



**Christine Griffin**

lives in Bellingham, Washington, with her husband, Steve, and two amazing children who were identified with hearing loss 11 years ago. She is the program coordinator for Parent to Parent of Whatcom County and for the Hands & Voices and Guide By Your Side programs in Washington State. She welcomes questions and comments about this article at [ghys@wahandsandvoices.org](mailto:ghys@wahandsandvoices.org). Readers can also visit [www.wahandsandvoices.org](http://www.wahandsandvoices.org) for more information about Washington State Hands & Voices.

# standing up for our children

*By Christine Griffin*

I stepped into the sound booth with our 2-year-old daughter, Tess, on a warm fall day, battling my own fears. Only six months earlier, I was here in the same sound booth with the same audiologist with our 5-year-old son, Sawyer. Here, we had learned that Sawyer had a bilateral hearing loss. He received his first hearing aids only one month before entering kindergarten.

Our son's diagnosis had not come easily. We had voiced concerns about our quirky, fun-loving, seemingly shy boy to our family doctor, called a local speech clinic whose representative educated me on the spectrum of language development in toddlers, and even failed an evaluation with our district's developmental preschool when Sawyer "shut down," eventually burying his head in my lap during the testing process. Still, it wasn't until we changed doctors that we began to make progress. At the end of Sawyer's 5-year-old "well check," our new physician asked, "Do you have any concerns?" Of course we did, and this simple question started us on an incredible journey.

As we began discovering what our son's hearing loss meant, I began to wonder about Tess, his younger sister who was then a toddler. I put my suspicions temporarily to rest, remembering that Tess had passed her newborn hearing screening during a re-screen after discharge from the hospital. She also nearly always responded when we called her name and by using simple gestures made her demands very clear. Still, our beautiful and brilliant girl wasn't talking. I had to find out why.

After the testing, we were escorted to an examining room where we sat while the ear, nose, and throat doctor and the audiologist stood and gazed down at us. No one said anything, but the audiologist slid an audiogram into my lap. I was confused, and after a moment I asked, "Why are you showing me *Sawyer's* audiogram?" "This isn't Sawyer's," she said. "This is Tess's." For the second time in my life, I felt like I was hit over the head with a brick. The audiologist gave me the contact number for the lead family resources coordinator in our county, explaining that this person could put me in touch with others who could help. This was an improvement from the moment when Sawyer had been

*Photos courtesy of Christine Griffin*



diagnosed. It was a great relief knowing I only had one phone number to call.

During our initial meeting, the lead family resources coordinator described options for the services from which we could choose. From that moment on, we all benefited. Our family began using signs to communicate with our daughter and unbeknownst to us, Sawyer, who had no services at all in his neighborhood kindergarten, was learning signs alongside his sister. I have a degree in theater, and I began to use signs along with gestures to tell our children elaborate stories before bed. *Good Night Gorilla*, *The Lady with the Alligator Purse*, *Jamberry*, *Dream Snow*, *Paper Bag Princess*, and so many others were part of our library in those early years. For Tess, progress came quickly. The gestures she was already using grew to a collection of over 300 signs by the time she was 3 years old.

Yet during the time while Tess was involved so successfully with Birth to Three services, we continued to search for services for Sawyer. We had continued concerns about how he was accessing information and the lack of progress he was

making as he struggled in a mainstreamed classroom without any supports. I thought the professional educators would know what to do. They didn't, and our frustration increased as did that of our son, who began developing coping strategies for himself.

Meanwhile extended family support was fragile. Both sides were consumed with the question of why this could happen. When the science finally arrived—a genetic testing process that identified Connexin 26 as the cause—I was in need of support, someone who could listen rather than try to fix our situation. I craved just talking about the weather. This is when I reached out to Parent to Parent, a little known statewide program in Washington State that supports families of children with delays, developmental disabilities, and ongoing health care needs. The other parents I met there understood our situation; I felt as if I could breathe again. Many of these parents of children with similar diagnoses and experiences were a few steps ahead of me. I recognized right away their strength, persistence, and incredible knowledge. They had learned everything about their children and about their



**For me—and for  
parents like me—the  
relationships that I’ve  
developed with  
others have kept me  
strong when I have  
felt most vulnerable.**

community resources—and they empowered me to learn the same.

Initially I began doing parent-to-parent volunteer work for the same reason most of us do—I didn’t want another person to go through what we had gone through. However, now it’s more than just that. As coordinator of Parent to Parent in our local county and the Guide By Your Side program for Washington State, I am thankful for others whom I have bumped into and rubbed shoulders with, discovering ways in which to empower our children. Connecting one to one, I enjoy offering support and guidance to other parents as they move through diagnosis to acceptance and empowerment. It is a moving and individual journey that not only shapes their child’s future but that of Washington State—and our nation—as well.

With Tess’s diagnosis, I was lucky to meet professionals and other parents who helped me. The challenges with our son’s education grew, however, and eventually we had to look at an environment where Sawyer’s academic, social, emotional, and self-advocacy skills would be supported.

By the end of kindergarten when we finally got Sawyer’s Individualized Education Program, we knew that an itinerant teacher for deaf and hard of hearing students would not be enough for him; he was too far behind. We also understood that Sawyer was a visual and kinesthetic learner. He could describe the color and the style of people’s clothing. He knew what kind of shoes they wore. Still, he did not know how to ask people their names or he would immediately forget their names if he caught them. In addition to the appropriately offered academics, I wanted Sawyer to have peer interaction and be with other children with whom he could communicate freely. This meant Sawyer would be least restricted by attending a program that supported his learning in a signing environment. It also meant that my husband, Steve, and I would need to learn sign language.

