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individualizing deaf education services: more important than ever before

By Janet DesGeorges

Every parent of a deaf or hard of hearing child has been there—sitting in an Individualized Education Program (IEP) meeting where services for their child are being determined by assumptions based on labels. Here are some of those labels:

- *Your child is deaf.*
- *Your child is hard of hearing.*
- *Your child uses spoken language.*
- *Your child uses sign language.*
- *Your child has no need for academic accessibility; therefore your child has no need for social accessibility.*
- *Your child has...unilateral/bilateral/mild/moderate/profound hearing loss.*

The list goes on, as educators fill in the blanks: “*Your child is X, so he or she needs Y.*”

As a parent just starting out with three children, one of whom was hard of hearing, navigating my way through communication and educational decisions was difficult. As a hearing person, I needed time to acclimate to what my hard of hearing daughter's life journey would look like. Also, I was inundated with people's opinions

Photos courtesy of Janet DesGeorges



about what I should or shouldn't do. As time went on and as I began to understand Sara, my daughter, more clearly, I became a stronger and more confident advocate. I was able to think about what she needed beyond the labels we often place on our own children and the children of others.

My thinking shifted as a result of my opportunities within the organization of Hands & Voices (www.handsandvoices.org), and the parents, deaf and hard of hearing adults, and professionals I met there. The organization supported the emerging culture of doing what works for an individual child rather than doing what others believed to be true for all deaf and hard of hearing children. I began to think that the primary goal for Sara was acquiring language, communication, and self-sufficiency—and not let modality drive our decision making. When each family does this, the steps may look different but the goal is the same. Our story is not, nor should it be, the story of every family, but the outcome should be the same: communication access and the success of the child.

An Interpreter for Our Daughter

Born with a moderate hearing loss, Sara had excellent speech, her primary communication was through voice, and her native language was obviously English. By the time she started school, people would make comments such as, “We would

never even guess....” However, when Sara was 7 years old, we began to question her communication access in the classroom. I had read *Our Forgotten Children: Hard of Hearing Pupils in the Schools* (Davis, 2001), an enlightening text that focused on education for kids who were not deaf and not hearing (i.e., hard of hearing); it cautioned about the potential for these children to “fall through the cracks,” not only in education but socially. We also had evidence that Sara’s hearing loss was progressing, and we wanted to think about her future, not just her current level of functioning.

A turning point came as I saw her results on *The Functional Listening Evaluation* (Deconde Johnson, 2010) that was administered in her classroom (available online at www.adevantage.com). This test showed that when Sara was in a quiet environment and close to the speaker, she could access 96 percent of spoken language. However, if she sat eight feet from the speaker in an environment with minimum background noise, and she had no access to the speaker’s lips, her speech reception dropped to 28 percent.

This was the data that convinced the IEP team that Sara needed more than listening to receive an appropriate education. At first there was some hesitancy: “After all,” some of her IEP team members said, “...Sara is hard of hearing” and “...Sara is oral.” It was my connection with other parents who



communication was through spoken language, signing would be a secondary support in the classroom. Therefore it made sense to provide signs in English word order—a type of signing that used to be called Pidgin Signed English and is now often referred to as Sign Supported Speech. Still, we also wanted Sara to become fluent in ASL so we incorporated acquisition of ASL grammar and structure into her day; at specified times, she would work with her interpreter to learn this language. As a family, we also gave her opportunities to be immersed in ASL through attending summer camps with other deaf and hard of hearing children.

had hard of hearing children that helped me begin to look beyond Sara's label—of *moderate hearing loss*, of *hard of hearing*—and seek fuller communication accessibility for her. Finally, the IEP team decided to pilot educational sign language interpreting services for Sara.

It proved to be a success, bringing Sara more fully into her classroom. I will always remember the day when she skipped through the door from school and said, “Today, the teacher said ‘*mumble, mumble, mumble*.’ I looked at the interpreter and understood to put my book in my desk.” I knew then that we had made the right decision.

As the years went by, Sara used both her visual and auditory skills as she stayed abreast of her work; she maintained her high level of spoken communication, and she maintained her good grades. When she started school as a high school freshman and walked through the door to her geography class, she was met with a teacher who had a full beard and a speaking style that resulted in her understanding nothing he said. Luckily, the interpreter was there for communication access.

