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creating community: balancing the personal and professional

By Connie Stevens

Since I was a young girl, I dreamed of having a family and feeling part of a community...but I never dreamed I'd be a mother to a child with Down syndrome who at seven months of age was diagnosed with profound hearing loss. Being a sociologist and researcher, I looked for direction, including reading about deaf history and memoirs of deaf adults and parents. There wasn't much support for families like ours; however, a movement was developing. With the help of dedicated professionals and Wisconsin mothers and fathers, a wide and diverse support system blossomed. I hope my story makes the road others travel less scary and that they reach out to the community that is there to help, attain the courage they need to advocate for their child, learn to manage the bumps and unplanned curves, and remember that they are parents first—and enjoy the ride.



Newborn hearing screening was just springing up across the country; our rural hospital did not offer it. Due to Tess's Down syndrome (which we found out about when she was placed on my belly just after birth) and the fact that one of my dearest friends had a son with Down syndrome, our family was enrolled in Wisconsin's Birth to Three program by the time Tess was a month old. Tess's speech therapist suggested we test her hearing early,

Photos courtesy of Connie Stevens



Left: Connie Stevens, daughters Grace and Tess, and husband Dan enjoy some family time.

and when we learned she had a profound hearing loss, down that new road we went, gaining new information and ridding ourselves of extra baggage we found wasn't true or didn't matter. In addition to appointments with multiple audiologists and ear, nose, and throat doctors, we sought emotional and social support.

We were welcomed into Shore to Shore, a language-focused family support group started by two mothers with children who were deaf. They knew it would be necessary for their kids to be around others who could communicate with them and help them develop as well-rounded children, with access to visual language to avoid typical developmental delays that can occur when there is not timely access to screening, diagnosis, and intervention services.

We also participated in and received much help from the University of Wisconsin as well as the Deaf Mentor Program. Supported through the Wisconsin Department of Public Instruction, the Deaf Mentor Program pairs employees who are deaf or hard of

hearing with children of families who want to learn about the culture and language of deaf and hard of hearing people. I attended conferences on Down syndrome and childhood deafness and hearing loss. I was becoming the expert on my child and her strongest advocate.

It wasn't easy. In fact, it was hard. Tess was one of the first deaf children to participate in our county's Birth to Three program and our school's early childhood program. I struggled with the professionals in both of these programs because they didn't seem to understand issues surrounding hearing loss and the importance of early and equal access to language. Although no one said to me, "You are just the parent; we're the professionals. We know better," I felt awkward stepping up, saying, "This is the way it needs to be for Tess. We know her best and we've studied our options."

Tess was not benefitting from her hearing aids, and with her frequent ear infections we knew she needed as much access to visual language as possible. My husband or I soon ended up on the highway for two

hours a day transporting Tess to a program in a different school district. We were doing this so that she could have a teacher who used her natural language—sign language—because we'd seen how it benefitted her. She attended that program for five years.

At the same time, we were learning that experts were reconsidering the option of cochlear implants (CI) for prelingually deaf children—and that in some cases CIs were now recommended for children like Tess. She was five years old when, after much reflection, we had the operation—I say *we* because preparing for and experiencing the hospital, sedation, operation, and readmittance to the operating room was a group effort. We found ourselves on a new roller coaster.

We didn't know what to expect. There were various appointments, surgeries, and therapy plus the ever-present lack of knowing how it really feels inside to be Tess. Her language skills were very basic. She gave very subtle indications of hearing and did not understand the tests. This made programing difficult. In addition, she has a habit of rubbing, sometimes roughly, the side of her head that is not implanted—and we do not know why she does this.

Thankfully, the roller coaster ride seems to be ending because Tess currently enjoys hearing. She doesn't ask for her CI, but she cooperates when it is time to pin it to a ponytail holder and have the wire clipped to her hair. I hope that soon she will be able to use the behind-the-ear piece so she can become more independent with the use and care of the CI.

For five years we had focused on signing because Tess couldn't hear, and then with the CI we switched tactics and start using our voices again. We had to again advocate for Tess and ask that others use their voice with her. We learned more about her auditory needs and discovered that, indeed, her delays



Above: Tess at age 4 with her sister, Grace.

were more related to Down syndrome. We learned to continue giving her access to visual language while we spoke with her. It was important to do both. When we spoke, we signed, and when we signed, we spoke.

