Vision After Hemispherectomy, TPO Disconnection, and Occipital Lobectomy: An Introductory Guide

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INTRODUCTION

Removing or disconnecting the occipital lobe, which occurs as part of hemispherectomy, temporo-parietal-occipital disconnection (commonly known as TPO disconnection), and occipital lobectomy, can have a profound impact on a child's ability to see the world. For example, homonymous hemianopia, a type of cortical vision impairment, is an unavoidable and permanent side effect of these procedures. It can affect daily function at home, in the classroom, as well as other natural environments, and can have a serious effect on the child's ability to read. This field loss, as well as problems with oculomotor control, visual processing, and other difficulties which may arise after surgery, must be understood by anyone who interacts with a child after these procedures.

Here, we summarize the various visual impairments a child will have after hemispherectomy, TPO disconnection, and occipital lobectomy, and how they can affect a child's daily living, functional mobility, and access to the educational curriculum in school.

Note: We refer to hemispherectomy, TPO disconnection, and occipital lobectomy as "surgery" or "surgeries" in this guide.

WHAT IS VISION?

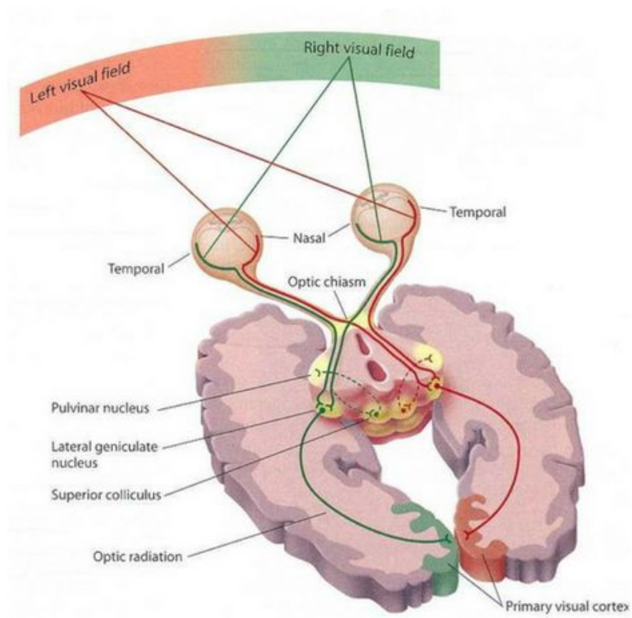
Vision is the ability to assimilate information about the environment by the brain's interpretation of the light that comes through the eyes. The eyes are the sensory organs that collect information; however, we "see" in the brain. Good vision is essential for a child's development. It allows the child to differentiate letters and words, participate in sports, and navigate the environment.

It is commonly thought that more than 80% of a child's learning comes from vision. Problems with vision can lead to movement or mobility challenges, as well as challenges with school and learning, and social and emotional difficulty.

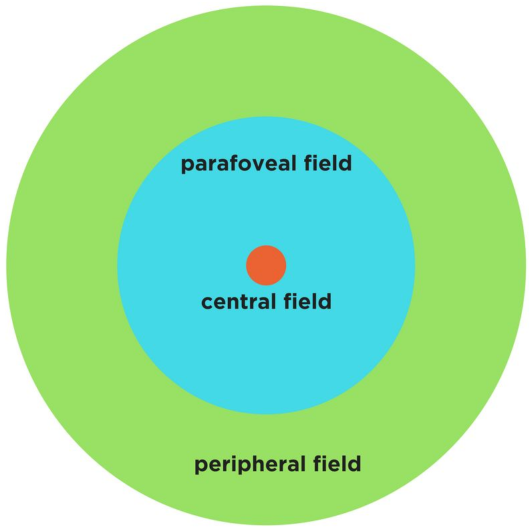
HOW THE TYPICAL BRAIN SEES

In typical individuals, the brain processes visual information that comes into both eyes. The eyes take a picture of an object, and that picture is then converted to electrical impulses which are sent to the brain first by way of the optic nerves which then connect to white matter tracts and fibers (also known as **optic radiations**) that eventually connect to the primary visual cortex of the occipital lobes of the brain.

Your field of vision is divided in half: the left occipital lobe of the brain processes information coming from the right half of *both* eyes; similarly, the right occipital lobe of the brain processes information from the left half of *both* eyes.



