Children's Vision Massachusetts Story Bank





hen my son Javi was born with a brain bleed, I knew that he was going to have some complications, but I had no idea that one consequence would be impaired vision. I knew that all babies don't see very well at first, and their eyes do funny things when they are born, but I noticed it a lot with him. I noticed he wasn't focusing very much but thought, he's a brand new baby and it will fix itself. I knew his development would be delayed because he was premature but when he turned four months, his primary doctor told me that he was not tracking at all and that even with his slight developmental delay due to prematurity, he should have had some sort of vision going on, but he had none. I felt my baby was looking through me. Even when I thought he was looking at me, it was kind of a blank look or stare. He only smiled when I tickled him, but he had a very surprised reaction to even being touched. Now I understand that it was because he didn't see the person coming as they were about to touch him.

We took him to an ophthalmologist, who checked Javi and told me the hemorrhage definitely affected his vision but there was nothing we could do about it. When I asked if he was blind, my biggest fear, the doctor told me that he was not completely blind because he could react to light. That was it. I was so angry because that's not what you should tell a parent. The doctor had not told me at two previous visits that this was a possibility, and Javi was already six months old. My baby had already started Early Intervention and the service coordinator asked if we'd like to try to get him enrolled with Perkins. Even if it was going to help him only slightly, I wanted to enroll him, to give him a chance to do his best. That's what all parents want for their children, to provide everything and anything so that their child can succeed in life. His Perkins Teacher for the Visually Impaired (TVI) started working with him. It was one of the only things that helped because I was finally told that my son was not blind. I was told his sight was not good, but there were things to work on. When his TVI first came and showed him a pom pom, it was one of the first times he looked at something consistently. Everything the TVI had was super shiny and bright. She had lots of lights and wands and Javi would reach for them and try to grab them. It was the first time I'd seen him look at something and be interested in it.

Then the TVI made an appointment for Javi on the New England College of Optometry Mobile Vision Clinic that was scheduled to come to the area for a few times only. It was insane when Dr. Moore put the glasses on Javi because for the first time, his eyes opened really wide and he looked at me. He had a confused look on his face because he heard my voice but saw Dr. Moore! He knew the man with the beard wasn't me, though he didn't really know what my face looked, only my voice. When Javi saw Dr. Moore, and Dr. Moore's colleague Dr. Srinivasan, he didn't know who he was looking at! His confused expression told me he was learning right there - that I was his mom and that I didn't look like Dr. Moore!

I am so thankful to the Mobile Vision Clinic because for months I was depressed and angry because my son didn't smile at me and all I could think of was that he didn't know what it is to see someone's face. I thought he would never know what it is like to see his mom. The first time he ever smiled at us was when he looked at us through his glasses and his TVI was there, taking his picture. I finally knew for a fact that he was able to see what was around him. It wasn't a complete sentence that he was going to be blind or have very little vision his whole life.

When we put his glasses on at home I watched as he began to understand his surroundings. There were noises around him that he didn't know and now he could look and see what was making the noise. He started looking around the whole room all the time. He was shocked to see the television! I remember crying because I thought, my baby's able to see his mommy for the first time. Now he knows his world and he can understand it....OK this is a person's face, and I can look this way and see more. Before I would talk to him and he would turn his head and not know where I was. Now, he knows where his hand is, a face, toys, and he can tell what different objects are. I'll take that! I'm more than happy to know that my baby can interact with his environment. Small isn't in Javi's vocabulary and we expect great things to happen for him in the future.

Prepared by Amy Pybus, TVI, Perkins School for the Blind Community Programs