PART ONE:

Until almost three years ago, I never knew a deaf-blind person. I had heard about Helen Keller while in grade school but I never knew anyone who was deaf let alone deaf and blind. After my son’s illness, and his diagnosis of deaf-blindness, I was thrown into a world of the unknown and believe you me; it was a very scary place to be! My son is completely deaf (without his cochlear implant processor) and completely blind. I thought that was the norm for a deaf-blind person. I was very wrong. My son is in the minority in the deaf-blind population (only two children in the state of Wisconsin are completely deaf and completely blind). Most of these individuals have some level of vision and hearing, however slight. Currently there are 136 children in the State of Wisconsin who are considered deaf-blind (Intervener.org website).

We all must have sensory information about the world around us in order to learn, function, and interact with others. For those of us with typically developing vision and hearing, the majority of this vital information comes to us through the major senses of vision and hearing. Deaf-blindness is defined as a disability of access to visual and auditory information in the environment. Individuals who are deaf-blind do not have enough residual vision to make up for their lack of hearing and do not have enough residual hearing to make up for the lack of vision. This unique disability is not just deaf plus blind, but closer to deaf multiplied by blind in terms of the severe impact it has on this access to the world. Visual and auditory information is a necessity to understand one’s world. As the losses get greater in scope, the ability to access sensory data diminishes. Just like no two snowflakes are exactly alike, no two deaf-blind individuals are alike. There is a great deal of variety in their attributes and marked differences exist from one to another.

Communication is one of the biggest hurdles for a deaf-blind child. The type and degree of vision and hearing loss is a vital piece of information necessary to determine the unique communication needs of these children. My son Liam is extremely fortunate to have been able to receive a cochlear implant and is able to understand quite a bit from what he is able to hear. He is non-verbal and has several signs he uses spontaneously to communicate but his stroke left him without the dexterity of his left fingers so his signs are a bit altered compared to the norm. We also use tactile sign — Continued on Page 2
Deaf Infusion - by Jennifer Koehn

What Accommodations Really Mean: SAME vs FAIR

Sometimes people believe that treating everyone the SAME is the only fair way to deal with others. That to do something different, is somehow giving an advantage. However, there is a big difference between the terms "same" and "fair" when it comes to accommodations. A few examples when interacting with individuals who are Deaf of the SAME way VS the FAIR way as a hearing person:

- Use spoken English as you would VS Communicate in the language the Deaf person anyone else prefers (usually sign language).
- Turn on the television show or movies with sound VS All electronic media, videos, etc. are captioned.
- Sound based entry (i.e. doorbell, calling a name) to announce someone has arrived VS Visual lighting to alert the person who is Deaf that someone is requesting admittance or is present in their house/room.

“If I treat everyone the same way, I am for sure being biased because each individual is unique” quoted by Robert Whipple.

Continued from Page 1: Understanding Deaf-Blindness

to help emphasize words for him. Deaf-blind persons use a variety of communication strategies such as sign language, tactile sign, braille, object cues, pictures, and large print for writing and reading. Knowledge of the level of vision and hearing would help one to know how to approach such an individual and what communication method is best. Normal sign language would not be appropriate for someone who is completely blind. For someone with limited hearing, you may need to get close and touch the individual so they know you are speaking to them.

Another important factor to understand the needs of a deaf-blind person is the onset of his or her issues. The etiology of their diagnosis may help in determining when the issues began or the extent the sensory losses may reach. The major causes of deaf-blindness include syndromes such as Ushers, CHARGE, and Trisomy 13; congenital anomalies such as hydrocephaly, microcephaly, and maternal drug use; prematurity and postnatal causes such as meningitis, stroke, and head injury. This information impacts the individual's learning and development. An adventitiously deaf-blind person (fancy word to mean someone who is not born deaf-blind but becomes that way sometime after birth, like my son Liam) will have a different base of knowledge than one who has been deaf-blind since birth.

Many deaf-blind individuals also have additional disabilities, whether cognitive, emotional, or physical. It is unusual for deaf-blindness to occur without other medical issues also involved. Liam had a stroke at the time of his meningitis, leaving him with a significant brain injury and all the associated issues related to that illness: seizures, feeding issues, inability to talk, and left sided weakness. He is not alone. Most parents of deaf-blind children must also deal with numerous medical complications from their child's diagnosis. Access to this information is crucial to understand the needs of the child. Modifications in the environment may create a better and more successful learning environment. Past illnesses also may interfere with helping these children because often touch is associated with negative medical experiences and trust is hard.