The entire scene that your eyes are able to see is known as your **visual field**. This visual field is divided into three main sections: the **central** field (or **fovea**), the **parafoveal** field, and the **peripheral** field.



HOW VISION IS AFFECTED BY SURGERY

Vision is best understood as a **combined function** of the eyes, the eye muscles, and the brain. There are several different parts to vision. These include **acuity, eye movement**, **depth perception**, **focusing ability**, **peripheral awareness** (also known as side vision), **color vision**, and **visual perception** and **processing**, which contribute to a child's overall visual ability. How well each part of vision works, both alone and together, are important for how a child sees and interacts with the world.

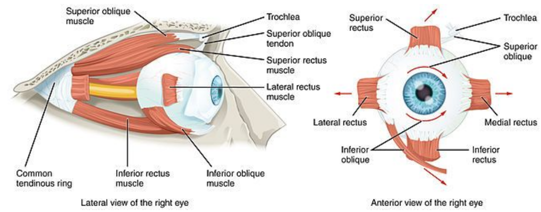
ACUITY

How sharply and clearly you see is known as **visual acuity**. A child with 20/20 vision is said to have normal visual acuity - this means that at 20 feet away from an object, the child sees that object clearly and sharply.

New research shows that some adults who had hemispherectomy in childhood had **reduced visual acuity** in the eye **opposite the removed hemisphere.**

For this reason, children after surgery should be followed by an eyecare provider and have regular visual acuity assessments since loss of visual acuity may happen over time. This should include examination for refractive errors that require correction (such as glasses) for the child to focus properly. These refractive errors include farsightedness (hyperopia), loss of focusing ability (presbyopia), nearsightedness (myopia), astigmatism (overall blurred image), additionally the eye may not accommodate or focus from distance to near; and additional prescription in glasses such as bifocal may be required.

EYE COORDINATION



Many parts of the brain control the movements of the eyes (known as **oculomotor control**) through six muscles on each eyeball. The electrical impulses from the brain to the muscles of the eyes make the eyeballs move extremely fast from one position to another (in split-second movements called **saccades**), very slowly (called **smooth pursuit**), or converge inward (convergence) or outward (divergence) slightly to focus on an object or word depending on how close or far away that word or object is from you (called **vergence**).

Numerous parts of the brain contribute to voluntary and involuntary eye movements, including the **frontal**, **parietal**, and **occipital** lobes, the **cerebellum**, as well as the **midbrain**, **brainstem**, and **vestibular nuclei**. Damage from seizures, stroke, or surgical removal/disconnection of any one of these areas can cause problems with eye control.

Eye control and reading

Good eye control is necessary for many important skills, **especially reading**. When reading a line of text, our eyes follow a path across the page that is from left-to-right and top-to-bottom in languages like English and Spanish.

While we may think that this path is smooth, **it is not**. The eyes actually alternate between rapid forward movements called **saccades** and then stop to **fixate** on a word. And all this happens in split seconds!

Sometimes the eyes will look at the same word (**refixate**) several times, or words are skipped entirely. Which words the eyes choose to look at next depends on the length of the upcoming words in the line of text. Our eyes tend to fixate on the longer words and skip over short words like *and*, *if*, and *so.*

If a child has poor eye movement control after surgery, following a line of text or properly fixating on a word can be very difficult. The child may spend too much time - often unconsciously - trying to get the eyes to fixate on a word rather than getting the meaning of the word. Because the child reads slowly due to poor eye movement control, the educator may think the child reads poorly. This is why educators should be cautious when assessing how fast a child reads - known as a **fluency** - because poor oculomotor control may be slowing down the child's reading speed. Just allowing the child more time may be all the accommodation necessary.

Strabismus or "eye turning"

The eyes must work together accurately in order to form **binocular vision**. Binocular vision overlaps the different views from both eyes, providing the child with **depth perception** and keeps the scene in **sharp focus.**

Surgery often results in one or both eyes turning in, up, or out - a condition known as **strabismus**. When one eye looks one way, and the other in a different direction, the brain receives two different visual images. This makes it impossible for the brain to form a single image, so the brain may ignore the image from the misaligned eye to avoid **double vision**. In a child, the brain may completely shut out visual input coming from the misaligned eye resulting in a **reduction or total loss** of vision in that eye known as **amblyopia.** This also affects the ability to have stereopsis or 3D vision.

