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Courtney Stelmack is 13 years old and attends a public middle school with a seventh grade class of approximately 500 students. She enjoys writing and reading and dislikes math and physical exercise.

Raising Courtney Just Like Her Sisters: Forging High Expectations

By Amie A. Stelmack

As a parent, I had high expectations for each of my children, even while they were in my womb. When Courtney was 9 months old, these expectations briefly shattered. It was September 13, 2001, two days after 9/11. My husband and I traveled into Boston for Courtney's sedated Auditory Brainstem Response (ABR) appointment. I had been concerned about her hearing and requested a hearing test. The initial assessment had been done locally and although she had no otoacoustic emissions (i.e., her cochlea emitted no soft sound as is typical for those who hear normally), those who tested Courtney reported that she was responding to speech at loud conversational levels. With this conflicting data, they suggested we have her sedated in order to have a more comprehensive hearing test—an ABR, which measures how well sound travels along the nerves that conduct the sound to the brain.

After waiting what seemed like several hours, my husband and I were brought into a small room with our screaming, groggy infant, a nurse, and an audiologist. Courtney wanted to nurse. She hadn't eaten in many hours due to the sedation, but she had to wait another moment. My husband, Ted, and I wanted to know the results of the testing. The audiologist gave us the news: Courtney didn't just have a hearing loss; she was deaf. The conversation continued and much more was said, but I heard nothing other than "deaf" and the sound of crying—crying from Courtney, who needed to nurse, and crying from myself. I could not stop. I needed to get out of that room. I needed to nurse my daughter, and I needed to get back home. Both my husband and I wanted the comfort and peace that only our home and family could provide.

Photos courtesy of Amie A. Stelmack



For nine months, Courtney had been treated like a hearing child, expected to enjoy the stories we read and the songs we sang. She was expected to be comforted by our familiar voices, expected to hear her sisters when they came home from school. Now we knew differently, and we believed we had denied our daughter access to language. Guilt overwhelmed us—and guilt quickly spurred us into action. The only language we knew without a doubt she could learn and understand was sign language. Our family would learn immediately, and so would Courtney. Sign language began in our home the very next day.

As one week led to the next, we began hearing frightening things about children who were deaf. Many people—including professionals—told us about shocking statistics. The statistics indicated that deaf children often didn't read beyond upper elementary level. They seemed to suggest that this would become our expectation for Courtney. Professionals told us that even with hearing aids our precious baby girl would never have access to

spoken English. An audiologist briefly mentioned a device called a cochlear implant, but this seemed strange to us: it would require surgery, drilling into her skull; it didn't guarantee she would speak; and it would change her hearing to a mechanical process controlled by a computer which was programmed by an audiologist. Further, even if we wanted to explore a cochlear implant, Courtney was too young. Ted and I decided to devote our energy to things we could do right away. Our family and friends rallied to support us, and anything we asked for was immediately granted.

Meanwhile I obsessed about the reading prediction that I felt had been made for my daughter. "Why?" I kept asking myself. If she were just deaf, why would she not read? What could be so detrimental? How is deafness related to reading? As a family we went to the library every other week and came home with literally no less than 30 books each time. We read at least 10 children's books every day. Reading nurtures us. It is what feeds our souls. It is our daily bread. Courtney's soul could not be

allowed to starve simply because she could not hear. What a ridiculous thought! After several weeks of feeling devastated and overwhelmed, my husband and I and the rest of our family simply decided we would not accept the statistics—at least not as they applied to Courtney. If Erica and Monika, my older daughters, would read 10 stories a day, then Courtney must need double. Courtney would read, just like her sisters. We would accept nothing less.

Over the next month, we continued to seek assistance from professionals. Hearing aids were ordered. Although the audiologist initially believed that Courtney had access to speech with the hearing aids, that opinion quickly changed. We invested in the best, but they did not provide sufficient access to sound; hearing aids would not work for Courtney. Early intervention specialists came to our home and offered us one hour a week of speech-language therapy. One hour a week? It didn't seem like enough. If a child who is deaf is offered one hour a week of services, what is a child who has a mild hearing loss offered? We were told that one hour a week was the typical recommendation to start, and that more services were not always better for the family and child. To me, this did not seem right. How was one hour a week of speech-language therapy going to help her speak the same language as her family? I thought this would consign Courtney, who was likely never going to hear speech, to not being able to talk. I needed time with expert professionals to learn; Courtney needed time for more therapy. I contacted the early intervention program director who reluctantly agreed to more time weekly with a speech-language pathologist and promised to add weekly group visits from the professionals from school once we selected a school for Courtney.

Ted and I reached out to professionals in special schools for children who are deaf. We felt that they would know best and provide us with information to assist us on our new journey. We visited the special program nearest to us, and decided that this was where Courtney needed to be. We would travel to the program twice a week. Courtney would attend a parent-infant program for two hours each time. In addition, we, as parents, would participate in a parental support group once a week for 90 minutes. Siblings were also sometimes allowed to come to the groups, and the school offered free American Sign Language (ASL) classes one night a week for two hours. Further, we



learned about a family sign language program offered by the state. We could have 20 weeks of ASL taught in our home. This service was free, and we could invite family, friends, and caregivers to attend at no cost. Although exhausted by the thought of all these new weekly activities and lessons, we signed up for everything that was offered.

