

HOW MUCH DOES HE SEE?

By Gloria Rodriguez-Gil

Introduction

Many children who are deaf-blind are not totally blind, but have some functional, usable vision. So for many children, the important question is this: how much vision does this child have? From my perspective, even the best vision tests will not give you a complete answer. You will need to carefully observe the child's visual functioning during typical activities of the day. This will need to include observations in different environments, under different lighting conditions, when the child feels at his best (e.g., after a good night's sleep), and also when he is fatigued or not feeling well (e.g., after spending hours awake during the night).

The various people on a child's educational team observe him at different times of the day, so data collected from everyone can contribute to a better, more complete picture of the child's actual visual functioning. But even with the best data collection of the child's vision, we cannot always know *exactly* how much he sees. How do we know whether he is using *just* his vision when he perceives something? How can we isolate this one sensory avenue when we know that perception is so complex? The eyes are part of the whole body, which gathers and integrates information about the environment from many sources. On top of this, sensory information is filtered through our minds, our personalities, experiences, preferences, etc.

Functional vision by itself is hard to measure for the same reason that it is hard to isolate vision and the act of seeing from the rest of perception. While a person perceives through individual senses, perception itself is an accumulation of information, a complex understanding of reality in which all available sensory information is automatically synthesized and interpreted.

So, while the child is *seeing* something, how much *vision* is he actually using? Is he using more of his sense of smell? Is he seeing more through vibration? Does he perceive something because of the person he is with, the place where he is, or the time of day the event is happening? It may be that in reality, vision is a combination of all of these and more.

The Stories of Adrian and Nathan

As mentioned before, one of the factors that makes it so hard to know how much a child who is deaf-blind can see is that most of the time the child cannot explain it in a language we can understand. There are, however, some exceptions.

Adrian

The first child I will describe was one of my former students. I'll call him Adrian. Adrian was born deaf and also had some vision problems that were not significant at that time. He learned about the world mainly through his sense of vision. When he was five years old, he received a cochlear implant and, through years of hard work, he learned to use his hearing and also learned to talk. At the age of eight, he started to lose his vision to the point where he couldn't see anything. He regained some vision with the help of medical intervention and then went through a period of time when his vision fluctuated quite a bit. During this time, it was hard for him to accept the fact that in addition to the hearing loss he was born with, he also had vision problems.

By the time he was seventeen years old, Adrian's vision loss had stabilized and he was able to recognize and talk about the fact that he was deaf-blind. I interviewed him during this time and he was able to tell me that he had no vision in his left eye and only tunnel vision in his right eye. With this level of vision, he was able to read enlarged high-contrast print using a CCTV or computer and, with optimal lighting conditions, he could text on his cell phone by bringing the phone very close to his good eye. He also started using a white cane when traveling in unfamiliar places.

What was amazing about Adrian was that people who didn't know him well would have never guessed he had so little vision. He could do so many things, like maintaining eye contact when talking to people and moving through space as if he was seeing almost everything. But what was even more interesting was that Adrian's eye doctors didn't know how he could use his vision as well as he did. According to the medical specialists, Adrian's retinas were too badly damaged for him to do what he was actually doing with his vision. The only explanation they had at that time was that Adrian's brain remembered everything it had seen through the years and it didn't want to stop seeing. In Adrian's case, the only reason we understood what he was seeing was because he could tell us exactly what he saw, despite the enormous complexities of his vision and perception.

Nathan

Nathan was born with CHARGE syndrome and at that time his eye doctors reported that Nathan had no vision in his left eye and just a little vision in his right eye. His parents explained to me that Nathan only saw through a small patch of retina in his right eye that was still attached.

As an infant, Nathan was very interested in looking at things. He would look at the faces of his parents and teachers when they held him on their laps. He would look at toys placed directly in front of him. Nathan would grab toys and bring them right in front of his eyes and forehead. (He liked to feel things with his forehead.) And he loved to look through toys that had holes.

When he started scooting independently around the house, he would search for places, objects and people he wanted to find. He was very fond of a rocking chair that he could rock with his feet. Later, in preschool, he could recognize objects and understand their use and meaning. At that time we didn't know if he could recognize photographs, until the day he placed his photo on a felt board upside-down and—to our complete surprise—he turned it over so it was right side up.

I imagine that in Nathan's case, he has a working patch of retina with all its cells very well connected to the brain through the optic nerve, and his brain taking maximum advantage of every strand or connection coming from that small patch of retina. It's important to remember that Nathan also has a moderate to profound hearing loss and, if you have ever been blindfolded and used earplugs simultaneously, you know how all the senses immediately enhance their capacity to compensate for the vision and hearing loss. I would not be surprised if Nathan's visual functioning is also working much better because of his hearing loss.

Conclusion

How much vision does a child have? You may not have a crystal-clear answer to this question. Vision is as complex as the human brain itself. If, however, you look very closely and carefully at a child, you will discover something about his vision and about the ways he really sees. Having this basic information is a critical part in helping him access the world around him.