For these reasons, children after surgery should be followed by an eye doctor who understands visual impairments caused by the brain, and how it affects the development and overall function of the child. Treatments to improve eye alignment include eye glasses, eye exercises, eye patching, prism glasses, and eye muscle surgery.

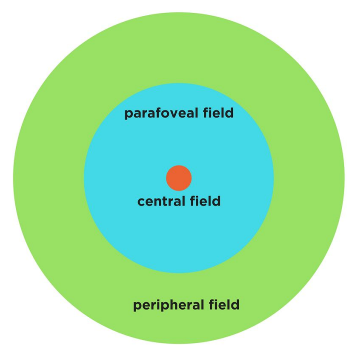
FIELDS OF VISION

The most significant visual impact a child will have after surgery is **loss of half** of the visual field in each eye, opposite the side of the surgery, including half the **central field** or **foveal field**, and the entire **parafoveal** and **peripheral** field on the opposite side. This is called complete **homonymous hemianopia.** (In rare circumstances, there may be sparing of the macula – meaning that some central vision is spared.)

Because these surgeries either remove one occipital lobe, or cut the fibers which carry the visual message to the affected occipital lobe from the eye, homonymous hemianopia is an **unavoidable** and **irreversible result**; however, the effect on function may be different in each child.

It is important to first understand how normal visual fields work before the effects of homonymous hemianopia can be fully understood. It is also important to understand that the visual field **in each eye** is affected.

The central field



If you think of the entire scene in front of you as huge target with three rings, your central vision is the middle of the target where you would aim your bow and arrow. The area that is in sharp focus when you look at something is called the **central field** or **fovea field**. This area is actually quite small - only about 2 - 5 degrees of your vision is in sharp focus at any given time.

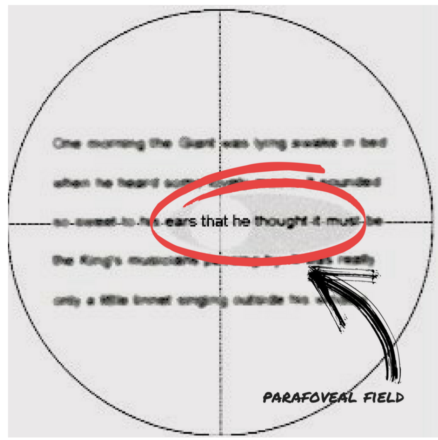
The best way to see your central vision is to extend one arm straight out, make a “thumbs up” gesture with your hand, and look at your thumbnail. You will see that only your thumbnail is in very sharp focus (known as **100% acuity**). This small area - literally the size of your thumbnail - is your central field of vision.

Why is only this small area in sharp focus? It’s because each eyeball has a very small pit in the back which is densely packed with only **cones** - highly specialized photoreceptor cells which allow the perception of color and are able to perceive finer detail and more rapid changes in images. Only these **cone cells** provide us with the vision required to see things clearly.

Good central vision is very important when **reading**. This is because your central vision allows you to view about **four to five letters** in sharp focus (**100% acuity**) at any given time.

The parafoveal field

The next ring of the target that is your field of vision is your **parafoveal** field. It allows you to get the “big picture” of the scene in front of you (such as whether a car is pulling up beside you), but things in your parafoveal field are not in sharp focus.



The parafoveal field is especially important when reading languages that are read from left to right, like English or Spanish. This is because the area of the line you are reading - known as the **perceptual span** - extends about 3 - 4 letters/spaces to the left and **up to 15 letters/spaces to the right**. This allows you to get an idea of the words that are coming up after the word being read so that you know where to fixate your eyes next.

The peripheral field

The outermost ring of the target that is your field of vision is your **peripheral** field. This is important for seeing movement, but everything is out of focus.

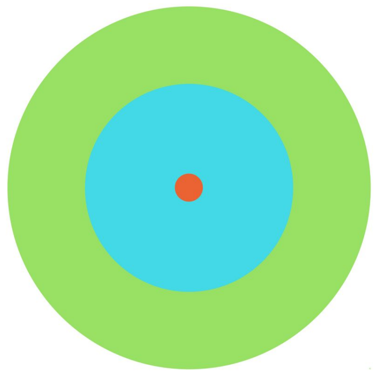
The peripheral field is extremely important when driving a car as it allows you to see the full scene of traffic. It allows the driver to see color and movement, signal changes, road signs, warning lights on the dashboard of the vehicle, and gives cues to stay within one’s lane.