Courtney began signing almost immediately. Her eyes would look at things, then dart up toward us for the word. Courtney loved the speech-language pathologist who came biweekly. At Courtney's biweekly play group at the school for the deaf, she watched her peers and seemed to absorb everything. However, I still felt that something wasn't right. During one of our visits, I was explaining my concerns to an audiologist when a parent overheard what I was saying and told me about her daughter, who had a condition called "auditory

neuropathy." She suggested that we contact their audiologist at Boston Children's Hospital. Although neither of us knew it at the time, that conversation would change our lives.

Marilyn Neault, the audiologist at Boston Children's Hospital, was experienced, patient, loving, and kind. She saw us at night after a long day and explained not only the type of hearing loss she believed Courtney had but also more about language development, and she told us about cochlear implants. Marilyn scheduled an appointment for another ABR to confirm her suspicion. We left knowing three critical things: 1) we must enjoy and love Courtney, 2) we must continue to provide her with language, and 3) we should never doubt ourselves as parents.

Courtney was finally diagnosed with auditory neuropathy and, at 22 months, she got her first cochlear implant. At that time, Courtney's ASL skills were age appropriate, both receptively and expressively. Although she made all kinds of noises with her voice, those sounds did not appear relevant to speech. Courtney's therapy increased once she was implanted. She joined another group at The Learning Center for the Deaf in Framingham, Massachusetts. This group, exclusively focused on children with cochlear implants, focused on learning to listen. Her weekly therapy at home with the speech-language pathologist changed to listening therapy and time spent on this increased as well. By this time, we, as a family, had completed our ASL program, and we all had basic skills. But now Courtney began to talk. Almost as quickly as she had learned to sign, she was learning to speak. Slowly, she stopped using signs.

The road she was traveling was shifting, and as her parents we had to continue to figure out what Courtney needed. Our expectations never changed—just the road along which we would travel. We continued to explore and advocate for options to assist Courtney in reaching her full potential.

Three months before her fourth birthday, Courtney could use speech, her cochlear implant, and lipreading to communicate. She entered the same private Montessori school as her sisters. When she was 8 years old, she began to advocate for a second implant. Now she wears two, and the second implant has made another substantial difference in her life. On the rare occasion when a battery dies and she has to function with only one implant, she is miserable. She has a friend with a cochlear implant, and she says she doesn't know how her friend manages with one implant only.

Looking Back—Looking Forward

Almost 13 years ago a miracle came into my life. That miracle changed our family's life and the lives of many others. When Courtney started the Montessori school, I returned to college to finish my degree in early childhood education and to pursue a master's degree in deaf education at Smith College. I sought this field of education to assist other parents in helping their children with hearing loss reach their full potential.

I realized my passion, and I am now a teacher of deaf and hard of hearing students. The students with whom I work are encouraged and pushed. They are challenged to be independent, to advocate, to listen, to be proud, to read, and to want to learn. Parents are expected to do their part and assist in their children's development as unique individuals. Working with each family as a team, we create goals so that these children with hearing loss will read on grade level and become academically successful.

Professionals and parents should not accept that the deplorable statistics involving deaf children and reading fit every child or that these statistics are not subject to change. Parents should not lower their academic expectations due to a diagnosis of hearing loss. Children with hearing loss should never be limited by expectations based on statistics garnered previously and from other children. Trust yourself as a parent. Love your child, keep your expectations high, and never give up. Together, we will raise our children and change the statistics for students who are deaf and hard of hearing.

The Extra Steps—Speaking Out

By Courtney Stelmack

When her mom asked her to write a short paragraph about her expectations for herself, Courtney agreed and requested that a poem she wrote recently during a 50-minute language arts period be published. The teacher asked Courtney to read the poem to her mainstream public school class, and it was selected by her teacher to be displayed on the author's tree. The poem has not been edited.

Hi, my name is Courtney. I am deaf, and I wear two cochlear implants. I have very high expectations for myself—to always do my best, even when it gets tough, and to never give up on my hopes and dreams. Life has always been challenging for me because, being deaf, I have to make some extra steps to get to success. One of my biggest hopes is that I will one day become a well-known author. I have always enjoyed reading and writing. It has never been tough for me to understand letters and words.

Recently, I wrote a poem for my seventh grade language arts class on some things that are very difficult, e.g., bullying and suicide. Don't worry, the poem is not about my life but a sad reality of how many teens feel today.

The Girl

By Courtney Stelmack

The girl with a broken smile
She's had it for a while
Her eyes, exotic as a rare and wilting jungle flower
Her personality was as radiant as the sun
Her mind was dark and dreary
They judged her on her ethnicity
They did not bluff
They were not afraid to specify every flaw she had
They played tough, never afraid
They looked at her with a menacing scowl
She buckled under the ferocity of the words they said
Her initial reaction was to back down, and not defend herself
Her lip would quiver, her eyes red; about to cry
No one could tell that deep inside, she was broken
They all thought she was outspoken
She acted okay with conviction
Truly, she was slowly withering away
She trudged to school every day with a heavy pain in her heart
She decided she didn't want to stay
The blade and her skin merged together
Her life ended that day
They all pretended to care
They didn't bother to shed a tear
They said they wished she was here
It was nothing but a convoluted lie
Now, the girl is free from her worries in the sky
She doesn't have to deal with her chaotic thoughts
She inevitability got rid of the chance of her life ever
getting better