ON THE HOME FRONT:

High Expectations Means Never Say “Never”

By Felicia Johnson

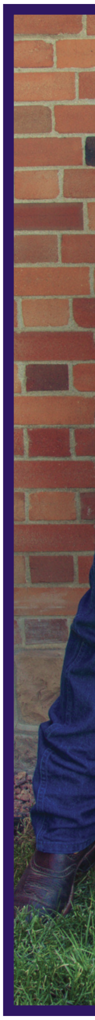
Shelby was our first child. She came into this world tiny yet strong—and loud. I took her home seven days later, seeing only my perfect little girl. At 6 months old, she was diagnosed as profoundly deaf, at 10 months old as an achondroplastic dwarf, and at 18 months old she was discovered to be missing 50 percent of her myelin sheath. We had an idea of what it meant to be deaf and a dwarf; we learned that missing the myelin sheath, the fibers that surround nerves like a stocking around a leg, meant that Shelby would think and move slower than most. This wasn’t quite the beginning I had envisioned for my precious gift.

Portrait of a Young Girl

Shelby was walking at 15 months old, earlier than most dwarfs. She was writing her name at 2 years old and holding the pencil correctly. She could use scissors very well. Many dwarfs struggle with that well into third grade. She was riding horses at 4 years old, controlling the large animals successfully and alone.

Many people tried to help direct me on the right path for her. Most of them included a negative in their instruction: “No sign language!” some said. “She will never speak!” said others. “She will never be tall!” still another added. The positively-stated advice was just as problematic: “Signs are the best for her!” “Surgery will fix her height problem!” “Try growth hormones!” There were so many conflicting messages. I just had to do what I thought was best, and that was to never say Shelby could not do something.

At 4 years old, Shelby was attending an oral deaf school where sign language was forbidden. Although she liked it there and she spoke very well, we felt that she needed more language and decided to homeschool her and introduce American Sign Language (ASL). When she was 5 years old, she received a cochlear implant. She is her mother’s daughter and has loved to talk from the beginning. When she was 9 years old, I asked



Photos courtesy of Felicia Johnson

Felicia Johnson is the wife of a combat medic in the U.S. Army and mother to six children. She has been active in the Deaf community through Isaiah's Place, Hands & Voices, parent-to-parent organizations, and other organizations that she finds wherever the army takes her with her family. She loves all things natural, making things from scratch, and sharing what she has learned with others. She operates a website, *http://talkingfingers.weebly.com*, for others wishing to homeschool special children. Johnson welcomes questions and comments about this article at *felipsha@gmail.com.*

Above and below: Shelby's first horse show; practicing hair cutting on her brother; and her first finished quilt.

her, "Do you want to be oral or use ASL?" Her answer? "I want to do both. Some people will never learn to sign, like my grandparents, and I want to talk to them, but I love ASL, so I want to do that, too."

Creating Opportunity

Believing in her independence, I refused to do things for Shelby. At 4 years old and two feet tall, she couldn't reach the light switches. She would grab anything and try to touch the switch. She had a short broom, as cleaning was something that she liked to do for fun, and my husband drilled a notch at the top of the handle. Then Shelby could lift the broom, hook the notch around the switch, and suddenly it was possible for her to turn the lights on and off. Stools entered our home and are positioned throughout. She uses them whenever she wants. She orders food for herself at restaurants. She has even used the videophone to buy her plane ticket, arrange accommodations, and fly alone.

Homeschooling has proven successful and allowed Shelby to see all that she can do. She could use power tools at 8 years old. She sews, crochets, and knits. She has given public presentations to hearing crowds. She has done horse shows, ranch rodeos, and performed with an equestrian drill team. She has raised, milked, and shown goats. She plays the piano. She is an amazing photographer, and she is now volunteering at a flower shop.

When she was around 10 years old, I had the opportunity to attend an American Society for Deaf Children conference. Since no doctor had been able to help me with her lack of myelin, a condition that has grown worse over the years, I was eager to meet someone who might help me understand how to help her. I found a

neurodevelopmentalist who took the time to talk with me. After I explained my daughter to her, she simply said, "It is amazing what she has already managed to accomplish. Her brain must have found a way to compensate, as moving information [something that the myelin sheath does for most people] is very difficult for her. Most people with that condition would find simple functions difficult." Her words overwhelmed me and changed my perspective.

I am guilty of telling Shelby she couldn't do something—just once. I was teaching her younger sister, Tobie, to play the piano. Shelby asked if I would teach her, too. I regret to say that I declined; I just didn't see the point. Then one day I came inside from the barn and heard notes being played to "Home on the Range." I stopped. I hadn't yet taught that to Tobie. I came around the corner and saw Shelby at the keyboard, beating out the song! Her sister had been drilling her on the value of each note and had taught her where each one was found. Shelby had figured out the rest. She had never heard the song played on the piano before, yet she was able to play it well enough that I recognized the tune. I started teaching Shelby that day. She now plays quite well.

As Shelby entered high school, we focused on vocational opportunities. In an effort to give her every opportunity to develop viable skills, we moved near Isaiah's Place. Isaiah's Place is a deaf retreat center in the heart of Texas. Shelby volunteers there, working with the horses, teaching sign language classes, working with a Wednesday night deaf ministry, and so much more. Isaiah's Place has also arranged for her to spend time interning at the local flower shop, a beauty shop, and with a local photographer. All these opportunities not only give her skills to obtain employment later on but also the chance to discover what she is good at and enjoys.

Shelby has struggled academically, but she still believes that one day she will be able to read. At 15 years old, she has an amazing vocabulary. Sentence structure in speech and reading is difficult for her. Our homeschooling focuses mostly on life skills, but we practice reading every day. Now at a first grade level, she is able to read stories to her younger siblings. She has found that even minimal skill in reading is useful and beneficial. In fact, the only skills Shelby has tried and hasn't mastered fully are reading and playing the violin. Our family loves music, and so does Shelby. While the violin wasn't something she wanted to pursue, she loves playing the piano.

We have found that having high expectations and never telling Shelby she can't do something has made her ready to try anything, and it has been our pleasure to give her the opportunity and the tools and to see her succeed. I would like to take credit for this amazing kid, but really it's her. She isn't scared to try new things, and she goes after what she wants. In living her rich life, Shelby has enriched our lives as well—immeasurably.

Left and below: Shelby tries her hand at showing and milking goats.