On the playground, it allows a child to see children running towards him, soccer balls being kicked in her direction, a child in mid-flight on a swing nearby, or a ball falling from the sky.

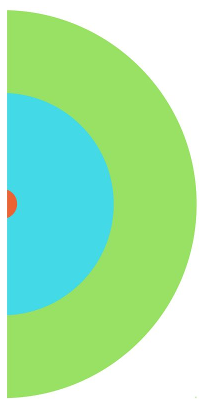
Peripheral vision is **extremely important** when crossing the street. It detects the motion of an oncoming car or bus, causing you to shift your gaze to make eye contact with the driver to make sure he stops before you step enter the crosswalk.

Homonymous hemianopia

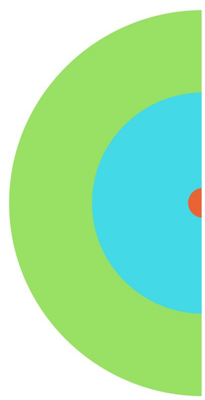
Homonymous hemianopia is a **loss of half the central field** as well as the **entire parafoveal and peripheral field** opposite the side of surgery. Homonymous hemianopia is a type of **cerebral** or **cortical visual impairment** (CVI). Cerebral/cortical vision impairment is a problem with how the brain processes what the eyes see and there are many different types of CVI.



Normal visual scene



Left homonymous hemianopia



Right homonymous hemianopia

When the eyes take a picture of the object and send the message to the brain, but the message is not properly processed because of problems with the optic nerves, damage to the optic tracts or radiations, or injury to the occipital lobe, CVI is the result. In other words, there is no problem with the structure or function of the eyes, but once the visual message reaches the brain, it is lost or distorted.

Some children may have homonymous hemianopia before surgery because of the brain malformation, stroke, or disease which caused the seizures in the first place. After these surgeries, however, homonymous hemianopia is an **irreversible and permanent** result.

Navigating the world

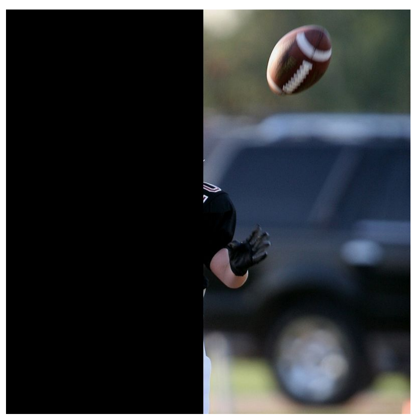
Children with homonymous hemianopia often require a lot of effort to recognize that there are moving objects, people, or obstacles in their missing visual field. This makes it difficult to move from one place to another with ease, especially outdoors or in an unfamiliar environment.

For example, they may bump into pedestrians or obstacles that they simply cannot see because the object or person is in the lost field of vision. They often have difficulty moving safely within their home, school, or community (known as **orientation and mobility skills**) and often have trouble with activities which require good vision, like team sport activities, playground games, or choosing food in a cafeteria line.

Some of these challenges can cause significant distress for the child which often makes them unable to fully participate in classroom and recreational activities. They may be startled when something suddenly appears in their field of vision - like a soccer ball in mid-flight - or may fear falling because they are unable to see obstacles. Although children with hemianopia may search the lost visual field by turning their head, this search may be slow. These slow search patterns do not allow them to fully understand the environment around them fast enough to avoid an obstacle, so children with homonymous hemianopia often avoid new environments altogether.

This may also affect the child's socio-emotional well-being. For example, the child may not be chosen for team sports during recess. Because the eyes look normal, other children and teachers may not understand how the visual field loss affects the child. They may think "they are not trying hard enough." Homonymous hemianopia may be **hidden to all**.

Regular vision



Left homonymous hemianopia

Right homonymous hemianopia

Does the child see black in the lost visual field? No. Just like you do not see black behind you, but rather lack vision, the child also lacks vision in the lost visual field. One way to understand this is by imagining that you have a cape or curtain which hides what you cannot see behind you. Now pull the curtain or the cape around so that it covers half your face as though a vertical line was dividing your face in two between your eyes. This gives you the jist of the lost visual field.