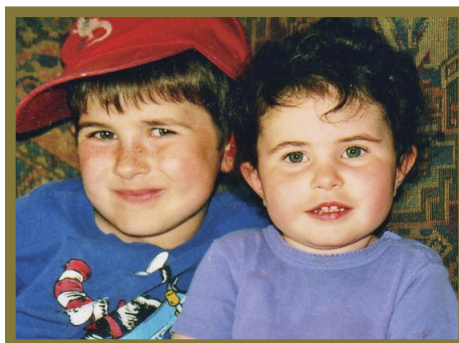
### **For Parents You are Not Alone**

As parents, we have a lot to consider in a very short period of time following identification of a hearing loss. It’s not enough that we want to love our child. Questions arise: How will we communicate with our child, and how will our child communicate with us? How will he or she form friendships with others? How will our child learn?

What makes it more difficult is that many families are caught in the ongoing argument over which communication is best for deaf and hard of hearing children. Experts and community members disagree—sometimes adamantly—about cochlear implants, the auditory/verbal system, Signing Exact English, American Sign Language, Cued Speech, Pidgin Signed English, and a variety of other communication beliefs that have turned the field of deaf education into a battleground.

Hands & Voices helps parents face this dilemma by offering information without bias towards any single communication mode. At Hands &

**Below:** Sawyer and Tess at about the time of their diagnosis with hearing loss.



Voices, we believe: “What works for your child is what makes the choice right.” Washington State formed a Hands & Voices chapter six years ago, adding the Guide By Your Side program two years ago. Our goal is to use trained parent guides to work with families individually, guiding and empowering parents to find and use the local, state, and national resources available for their children. We also offer an empathetic ear and help families make informed decisions for their children.

Through experience, I have learned about understanding perspectives that others bring. It’s essential to remember that as a parent, I am part of the system that serves my children and the children of others. I used to trust professionals completely. However, slowly through my own trial and error investigations and working with other parents, I have learned that often the most informed, enlightened, and dedicated advocate for a child is his or her family. If I do not raise my voice with other team members when decisions are made about my children, the wholeness is lost.

It is nice that educators acknowledge and often tell us that as parents we know our children best, and that we are our children’s best advocates. Still, knowing the skills to carry out such a role is another thing all together. What questions do we ask? How do we respond to comments made by others less knowledgeable about our children? And where do we find our courage and stamina to carry through? For me—and for parents like me—the relationships that I’ve developed with others have kept me strong when I have felt most vulnerable.

Today Tess is 13 and Sawyer is 16, and, despite attacks of typical teenage foibles from time to time, they are doing well. There is no doubt that early intervention was absolutely crucial. However, it’s not enough that we ask ourselves to merely survive, but rather we must actively explore in order to live productive and meaningful lives—both for ourselves and for our children.

# Parents...Be Prepared! Check Out the On-line IEP

By Christine Griffin

The National Center on Severe and Sensory Disabilities (NCSSD) at the University of Northern Colorado posts a graph ([www.unco.edu/ncssd/dhhIEP](http://www.unco.edu/ncssd/dhhIEP)) to help parents of deaf and hard of hearing children prepare for working with school professionals on the Individualized Education Program (IEP). In the squares appear some of the possible explanations—called “conversation stoppers” by the NCSSD—that school officials use to deny a child services.

By clicking on the sentence in each square, parents can see possible responses to these often-used explanations. Using these responses, the NCSSD promises to help parents get the IEP team meetings moving again—in a more positive direction.

For each number, the NCSSD lays out the problem that the response represents. A possible parental response to this problem and the law supporting it are available with additional clicks.

For example:

## 14. Official explanation:

“Your child is two years delayed in language...we can’t really expect more than that.”

## The problem:

Is this communication delay due to cognitive potential or lack of access to communication?

## Possible responses:

- *Let’s make sure that my child is getting the communication he/she needs to learn.*
- *Let’s look at my child’s IQ scores again. What do we need to do to get his/her work in congruence with the IQ score?*
- *Lets look at tutoring...summer school...extra help.*

## The law:

The Individuals with Disabilities Education Act of 2004 specifies that higher expectations for children should be assured, as should their access to the general curriculum to the maximum extent possible. Further, the law notes that in developing the IEP, the team shall consider the strengths of the child, the concerns of the parent...and establish short-term objectives related to the child’s needs.

1. “Sorry... we don’t have the money.”	2. “We’re not convinced your child needs that.”	3. “I have 400 other children in this building.”	4. “We assess your child using only teacher observation.”
5. “The general education teacher couldn’t be here today.”	6. “We’re the professionals, we know what’s best for your child.”	7. “Let us get back to you on how that might work.”	8. “I don’t have the authority to make that decision.”
9. “Your child is doing great... compared to other deaf/hh kids.”	10. “If you don’t teach your child sign, he’ll use it anyway when he grows up. You better do it now.”	11. “If you teach your child to sign, she will never learn to talk.”	12. “We took the liberty of filling out a ‘draft’ IEP ... please sign here.”
13. “Your child will have to use signed exact English. We don’t do ASL here.”	14. “Your child is two years delayed in language... we can’t really expect more than that.”	15. “You must be in denial, your expectations are too high for your child.”	16. “We don’t need to write that suggestion down in the IEP, we’ll do the best we can to get that done.”

Developed by Families for Hands & Voices

Copyright © 2008 National Center on Severe and Sensory Disabilities

Copyright © 2002, 2006 National Center on Low-Incidence Disabilities

Permission to use for educational purposes granted.