



Complex Child E-Magazine

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Assessing Vision in Children who are Non-Verbal or have Multiple Disabilities

by Susan Agrawal

We knew early on that our daughter, who is diagnosed with hypoxic-ischemic encephalopathy, had problems with her vision. While she did track an object somewhat, she was very inconsistent and often unable to follow the object very far. She also clearly had limited distance vision. Despite her obvious deficits, we were confident that she had some vision since she spent hours reaching for herself when placed next to a mirror. Her vision therapist, who was provided by Early Intervention, agreed with our perceptions.

At around nine months of age, we took her to see an ophthalmologist who supposedly had experience evaluating children with neurological issues. We waited for four hours in the waiting room, and then were only seen by a resident. After a few lights were shined in her eyes and a tongue depressor moved in front of her face, she was pronounced to be completely blind by the resident. He claimed her eyes were unresponsive to light and she was unable to track. When the doctor finally saw us, she agreed with the resident's findings.

We left exhausted, frustrated, and confused. Despite the doctor's opinion, I was confident my daughter had some usable vision. After all, I watched her twenty-four hours a day and clearly saw visual behaviors. This ophthalmologist and resident only saw her for 10 minutes in a strange dark room after a really, really long wait.

After hearing our story, my daughter's vision therapist sent her to see a low vision optometrist at the Chicago Lighthouse for People Who are Blind or Visually Impaired. We learned quickly that our experience with the ophthalmologist was neither unique nor uncommon. Many children like my daughter, who has limited motor skills and is unable to talk or gesture, end up being diagnosed as "blind" because the usual tests are not particularly useful in assessing their vision.

The primary difference between the ophthalmology visit and our meeting with the low vision optometrist was the length of the appointment. We were scheduled to see the optometrist for a full 90 minutes. During the appointment, we described what visual activities we saw our daughter performing, and then the optometrist assessed her vision using a wide variety of toys and tools. The optometrist recognized that determining visual acuity in a child with multiple disabilities would take a lot of time...probably multiple appointments.

A major portion of the evaluation is the parent report: what you see your child doing on a day-to-day basis. Simple questions can often help to determine what your child is able to see. These are some of the type of questions that you may be asked:

- Does your child smile when a parent comes up to her? (assesses near vision)
- Does your child smile when a parent enters the room? (assesses distance vision)
- Does your child blink or close his eyes when a light is turned on or he is brought outside? (response to light)
- Does your child see herself in the mirror and respond (reaching toward mirror, vocalizing, etc.)? (assesses near vision)
- Does your child reach for an object placed in front of him? (assesses near vision)
- If the lights are turned off, does your child respond? (assesses response to light)
- Does your child blink when a hand is moved in front of or toward his face? (blink reflex)
- Does your child pick up a toy or piece of food and put it in her mouth? (assesses near vision)
- Does your child imitate facial expressions? (assesses distance vision)

The optometrist also will assess the child's vision directly using standard tests and procedures. A common test employs Teller Acuity Cards. Each card in the set, which is pictured below, contains a series of black lines a certain distance apart. Using the concept of Preferential Viewing or Looking, babies, toddlers, and children with cognitive impairments will look directly at the area of the card where the lines are as long as they are able to distinguish the details of the lines. Once the lines are too close together for them to separate out visually, they will no longer prefer or look at the striped area of each card. These cards provide a good test of overall visual acuity for a child, but are limited since children above a certain age or cognitive level no longer find the cards particularly interesting.

Teller Acuity Cards:



Other tests may also be used, including moving a toy in front of the child's eyes, first with sound and then without. Some children, particularly those with cortical visual

problems, may be able to see objects when they are moving better than when they are still. For older children with decent cognitive abilities, other tests may be used, including symbol cards or charts. It is also common for the optometrist to evaluate the child for refractive errors (the natural nearsightedness or farsightedness of the eyes, apart from any cortical issues) and astigmatism.

Typically, the optometrist will assess the child's ability to use both eyes together to determine if one or both eyes wander. Checking the blink reflex and light reflex, as well as the general eye health, including eye pressure and a look at the structures of the eye, completes the exam.