Homonymous hemianopia can seriously affect daily activities such as walking in crowded areas, sidewalks, shopping malls and supermarkets, classroom hallways and playgrounds, seeing playmates or teammates, identifying and finding objects, crossing the street, reading and learning, and other activities of daily living such as cooking, pouring beverages, and especially driving. These problems can lead to leaving out of important parts of a scene and, consequently, to poor comprehension and social misunderstanding.

Reading with homonymous hemianopia

Reading requires us to move our eyes smoothly across a line of text, see each word, and understand the meaning of each word in a **fraction of a second.** In languages like English, Spanish, and French, the eyes must scan smoothly from left to right and top to bottom across the page, briefly fixating on a word before moving on to the next word.

Because homonymous hemianopia causes a **loss of half the central field of vision**, the child **only sees part of the word** when looking at it. This makes **word identification** very difficult. The child must scan to see the entire word before reading it, adding an additional step to the process of reading the word. Longer words are never seen as a whole word resulting in various reading **accuracy errors**. This can include misidentifying a word, omitting letters, syllables, skipping over short words unintentionally, or guessing errors.

bullfrog

What you see

bull

Right homonymous hemianopsia

frog

Left homonymous hemianopsia

Guessing errors can be frequent because the child does not see the entire word. The child may identify the prefix only and then fill in the rest of the word based on prior experience. (As an example, a child with left homonymous hemianopia may be attempting to read the word *peach* for the first time, but sees only *each*. She may then guess that the word being read is either *each* or *beach* depending on the context within the sentence or prior experience, rather than actually reading the entire word.)

Right-sided homonymous hemianopia, which results after left-sided surgeries, can have a **severe impact** on learning to read in children who read languages that are written and read from left to right (English, French, Spanish) as the child is always reading into the blind field.

As a reminder, skilled readers take in words from a small area around the eyes' **fixation point** - about four letters to the left and 15 letters to the right. The more letters you can see on the right, the faster your reading speed (known as **fluency**) because you know which word to focus on next. Reading after left-sided surgeries is particularly challenging because not only is most of the word missing, but the right parafoveal vision - which includes those 15 letters to right - is gone.

This loss of the right perceptual span creates a **bottleneck:** the child will spend too much time finding the next word, focusing on it, re-fixating on it if necessary, and then extracting its meaning. This makes oral reading performance (how fast and clearly you read out loud, known as **fluency**) very challenging.

Adult readers with left-sided brain injury resulting in right-sided hemianopia describe **severe frustration** when reading because they are attempting to **read into nothingness**. For a child learning to read with right homonymous hemianopia, this can cause a dislike of reading at a very early age.

Left-sided homonymous hemianopia, which results after right-sided surgeries, can also have a significant impact on reading. Children may have problems finding the next line of text or may skip the next line altogether. Also, because the first part of a word often contains information to quickly identify it, they may have frequent reading errors. This can be especially difficult for the beginning reader.

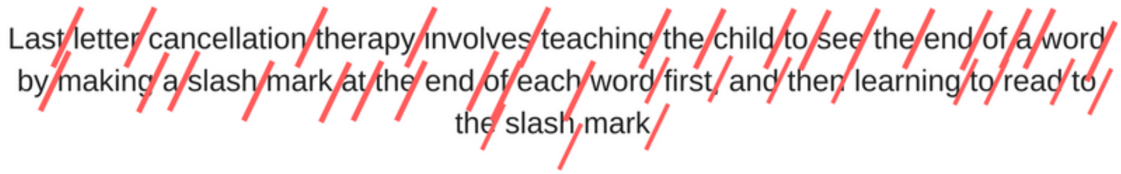
Accommodations, modifications, and helpful strategies

The child should learn as early as possible to advocate for themselves. This should be part of the Individual Education Plan (IEP). The educational staff should allow the child to **advocate** for themselves what he/she cannot see, in what position in the class they see best, or if they do not feel safe. Self-advocacy is one of the most important social, emotional, and educational skills we can teach.

