



Complex Child E-Magazine

www.ComplexChild.com

Understanding What It Means to Have a Child Who Has Combined Hearing and Visual Impairments

by Michelle Doty

“Everything has its wonders, even darkness and silence, and I learn, whatever state I may be in, therein to be content.” Helen Keller

When my daughter Campbell turned three, she was no longer covered under our state’s early intervention system. We had a great team of therapists and a wonderful case manager who guided us in making preparations for her transition into preschool. It was still a very anxious time, having to change therapists and programs that we had been involved with since Campbell was six months old. Campbell was born with multiple genetic anomalies including cleft lip/palate and microcephaly. She also has hypotonia of unknown etiology, cortical vision impairment, epilepsy and mild to moderate hearing loss. The actual “cause” is unknown and she falls within the undiagnosed syndrome category.



Campbell received vision therapy before age three, but was never really diagnosed with any hearing loss at that time. We were aware that she had slow processing with both her vision and hearing. When one of her therapists suggested our state’s deaf-blind project as a possible resource for Campbell, I was somewhat shocked. Deaf and blind? These were not terms that I would have used to describe Campbell at that time. Sure, she had significant visual impairment, but she had made tremendous progress with therapy. She did need time to process auditory input and was not always consistent with her responses.

But deaf AND blind?

Defining Deaf and Blind

The first image that came to my mind was Helen Keller, whom I greatly admire. So not unlike many special needs moms, I went into research mode and started to learn what it really means to be deaf-blind. I soon found out that there are actually just a small number of cases (approximately six percent) where a child is completely deaf and blind like Helen Keller. Deaf-blindness is a condition in which a person has a combination of both visual and auditory losses in varying degrees of severity. This combination of multiple sensory losses causes severe communication and other developmental needs that make categorizing a child as either blind or deaf insufficient. Children who are deaf-blind have deficits in both senses, but may not have a complete loss of function of one or both senses. A child may have more usable vision than hearing or vice versa. The following table describes the five categories of combined vision and hearing impairment.

Table 1: Five Categories of Vision and Hearing Impairment¹

- Visually Impaired and Hearing Impaired with Vision being the primary disability
- Visually Impaired and Hearing Impaired with Hearing being the primary disability
- Deaf and Visually Impaired
- Blind and Hearing Impaired
- Deaf and Blind

There are several possible causes for a child to be deaf-blind. These causes include genetic syndromes, multiple congenital anomalies, prematurity, congenital prenatal dysfunction and post-natal causes such as asphyxia or meningitis. It is common for a deaf-blind child to have additional disabilities such as cognitive and/or physical disabilities, complex health care needs and behavior challenges. However, there are some conditions where hearing and vision loss are the only symptoms.

Challenges for a Child who is Deaf-Blind

A child who is deaf-blind faces numerous challenges based upon the level of his or her sensory impairments. One of the most prevalent challenges in the child who is deaf-blind is communication. When communicating with a child who is deaf-blind, it is important to use touch so that the child knows that you share the focus of attention. For example, a parent may use hand-over-hand touch to play with a favorite toy or imitate an action.

Another communication strategy would be to allow sufficient time for the child to respond during any interaction. Children with multiple disabilities and/or sensory impairments often have a slow response time. It is beneficial to make available multiple opportunities for interactions throughout the day. Consistently practicing back and forth interactions multiple times will allow for language development in the child who is deaf-

blind.

Using objects and/or gestures while communicating will aid in assisting the child who is deaf-blind in language development. Verbalizing, touching and gesturing in regards to an object or action will help him or her to make a meaningful connection between the word and its meaning. With Campbell, we started by using objects for her to identify. Now we are trying to use pictures/symbols of the objects to create a picture communication system.

It is important for parents, caregivers, therapists and teachers to provide a consistent environment to facilitate communication. Some examples of communication strategies for a child who is deaf-blind are:²

- Touch cues
- Object symbols
- Sign language
- Gestures
- Picture symbols
- Fingerspelling
- Signed English
- Braille
- American Sign Language
- Lip-reading speech
- Pidgin Signed English
- Tadoma method of speech reading
- Large print writing and reading

Another challenge with children who are deaf-blind is behavioral and emotional problems. These are natural reactions for a child who has problems with communication and/or lacks a predictable routine. For example, when approaching a child who is deaf-blind, it is important to prepare the child by signaling through verbal introduction and touch. Also, giving the child an appropriate amount of time to process the information before going to the next step helps the child feel safe. Without doing some of these strategies, the world of a child who is deaf-blind can be a frightening and unpredictable place.

Orientation and mobility are also challenges that the child who is deaf-blind will face starting at an early age. Exploring the environment can produce a lot of anxiety and apprehension. It is important to work on orientation and mobility as early as possible. As an infant, you can reward any movements such as rolling and crawling. As the child starts to walk, using a push toy will help with orientation and pre-cane skills. An orientation and mobility specialist can work with the child, family and teachers to provide strategies to move within a safe environment.

Accepting and Getting Help

As with many children who are complex, the need for early identification and intervention is critical. Each state has a federally funded program that provides training and support. In Kentucky where we live, the KY Deaf-Blind Project works with Campbell, our family and the school system to provide proper training and support.

Finding out that your child has both vision and hearing loss on top of other complex needs can feel extremely overwhelming. Like I said, the first time I heard those two words--deaf and blind--in reference to Campbell, I panicked. After educating myself about the diagnosis, I feel much more comfortable with the labels and understand the meaning of deaf-blind. I have always been one to flinch at labels. I have never really liked classifying people by the things they can't do or their unique characteristics. However, in today's society, especially the school system and insurance, labels and diagnoses are a necessary evil.

Despite her diagnosis, Campbell is thriving. If someone who didn't know Campbell were to read her medical and school reports, they would not get an accurate picture of her. They might picture a child who is bed bound without much interaction with people and her surroundings. However, that is completely untrue. She is a very happy four-year-old who loves princesses, music, playing with her stuffed animals, interacting with her family and friends, and who also goes to preschool and church.

As overwhelming as some of these diagnoses can be, providing a meaningful and joyful life for Campbell is a very reachable goal. It takes a lot of hard work, research, patience, time and dedication, but it is a beautiful journey.

Michelle Doty is the mom of Matthew, who is ten, and Campbell, who is four. She is a full-time caregiver to Campbell and works part-time from home for Visually Impaired Preschool Services (VIPS) as their Family Services Coordinator, providing support and education to families of infants, toddlers and preschoolers in Kentucky who are visually impaired. In her "former life," she was an occupational therapist, which has helped prepare her to be a special needs mom.

¹ Taken from Lisa Poff, *Combined Vision And Hearing Loss: What Does It Mean?* The Sooner The Better Indiana Deafblind Services Project Fact Sheet.

² Adapted from Barbara Miles, *DB-Link: Overview on Deaf-Blindness*. The National Information Clearinghouse On Children Who Are Deaf-Blind, 2008.