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Pancakes and Lemonade

by Janee

"Oh, he's a boy and boys sometimes take longer to talk." The words reverberated every week or so as a family member, friend, or acquaintance would meet my son Kohner. More of these comments began to occur around the ages of two and three. I thought maybe they were right, but the lack of mama's, dada's, down, and many other expected words at a young age were beginning to bother me. I knew he wasn't hitting the milestone check boxes on the handouts provided to parents.

Well, the words didn't come, although one day leaving the neighbor's daycare he said, "Bye, Bye." I was flabbergasted, but little did I know my joy of hearing these words would be overridden with a "Bye-Bye" to Kohner from the daycare provider who happened to be my neighbor. My neighbor showed up at the door with the excuse that her husband wanted her to watch fewer children though I knew that it was due to the fact that Kohner just wasn't "the fit." As the door closed after I received the news, I knew it was just the beginning of fighting for my son's rights as a human being. While therapists hesitated to use the "autism" word, Kohner was initially described as having Pervasive Developmental Disorder.

Life with Kohner

My husband and I were used to Kohner's sounds and the unique ways he communicated his needs. They are rhythmic to us, but it seemed in public his vocalizations sounded more like animal noises to other people. When we were walking toward my car, I often heard people say, "Where is the horse?" I thought to myself, "How could anyone be so insensitive as to call a child an animal name?" Some weeks it happened too often, and I just didn't know where to put my hurt feelings and emotions.

One day a grown couple walking in the parking lot said, "Where's the horse?" I couldn't help it that day, and I just turned and yelled back "Where are the idiots?" I went to the car and cried my heart out. Was this Kohner's future? He didn't even have a way to defend himself to people's destructive ways! I didn't know what we were going to do.

We had an opportunity to relocate to another state when Kohner was four. The last week before the move I was eating an ice cream with Kohner in a fast food place. An older gentleman told me how handsome Kohner was, and then he realized Kohner couldn't talk.

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Well, then his comment was, "He must be possessed and needs a lot of prayer." I thought, "I just didn't hear that, did I?" I quickly left with my son totally infuriated!

I could go on and on, but it was the public experiences that I was having with Kohner that astounded me during those years. I wasn't prepared to go through life with a non-verbal child. I love to talk and learn other languages. As a bilingual teacher, language has been my life and communication.

I knew more than ever that it was going to be a life of educating the public about disabilities and especially non-verbal autism. I also knew I was going to have to become emotionally, spiritually, and mentally stronger to do my best on this journey with my son.

Learning about Augmentative Communication

After we moved, Kohner entered an inclusive preschool. We finally got the diagnosis of autism, but the diagnosis was unfortunately used to define the ways Kohner would learn in his elementary years. In preschool, all the teachers thought he would be the model signing student with autism. Unfortunately, many children with autism and low muscle tone aren't good at signing. While at four he was the fastest in the class with a computer mouse, he had only learned about three signs in a year of school.

I knew something was wrong with this picture, yet at home he clearly indicated the ability to communicate. When he would get the bread and peanut butter, we knew he wanted a sandwich, but he could only tell us with pictures or tug at our arm or shirt. He knew what he wanted, but couldn't communicate it very well.

During yet another stressful educational year, my husband and I began researching, reading books, and trying to find out the learning style of our son. He had begun to track sentences with photos with his private speech pathologist and seemed to know what he wanted. He would try to solve his own problems, especially in the kitchen.

My husband and I had been taking a Hanen “More the Words" class and thankfully that instructor introduced the idea of augmentative communication to us. She observed Kohner at our home and commented that he clearly knew what he wanted to say. One evening he was standing in front of her after getting the peanut butter jar, bread, and a spoon. Kohner wanted to make a sandwich. He just couldn't verbally get the words out!

One thing led to another with private assessments and the recommendation for a talking device. While we were met with resistance from the school district, at this point, I wasn't allowing any more time to be taken from my son waiting for a communication system.

He received a loaner device near the end of his kindergarten year, but it was not implemented well in school. His teacher's goals for first grade Reading were lining up blocks left to right. The speech pathologist misused his device by taping off keys to hit and boring him with silly phrases like "I want a cracker!" To say the least, Kohner was

removed from that school based on huge philosophical differences. We didn't have months to debate District Programs versus what was working for my son to learn and communicate!

After a long year and a half, he now finally has his own device and an amazing augmentative communication specialist. As Kohner began using his device, he was becoming more and more empowered. We began the focus at home and school. Of course, we are learning right along with our son. We didn't know anything about the augmentative communication field.

Kohner has a Voice!

Kohner loves to go out for breakfast and his favorite thing to eat is pancakes. My husband and I would always order for him, and he loves to pour the syrup all over. It had been a month or so that Kohner had his device, and we took it with us out to breakfast. We thought we would have him try and order his breakfast. When the waitress came she asked all of us what we would like to order. Kohner hit one of his keys on the talker and said, "Pancakes and lemonade." The waitress proceeded to my husband and me for our orders. She left and thanked us.

My husband looked at me. He said, "Did you see that?" I knew without answering what he was referring to. "Oh, you mean how she treated Kohner as though he was any ordinary customer?" "Yes," he replied.

It was an unforgettable moment due to a device sitting in front of Kohner that was his voice. He was heard, honored, and respected! That moment gave me great hope for Kohner's life. He could be known in public as a great kid with a voice, humor, thoughts, and feelings.

Kohner and his device are educating people and hopefully breaking down prejudices and stereotypes. Well, his mom helps too! One evening when we were having dinner in a restaurant an elderly couple asked me what game Kohner was playing. He actually was enjoying the songs programmed on his device. He was listening to Old McDonald and grinning. Little did they know they would get a mini-lecture over spaghetti on the field of augmentative communication. What is amazing to me is how so many people know of a child or adult whose family needs to know this technology is available to them.

Our latest public experience occurred in Montana were we had traveled for an anniversary party and had a wonderful time. The day after the party we were traumatized by a grand mal seizure Kohner experienced. After eight hours in the Emergency Room, we returned to our hotel room. Kohner was fine, but I kept wondering if he could still use his talking device the same as he had been. Since he was fine, we went to breakfast the following morning at the hotel. I took the talker and was going to do the "mom's post-seizure neurological test."

A waitress walked up to my son and asked him, "Kohner, what do you want for breakfast?" He responded, "Pancakes and lemonade." He passed mom's test with flying colors.

This same waitress took a strong interest in Kohner's life and talking device. Again, she had a story about a friend whose teenage son had no communication system. She was fascinated with learning about augmentative communication. After seeing Kohner use his device, she was in tears and asked, "Is there a need to help people with funding for these?" She was trying to decide on a major for college and loved business and people. Well, we would have talked for hours after that question, but she didn't want to get fired. We exchanged telephone numbers, and she wants to know about how she could combine business and become involved in the field of augmentative communication.

Opening New Doors

All I know is that Kohner is touching people's lives in a powerful way since he now has a voice. I have seen in a few months' time how people have to reach deep down in their souls and question themselves. I see the diffusion of prejudice, views about intellectual ability, and overall acceptance of difference when you enter Kohner's world.

Now if anyone says, "Where's the horse?" Kohner can say, "I don't know, but you want to hear the song Old McDonald? He had a horse on his farm! I'm Kohner and this is my voice!"

Janee Haniuk is a mom and educator living in Fort Collins, Colorado. Her son Kohner has autism and is non-verbal. Her son Kohner has led her to become a strong advocate for the intellect and voices that need to be heard through the use of augmentative communication and assistive technology.