Because we understand how adults with hemianopic reading impairment (sometimes referred to as hemianopic dyslexia) relearn reading skills after brain injury or stroke, these same interventions may be helpful for children with homonymous hemianopia who are learning how to read. They include:

- **Oblique presentation** Rotating the page 45-90 degrees, so that the entire line of text is in the remaining visual field, can be helpful for some children. Research shows that it is most helpful for right hemianopia.
- **Wood stick method** This method has the child use a long wooden stick on a chalkboard or whiteboard which they move from word to word as they read off a board. Children with left-sided hemianopia (which results after right-sided surgeries) are asked to tap the wooden stick on the beginning of the next word. Children with right-sided hemianopia (which results after left-sided surgeries) are asked to tap the wooden stick on the end of the next word. This teaches the child to shift his gaze intentionally (known as attentional gaze shift) into the blind field. In adults who have hemianopic visual loss, this method showed improve reading after a few weeks.
- **Long gaze shift method** This method requires the reader to scan all the way to the end of the line first so she understands how many words are in the line as well as the length of each word. This requires the child to perceive each word as a whole first before reading it.
- **Electronic reading aids with gliding text** Electronic reading aids magnify text from a book or magazine onto a computer screen. This allows the reader to view the words in larger print against a bright background which improves oculomotor control. Examples of electronic reading aids include:
  - EzRead Electronic Reading Aid
  - Carson E-ZRead Digital Magnifier
  - Reizen Electronic Reading Aid
- **Boundary marking devices** Boundary marking devices, such as translucent plastic with a bright red boundary line, can help the child scan to the next line of text.

● **Last letter cancellation therapy** Similar to the wood stick method above, this strategy requires the child with right hemianopia to first mark the last letter of a word before reading it. This trains the child to scan to the end of a word before reading it.



● **Next line/first part of word therapy** Similar to last line cancellation therapy, this method is for right-sided surgeries which result in left hemianopia. These children show difficulties locating the next line of text. This method teaches the child to scan to the subsequent line of text as well as to see the first part of the word.

● **Seeing the whole word** Provide the child with strategies so that the child sees the entire word and is trained to look at the middle/root of the word.

In school, accommodations should be provided to ensure that all instructional material are accessible for the child. This may include:

● When appropriate, **smaller text** ensures that more of a word is in the remaining visual field.

● **Vertical presentation** can be beneficial so that material is not missed. Columns of text may be easier to read than whole pages of uncolumned text. Present visual materials on a slanted surface for viewing. A computer screen is ideal as the surface is vertical. The position of the child's face relative to the slanted surface or screen is important. The surface should be biased toward the child's seeing field (leftward in the case of right field loss, and rightward in the case of a left field loss.)

● **Oblique presentation** of lines of text (such as when turning the page 45 -90 degrees) and allowing the child to **tilt his/her head** to see the whole line of text better. These adjustments should be understood as a helpful and functional adaptations by the child;

● Teach the child to systematically **scan visual materials** during any task which requires vision. Scanning a page of images should be taught from the left to right and top to bottom. This will help set a habit for reading languages that are read from left to right, like English or Spanish;

● When reading a line of text, help the child understand the sequence of words by **moving your finger underneath** each word. Also, a ruler can be placed underneath the line of text to guide the eye. **Reading guide highlighter strips** are simple devices which form a window that masks the lines above and below the line of text and can be slid along the line while reading so that the child sees only the line of text being read;

● For a child with left hemianopia, the problem in reading involves returning from the right end of a line to the left and down to the next line. This can be difficult especially for the beginning reader. **Use your finger** to follow back along the line that was read, and down to the next line may be helpful. To guide the eyes to the left and down, a ruler placed along the left edge of the text or an L-shaped guide shifted down to the next line can be used. **Color coding of left and right margins** may be helpful;

● Make the child aware of the **whole array of objects** and both pages in a book. Ask him/her to point out different things on the page and make them aware of both pages, starting from the left;

● Children with hemianopia may forget to write or draw on the part of the paper that falls into their lost field. Compensatory strategies like **oblique presentation** with **head tilt** may be helpful;

● A **slanted surface** for writing may be helpful;