Late access to auditory stimulation combined with Down syndrome and the speech problems that many kids with Down syndrome experience means that Tess has not learned to talk. However, she expresses herself through sign language and uses her voice to get our attention, to alert us to her feelings of pain, surprise, fear, and laughter. She is quite the actor and a continual puzzle. My husband and I typically team-interpret her stories, which are invariably based on the latest thing she's seen on TV or experienced in her life. We maintain a daily home/school communication notebook so we can try to be on top of what's going on in her wonderfully imaginative head.

When the Road Takes a Professional Turn

Soon into my journey with Tess, Wisconsin's Early Hearing Detection and Intervention program (EHDI), Wisconsin Sound Beginnings, contacted me and asked me to share my family's experiences with early intervention. This was another new road—a professional highway—and I was excited to explore it. I helped co-author an extensive resource guide for newly diagnosed families and was secretary and founding board member

of Wisconsin's Families for Hands & Voices chapter. I also became parent educator/program coordinator of Shore to Shore, the program that we found so essential in Tess's early years. I helped other families

learn how to bond and communicate with their children through story hours, education, presentations, home visits, and sign language classes taught by deaf adults. In my role, I was also helping these families become their own strongest advocates and, for some of them, supporters of other families.

Now I work for the state, dividing my time between two agencies that have collaboratively created a Hands & Voices Guide By Your Side Program for Wisconsin. The program offers parent-to-parent support from screening through intervention. With the Department of Health and Wisconsin Sound Beginnings, my team and I help ensure that all babies born in Wisconsin have their hearing checked and, if necessary, receive timely services. I contact medical providers, birthing hospitals, primary care physicians, audiologists, and individual families to discuss case-by-case issues and ways to improve practice. What every family wants is: to know their options, to be understood and respected for their choices, and to have their children attain equal access.

With the Wisconsin Department of



Public Instruction's Educational Services Program for the Deaf and Hard of Hearing Outreach Program, I am one of 20 or so parent guides throughout the state. Parent guides meet with families in their homes—either shortly after diagnosis or when the family is ready to participate—to provide parents with the opportunity to establish a supportive relationship with another parent of a child who is deaf, hard of hearing, deaf-blind, or deaf with additional disabilities. Parent guides can share the unique needs of infants, children, and teenagers who have hearing loss. They are trained to offer unbiased information and support, as well as to connect families with resources (locally, regionally, statewide, and nationally), so families have the information and knowledge they need to make informed decisions on behalf of their child. In my role as a parent guide, I've helped plan our annual state family conference and participated in the national EHDI conferences.

We often say that we wear many hats in our lives. Lately, I've felt like I am collecting them. Balancing all these hats is tricky. Being a parent and professional, I feel the need to be positive all the time and show how well

Tess has grown. I hesitate to talk about our struggles because I don't want to discourage people, but I remember wanting people to be honest with me when we started this journey. In my Guide work, I usually say, "In my experience..." so parents know I am only one story among thousands. For instance,

sometimes I feel that I must explain both Tess's use of sign language and her CI. If she'd had the CI earlier, would her ability to use it be different? We don't know—and to assume that early use would have meant that she could hear and speak better than she does negates the reality of the problems we've experienced as well as the realities experienced by other families. If we had chosen only the auditory method, how could we communicate when we were sledding outside and her CI wouldn't stay on? Or during the summer when she is almost always in the water? Or when she's sick and the CI coil won't stay on her head because she is lying down and throwing up? As a result of these experiences, I've always strongly supported full opportunities for visual and auditory access to communication. I



also keep in mind the mantra of Hands & Voices when making decisions: "What works for your child is what makes the choice right."

Being a parent guide involves connecting to others on their schedule. This works fine when I'm away from home. It's much easier to be the professional. However, once I get home my family needs me, too. For this reason, I am very protective of the families I work with when there is a need for more parent input or parent guides. I know how much guilt there can be when you try to do too much and be there for everyone. A Brazilian doctor, who became an expert on brain trauma after his own son suffered an injury, said, "It's okay to focus on your own child. You are not being selfish." In addition, my mother-in-law's words, echoed recently during a conversation with members of Hands & Voices—"You are doing the best with what you have at the moment you have it."—help me to be comfortable with what I achieve.

I've felt very blessed to have a daughter who wants to look in my eyes and pretend that we're giraffes and elephants and communicate on a different level. I'm blessed to have another daughter who understands these highs and lows, loves her sister unconditionally, and encourages me to keep going. I'm blessed to be married to a man who supports my choices, and I feel honored to share my story and to meet other families, gain their insight, and help build a community.

