

A Mom's View on Vision

Michelle Westmaas

My eleven-year-old daughter, Aubrie, is deafblind. For a long time, I didn't really understand how that term applied to her. She has one "bad" eye and one "bad" ear and the vision in her better eye and the hearing in her better ear are too good to qualify for a more narrow definition of deafblindness. However, she certainly benefits from support of professionals in the field of deafblindness.

Aubrie is not just a kid with deficits in one eye and one ear. She has challenges in virtually every sensory system. She was initially diagnosed with CHARGE syndrome but the diagnosis changed when a specialist recognized the distinguishing features of Kabuki Syndrome during a routine genetics visit. She has difficulties in the areas of body awareness and balance. She has some tactile defensiveness and sensory integration and regulation issues. She was tube-fed as a baby and, although she is now an oral eater, her senses of taste and smell are somewhat altered. When one sense is impaired, we look to the others to make up for what's lacking, but what happens when there are deficiencies in all the senses? How does a child understand the world when every bit of sensory information comes in at least a bit skewed, missing, or altered?

As a baby, Aubrie didn't visually recognize Mommy entering a room until she was nearly 4 months old. Only in recent years has she been able to identify birds and planes in the sky. When her older brother was a baby, he watched for the silos as we drove across our midwestern landscape. His favorite landmark in Springfield, Illinois was the billowing clouds from smokestacks. Living in a rural community, we made many long trips during which he enjoyed observing his world. Aubrie also makes many long trips to frequent doctor appointments. Her observations have been limited to the world inside our vehicle. She still does not recognize and enjoy the objects outside.

Considering only the limited context of travel, imagine the very different world understandings developing in these two little brains. Now imagine the effects of hearing and other sensory impairments on understanding when applied to a lifetime of situations. Not only does Aubrie miss the incidental learning that is a natural part of her brother's travel times, but she also misses incidental learning in other circumstances when she doesn't clearly see or hear what is happening in the world around her.

Early on, I didn't understand the impact that "slight" vision impairment would have on my daughter. As a baby, Aubrie was diagnosed with a malformation of the eye severely limiting the vision in her left eye. However, her right eye was "near normal". It turns out that you need both eyes working together to see distance and depth. And there's much more to vision than acuity. Aubrie has had qualified, caring specialists in her life from the start. Her team has always included vision specialists, deafblind specialists, and a respected ophthalmologist. She has attended low vision clinics and summer camps at our state school for the visually impaired. Even with consistent and

quality care, we have struggled to understand exactly what she sees and how to best support her in the classroom. How can a child tell you what she or he sees or doesn't see? She doesn't know what the world should look like. She doesn't know what she is missing. When does a child begin to understand that what she sees is different than what is seen by others? A few years ago, at the low vision clinic, the doctor asked Aubrie to cover her good eye with her hand. The doctor asked, "What do you see?" Aubrie replied, "The inside of my hand." For nearly a year after that exam, Aubrie would periodically remind me of that crazy doctor who covered her eye and then asked what she could see. She was so puzzled by that crazy exam. I repeatedly explained to her that I have two eyes. When I cover one, the other can still see. One day, an "aha" look crossed her face. Aubrie finally understood that her experience was not like mine. She said, "I wish I had three eyes. Then two would be able to see."

Usually, when we covered her good eye, Aubrie would shut down, sway her head, and say that she couldn't see anything. But during an exam at about age 8, Aubrie was able to follow directions and persist in the difficult task of seeking an object with her bad eye. With her good eye covered, she turned and tilted her head and struggled to find the position in which she could see the largest letter on the vision chart. It was the first time that we had evidence that she could see something. We learned that she had a very limited field of vision with very poor acuity in that eye.

Because I didn't understand the impact her vision impairment would have on her learning, I didn't expect that Aubrie would ever need or benefit from a long white cane or a closed-circuit TV (CCTV). We have used large-print books, enlarged copies of worksheets, magnifiers and other low-vision tools. Sometimes, members of her educational team would wonder if those supports were really necessary. Aubrie appears to function fine and doesn't always realize her own limitations in order to ask for supports.

Think about your own vision. You are probably able to read fine print. But would you want to read an entire novel of fine print? If so, you might spend so much effort straining to see that you would have little effort left to comprehend what you read. This is true for Aubrie. Add difficulties with balance, hearing, and muscle tone so that you not only have to strain to see, but you have to work hard to hear, to keep your body upright in your chair, and to hold your pencil in your hand. Attending to the visual aspects of learning in the classroom can be tiring for Aubrie.

One day, at the School for the Deaf where Aubrie attended for a few years, the vision specialist noticed that Aubrie had her head on her desk and her eyes closed. A casual observer might have assumed that she wasn't paying attention. Some teachers may have scolded her. But this specialist watched closely and determined that Aubrie was resting her eyes after a visually taxing day and was paying attention by listening. This was another clue that large-print texts, magnifiers, and those other tools we'd been providing were necessary and helpful.

In Aubrie's classrooms, the walls are covered with all the information a student needs for success - clock, calendar, schedule, formulas, rules, definitions, word banks, number charts, writing guides.

None of these have been available to Aubrie until this year, when she began using a portable CCTV at her desk. It uses a video camera to project a magnified image onto a TV screen. She can use the camera to enlarge the view of any of those learning tools on the wall, a person speaking to the class, or a page from a book. Suddenly, she has visual access to everything in the room - just as her classmates have always had. Aubrie didn't know that she was lacking anything so she didn't ask for help to see these things. When the vision specialist suggested a CCTV for her, the team wasn't sure it was necessary. But when Aubrie first used the CCTV to see materials on the wall clearly from her desk, the look on her face convinced us all.

Aubrie has also learned to use the long white cane. She is capable of maneuvering around her school, home, and community and the cane is not a necessary tool right now because she is always with an adult when traveling outside of her community. In new settings, she usually holds my hand. But, when Aubrie is a young adult, the cane will allow her to travel independently in new and crowded settings. The first time Aubrie brought her cane to the ophthalmologist's office, he thought that she didn't need it based on his assessment of her visual health and acuity. But when I asked Aubrie if she thought the cane was helpful to her, she said it was. So we continue to learn cane skills. For me, the test of whether a tool is useful or not is to give it to Aubrie and let her decide.

Why would we withhold a tool that can make learning easier? As a parent, I expect the specialists on her team to fill her toolbox with the appropriate tools for her. Just because she is capable of reading regular print for a line or a paragraph doesn't mean it makes sense to ask her to do it for a full chapter. If our goal is learning, then we should provide tools that allow her to expend her energy on learning - not on seeing or hearing. There have been times when I have found out about a tool, and I have been the one to introduce it to the team. Those times are frustrating to me because I wonder how much sooner Aubrie would have benefited if the appropriate specialist had made it available to her.

As a parent, I believe that my job is to learn all that I can about my child, her challenges, and the best ways to support her success through those challenges. I expect the professionals on Aubrie's team to know what other people have experienced when facing similar challenges, what technology and supports are available, and how to access those supports if they might help Aubrie. I expect them to share their knowledge with me and others on Aubrie's team. I expect them to make suggestions as appropriate, research when they need more information, and give Aubrie every chance for success. I also expect them to remember the combined effects of all of Aubrie's sensory impairments. As they share their very important focused expertise, they must also be mindful of the big picture that is Aubrie and her future.



Published in DVI Quarterly, Vol 54, #3, Spring 2009

[RETURN TO TOC](#)