities as them. The one that tells you that your son will probably have to have the doors opened for him. The one that tells you, your son will never be a firefighter or pilot. But if you think we are going to lay down and not fight, you do not know us very well. And by us, I mean all the parents of children with Autism and special needs. We will not quit fighting for our children.

We know for a fact that early intervention is the key to getting these kids to an independent adulthood. Now that we had our diagnosis we could start the Applied Behavioral Analysis (ABA) training. We were fortunate enough to find a wonderful lady who was qualified to teach us and Maverick the therapy

needed to help him. I believe she was the only one certified covered by our insurance in the whole State of Kansas. This just reminded us of how many families must be suffering because of a lack of resources. We felt blessed to have found this lady and there was a great weight lifted off of our shoulders. We had just found the ABA therapist when we found out that we and everybody else might be losing our insurance coverage at the end of the year. Here came that punch in the gut feeling again. When you have hope for your child then it is taken away by the word Autism, you get the help you need, then it is taken away because of no coverage. It is almost impossible to image having to cover all the costs out of pocket. For example, Maverick just had blood drawn for the geneticist. This bill alone was \$3500.00. That is almost two months of pay for me. How do we afford that?

Both my wife and I work full time jobs and I took on a second job to help pay the bills and we are still barely able to tread water. Between the bills, and the gas to drive all over to appointments it is difficult enough with insurance. Without it, I can't even begin to imagine that life. However, if the Autism Bill is not passed, I and hundreds of others will find out what that life will be like. I ask you to remember that 1 in 88 kids is diagnosed with Autism. These numbers are not getting any better. If we get them the treatment they need at an early age, then they stand a better chance of living a somewhat independent life. If this bill fails to pass then they suffer and most likely will cost the State of Kansas millions in state funded services.

I pray that you will take these testimonies and facts into consideration.

Jon Shaffer, Parent of an Autistic Child