- A **bold dark felt tip pen** may provide better writing and drawing than a pencil. This increases contrast between the letters and papers when learning to write. **Lined paper** can also be helpful for writing as well as **graph paper** for math;
- Make sure the child is aware of the **entire piece of lined paper** before writing;
- **Seating in the classroom** should be where the child's remaining visual field can take in what the teacher presents to the class as a whole. **This may be in the back of the classroom for some activities, or in the front for others.** The child should advocate for themselves and provide feedback. When facing the front of the classroom and the teacher, the child with a right field loss should be seated to the RIGHT facing the front, with the teacher on the child's LEFT. And the child with a left field loss should be seated to the LEFT facing front with the teacher on the child's RIGHT. In a semicircular group, placement of the child with a visual field loss **should be guided by the activities** and where the child's attention should be directed. If the goal is to attend to the teacher, then the teacher should be well in the child's seeing field. If the goal is to interact with the other children, then the child with a field defect should be positioned so that as many of the other children as possible are in the seeing field. **Positioning in the classroom** needs **continuous reevaluation** by the educational staff. If the child can advocate for themselves, they can vocalize where the best position for their access to information is.
- **Independence** and **safety** are important for the child and require **continuous reevaluation**;
- Provide **additional lighting** so that the child can see things clearly;
- Children with field loss may have **difficulty locating objects** and **people at distance**, even if their distance visual acuity is normal. The child should be taught to scan objects at various distances must be designed and implemented across activities and environments;
- The child's classroom, hallways, stairways, and playground should be evaluated for **potential hazards** often;
- **Mark crucial features** such as stairs and railings for better visibility as needed. Furniture and other objects should be located in the same place every day so as not to confuse the child. Introduce safety features such as Exit signs early and often.

Compensatory strategies

Some children compensate for their visual field loss automatically with various adaptive mechanisms to increase their visual access to the remaining visual field. These adaptive mechanisms include:

- Atypical head posturing such as head tilt or face turn (note: head turn **does not** adequately correct for issues with reading/foveal vision);
- Exotropia or "turning out of the eye" which may create a more panoramic view and expand the visual field; however, this causes a lack of depth perception and more importantly binocular vision which is critical for reading.
- Children may adopt their own strategies that we do not understand. We need to be sure to understand that not only is each child unique, but compensatory strategies may be unique. Learning to understand the child and the way they see is important.

Also, there are many different interventional techniques designed for patients with visual field loss from brain damage. **These may work for some children, but need to be individualized.** These include:

- optical therapies where the lost visual field is brought into view by the use of optical devices (such as prism glasses);

- eye movement-based therapies where the lost visual field is scanned with compensatory or adaptive eye movements.

Optical therapies
Optical visual field expanders such as the EP Horizontal Lens, the Gottlieb Visual Field Awareness System, the Chadwick hemianopia Lens, or prisms may be useful in select cases.

Prisms placed on (or in) glasses shift the seeing field by a certain amount (15-20 degrees) so that the non-seeing field is moved optically toward the seeing field. It's important to understand that these glasses don't actually expand the field, but rather compress some of the lost visual field into the existing visual field. This is similar to how the side view mirror allows a driver to see vehicles in the left lane that would otherwise be out of the normal visual field.

Not every child will be able to use a visual field expander, and those with potential to benefit should be fit by an eye doctor with experience in vision rehabilitation of hemianopia.

Eye movement based therapies
Compensatory approaches (known as **vision therapy** or **visual capacities training**) are often done with a developmental optometrist or an occupational therapist. These therapies attempt to show children more effective ways of using their vision, principally to reinforce their visual search strategies and by training them in various oculomotor strategies. These include:

- Consult first with your eye care provider to determine the efficacy;
- Saccadic eye movement therapy, such as Explorative Saccade Training (EST), includes visual search and training of saccadic eye movements to scan into the impaired visual field to develop more efficiency. Studies shows that adults with homonymous hemianopia generally perform saccades that are too short to compensate for their visual field loss. Improving the child's ability to accurately perform both larger and more accurate saccadic eye movements to the side of the loss may improve the child's functioning in mobility and activities of daily living;
- **Reading training** that includes training of saccadic eye movements may help improve reading, however, often more specific therapies and strategies are required, particularly in patients with right homonymous hemianopia (such as **boundary marking devices**);
- **Visual perceptual enrichment program**s such as the Perceptual Enrichment Program (PEP) are usually administered by an occupational therapist. These programs identify visual perception difficulties. Through a series of tabletop puzzles and activities, students are taught to solve increasingly difficult perceptual problems. Areas of focus include: spatial organization, recognition of parts to whole relationships, figure ground perception, classification (attention to details) and inferences and abstractions (logic).
- **Visual therapeutic websites** such as eyecanlearn.com and coolmath.com provide online visual training.