For a child who is physically or cognitively unable to perform some or all of these tests, a VEP, or Visually Evoked Potential, may be another way to determine what she can see. A basic VEP uses several electrodes similar to those used in an EEG by detecting whether lines or checkerboards displayed for the child on a monitor are transmitted to the brain. This type of VEP requires little more than keeping the eyes open. A more detailed test, called a Sweep VEP, displays lines or checkerboards of different widths or sizes and is better able to assess the approximate visual acuity of each eye. This test does require the child to be attentive. If a child "passes" a simple VEG, he or she most likely has some usable vision, though it may still be inconsistent or limited by cortical visual impairment. If the child fails the VEP, it does not necessarily mean he or she is completely blind. My daughter failed the majority of her first VEP because she was ill and lethargic, barely opening her eyes. A Sweep VEP done several weeks later showed her to definitively have vision.

It is important to note that the child's medical problems and medications must be taken into account. Many children with seizures have difficulty with their vision during and after seizures, which may make assessment difficult. Medications, including seizure medications, medications to reduce secretions, and many other medications, may cause blurred vision, double vision, or a change in how the pupil responds to light. Other medical issues, such as problems with blood sugar regulation or the presence of a shunt in the brain, may also cause vision problems. In my daughter's case, her autonomic dysfunction causes her eyes to be very dilated at all times, and her pupils do not always respond appropriately to light. Two of her medications also are known to cause vision problems.

Children with brain injuries or cerebral palsy often have very inconsistent vision. These children, who may have delayed visual maturation (a delay in the development of visual skills) or cortical visual impairment, may use their eyes perfectly on the first trial, and then be unable to respond visually on the second and third trials. Multiple attempts must be made to assess their vision by repeating tests, varying how the tests are administered, or simply trying again at a later visit. Some of the following strategies may be helpful:

- ❑ Since children may turn their vision on and off, give them frequent breaks, try different things to stimulate their senses, and do not expect one appointment to give a definitive visual assessment.

- ❑ Try testing the child's vision in different positions. Children with multiple disabilities may find it easier to use their vision in positions that are less stressful or physically demanding. Depending on the child, this may include side-lying, lying prone on the belly, lying on the back, sitting in a supportive positioning chair, standing up, or using a stander.
- ❑ Children may only use their vision with familiar objects or people. Bring in objects the child knows (such as a favorite toy or stuffed animal) and use the parent to hold test materials whenever possible.
- ❑ Children may need highly stimulating or interesting toys, pictures, or lights to get them to cooperate. If they do not look at Teller cards or other visual acuity tools, it may be because they simply do not find them interesting. Try presenting something more visually stimulating.
- ❑ It may be helpful to engage the other senses using sound or touch in order to get a child's attention. Once the child is engaged, try to reduce or eliminate the elements of touch and sound to focus on vision exclusively. For example, have the child touch a toy with a bell on it. Have the child track the toy while ringing the bell. Then have the child track the toy without ringing the bell. Also note that when a child is presented with a toy with sound, a child without vision does not typically turn his head to "look" for the sound and toy. If a child turns his head toward a sound, it is likely that he has some vision.

The importance of assessing a child's vision cannot be underestimated. The results of my daughter's continuing vision assessments have led us to change the way things are presented and taught to her. She uses a large augmentative communication device with a zoom feature, is often taught with a lightbox to enhance her ability to see, and has multiple adaptations at school, ranging from preferential seating to presentation of new material in an uncluttered, simple visual setting.

Even more importantly, we learned that the ophthalmologist who stated that my daughter was blind was completely wrong. It is exceptionally important for children with visual impairments, particularly delayed maturation or cortical visual impairment, to begin vision therapy and be provided with a multi-sensory environment to help improve their visual skills. If a child is not assessed properly and simply labeled as "blind," early intervention and school services may not be provided, and the family might not introduce stimulating visual objects during the early years, when the child's brain is growing and adapting the most. An accurate and detailed visual assessment is a must for all children who are nonverbal or have multiple disabilities.