Of course, interpreting services were just part of the accessibility toolbox we delved into with Sara. Like many parents, not only did we have to identify the need for an interpreter, but we also had to discuss the signs that would be used. At first I advocated for American Sign Language (ASL), understanding that it was the form of signing that most deaf adults use and wanting Sara to be competent in that language. However, as we began to discuss Sara's individualized needs, it became apparent that because her primary access to

Over the years, we faced many issues that resulted from Sara being an atypical interpreter user. She has good speech, so people think that she must be hearing well, even hearing everything. We have had to negotiate with the interpreters themselves to create a new level of awareness that the interpreting services would be her back up, not be her primary mode of communication. We have also had to deal with other issues such as boundaries, an important part of the personal relationship that develops in this unique and extended relationship between an interpreter and a student. We managed to navigate these issues, but if the IEP team, including myself, had been stuck on labels—*excellent speech, moderate loss, good grades*—we may not have gotten to the best solution for Sara's access.

Some of the benefits of utilizing interpreting services have been an increased competency in sign language skills, enhancement of social life through access to other deaf kids and adults, and possession of a tool that will be at her disposal whenever she so desires. Although everything has positives and negatives, neither Sara nor I have ever regretted the decision.

When Sara went to college, she chose other methods to access communication, such as using an FM system and increasing communication between herself and her teachers. To me, this was coming full circle; I'm glad Sara has felt the freedom in her own life to explore communication accessibility and make her own decisions.

Putz (2012) notes in *The Parenting Journey: Raising Deaf and Hard of Hearing Children* that, “Sometimes on the course of the

journey...the path changes in ways we can't imagine. As our kids get older, they begin to weigh in on our decisions and make decisions of their own. Sometimes their decisions go against everything we've known" (p. 55).

A New Generation of Children— Different and Yet the Same

The Individuals with Disabilities Education Act (IDEA) has always had *individual* as part of its spirit and its letter. However, as a parent and an advocate who has attended many IEP meetings, I've found that getting to *individual* can sometimes be a challenge, particularly with the low incidence of deaf and hard of hearing students in the special education system.

This generation of children who are deaf and hard of hearing are emerging with different needs than in the past. Due to advances in technology, early identification of hearing loss, and societal shifts, the old labels have blurred. Yet the differences of today's generation have not negated the truisms of old. It remains true that children today share the same heritage of those who have come before them—that high expectations and access to a solid education for individuals who are deaf and hard of hearing should be pursued relentlessly, developed individually, and enhanced through partnerships.

We, as parents, must partner with educators and support personnel to approach our children as individuals. A child's label—whatever it is—should not determine eligibility, school placement considerations, access to a critical mass of peers, or related services. IEP decisions should not be guided by a child's labels. Of course, there are shared and unifying rights for all

children who are deaf and hard of hearing, including rights to language, but there are individualized approaches to getting there. The paths to success are unique to each child.

Portions of this material were derived with permission from an article by the author on www.classroominterpreting.org.

References

Davis, J. (2001). *Our forgotten children: Hard of hearing pupils in the schools*. SHHH publications.

Deconde Johnson, C. (2010, revised). *The functional listening evaluation*. Available at <http://www.adevantage.com>

Putz, K. (2012). *The parenting journey: Raising deaf and hard of hearing children*. Barefoot Publications.

U. S. Department of Education. (2004). *Individuals with Disabilities Education Act*, Section 1400 Part A(d) Finding and Purposes.

Resource

DesGeorges, J., & DesGeorges S. (2008). A "Why me?" *The story of an oral, hard of hearing atypical educational interpreter user*. Available at <http://www.classroominterpreting.org/parents/CaseStudies/DesGeorges.asp>

Strategies for Convincing the IEP Team

By Janet DesGeorges

The strategies that we used to convince the IEP team that our daughter needed additional support (i.e., a sign language interpreter) to access classroom communication included:

- **Objective testing/data**, i.e., *The Functional Listening Evaluation* indicated need
- **Subjective beliefs**, i.e., I, as a parent, was able to articulate to the team in a practical manner with support from research and articles what my daughter needed
- **Mastering details about who, what, when, why, and how** interpreting services would be used in Sara's particular case, including the need to build Sara's sign language skills in order to access interpreting effectively
- **Considering future needs**, as the IDEA specifies that the purpose of special education services is "to prepare students for further education, employment, and independent living" (U.S. Department of Education, 2004).
- **Agreeing to a time-limited pilot** to see if indeed this support service would be beneficial