Each deaf-blind individual is distinct and unique. It is important to get to know the individual so an appropriate strategy can be used to help meet his or her needs. There is hope for deaf-blind children and their ability to learn and develop. With the proper interventions, these children are able to develop their brain to their full potentials and improve their circumstances. Understanding these differences make each person special and just like a snowflake, beautiful in their own way.

Next - Part Two: Intervention and Interveners
HELP OTHERS BY DONATING USED HEARING AIDS!

WI Families for Hands & Voices is now accepting hearing aids donations as part of a partnership with Starkey. If you have old hearing aids that are not being used and would like to make a charitable donation to help WI Families for Hands & Voices, please call Michelle Kihntopf at 920-609-7815 for a self-addressed, stamped envelope to send to Starkey.

Our Mission:

Wisconsin Families for Hands & Voices is a non-profit organization dedicated to supporting families statewide who have children who are Deaf, Hard of Hearing and Deaf-Blind without bias around communication modes or methodology. We are a parent-driven organization providing families with the resources, networking and information they need to improve communication access and educational outcomes for their children. Our outreach activities, parent/professional collaboration and advocacy efforts are focused on enabling Deaf, Hard of Hearing and Deaf-Blind children to reach their highest potential.

Board Member Spotlight: Beth Hall

Beth Hall serves as the Secretary for WI Families for Hands & Voices. Originally from De Pere, WI in the greater Green Bay area, Beth currently calls La Crosse, WI home. Beth received her Bachelor's degree in Archaeological Sciences from UW-La Crosse in 2008. She and her husband of six years, Sam, have two children, Johanna (5) who is profoundly deaf and wears cochlear implants, and Charlie (2) who is hearing. Her family communicates using spoken English and ASL. She currently is employed as a server at the Waterfront Restaurant and Tavern in La Crosse and as a Parent Guide with Guide By Your Side.

Beth became a member of WI Families for Hands & Voices and organized a DHH playgroup for preschoolers for two years in the La Crosse area after learning that her daughter was profoundly deaf at two months of age. She later decided to become active with the board because of the sense of welcoming Hands & Voices offers families regardless of communication choice and wanting to further facilitate networking and connection for other families who have children with hearing loss. In her spare time, you can find Beth outside working in her vegetable garden or walking with her dog, Murray.

2013 Hands & Voices WI Membership

Please circle one of the following:

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Using Humor to Explain English Phrases Beyond their Literal Meaning

By: Beth Hall

Often, as a parent of a deaf preschooler, I have wondered what is the best way to convey the meaning of English idioms and expressions in a way in which the concept will be best understood. Whether your child is aided, speaks, or signs, it can often be a challenge for our DHH children to understand the intended meaning of an English phrase or idiom instead of just the literal meaning. This ability to look past the literal meaning in the English language is especially important when considering many of our DHH children will rely more heavily on written English than their hearing peers to access curriculum at school and other information.

One method that I have found that can help bridge the gap of understanding when it comes to English idioms is using humor. My daughter loves knock-knock jokes and we have a great time looking up and trying out various versions. This gives us time together where she is engaged with the concept of language and I can take the time to explain why the joke is funny and what the play on words in this particular joke means. Knock-knock jokes and joke books also give us the opportunity to talk about things that sound like another thing when they mean something different. One favorite joke book is How do Dinosaurs Laugh Out Loud? By Jane Yolen and Mark Teague.

I also love to use illustrated children’s books. Jokes in children’s books often tend to be a subtle tongue-in-cheek play that works with the illustrations. The words will read one thing while the pictures will describe what is actually happening in the story. This allows for conversation about the English phrase and helps my daughter to make the connection between what she is literally reading and what she is seeing and understanding. Some books that I think are great for this connect-the-dot approach include Sally Goes to the Farm by Stephen Huneck, Buzby by Julia Hoban, and Amelia Bedelia by Peggy Parish.

So what are some of our favorite jokes? In Amelia Bedelia, my daughter thinks its super silly that Amelia puts a turkey in overalls and socks when she was asked to “dress the turkey.” And Buzby the hotel cat always gets a laugh when he tries to clear the dishes as a busboy by licking all the dishes clean. And we always giggle when the dogs Sally and Molly are invited to share lunch with Penelope the hog – they eat like pigs.