COLOR VISION

How a child sees color is a function of both the color receptors in the retina of the eye as well as specialized neurons in the occipital lobe of the brain. **Color vision deficiency** (sometimes called "color blindness") can be caused by issues with the receptor cells of the eye's retina or by damage to the color processing centers in the brain caused by stroke, traumatic brain injury, or seizures. Certain types of anti-epileptic drugs can also cause issues with color vision as well.

Brain-based color blindness is called **cerebral achromatopsia**. Usually both sides of the brain would have to be affected. While no research shows that hemispherectomy, TPO, or occipital lobectomy is correlated with cerebral achromatopsia, a history of seizures, stroke, cortical dysplasia, or anti-epileptic drug use can cause it. Assessments for color vision should be regularly performed on a child after these procedures as appropriate. Challenges from color vision deficiency, if recognized, are able to be addressed easily in the classroom. If unrecognized, however, it may be frustrating for the teacher and the child.

VISUAL PROCESSING AND PERCEPTION

Visual processing (or **visual perception**) describes the brain's ability to understand and process what the eyes see. Visual processing is comprised of several different parts and includes:

1. **visual closure** - knowing what an object is when seeing only part of it. A child with visual closure issues may struggle to identify a word when they can only see a few letters (as may occur due to homonymous hemianopia);
2. **visual discrimination** - using eyesight to compare features, like color and shape, from one to another object. A child with visual discrimination issues may confuse one letter for another;
3. **visual figure-ground discrimination** - differentiating a shape or word from its background. A child with visual figure-ground discrimination may struggle to pick out numbers or words from a page;
4. **visual memory** - recalling something the child saw recently. A child with visual memory problems may struggle to recall a written phone number or how a word is spelled;
5. **visual sequencing** - distinguishing the order of numbers, letters, words, or images. Problems with visual sequencing may cause a child to struggle with filling in the bubbles on a test, aligning numbers for addition or subtraction, or keeping their place when reading a page;
6. **visual-spatial processing** - understanding how an object's location relates to you. A child with visual-spatial processing issues may struggle with judging time, reading a map, etc.
7. **visual-motor processing** - using the eyes to coordinate body movements. Children with visual-motor processing may be unable to copy words or judge the distance of an object.

The dorsal and ventral streams

After the visual stimulus leaves the eyes, it is first processed through distinct points in the brain (known as lateral geniculate bodies) along the path to the occipital lobes. Then, that information exits the occipital lobes in white matter tract pathways called streams to other parts of the brain. The **ventral stream** (also known as the **"what pathway"**) is involved with object and visual identification and recognition. The **dorsal stream** ("or **where pathway"**) is involved with processing the object's spatial location. In other words, the brain is figuring out what to do with the visual information it has received, how to use it to recognize persons seen before, map routes, recognize symbols and letters, and many other interpretations. These streams run through the temporal and parietal lobes, which is why sometimes surgery to these parts of the brain can affect visual processing as well.

The **dorsal stream** guides your actions and helps you recognize where objects are in space. Also known as the **parietal stream** (because it flows to the parietal lobe), the **"where" stream**, or the **"how" stream**, this pathway stretches from the primary visual cortex (V1) in the occipital lobe forward into the parietal lobe. It is interconnected with the parallel ventral stream (the "what" stream) which runs downward from V1 into the temporal lobe.

The dorsal stream is primarily involved with the perception and interpretation of spatial relationships, accurate body image, and the learning of tasks involving coordination of the body in space. Damage or disruption to this stream can cause visual processing issues, including:

- **Simultanagnosia**: The child can only see single objects without the ability to perceive it as a component of a set of details or objects in a context (e.g. the child can describe various trees and animals in a scene, but does not recognize the scene as a forest);
- **Optic ataxia**: The child cannot cannot use visuospatial information to guide arm movements, so reach is not accurate, they overshoot an object, or use a sweeping motion;
- **Hemispatial neglect**: The child is unaware of the space that exist in his/her blind field. For example, they are unaware of things in their left field of view and focus only on objects in the right field of view. Or they may appear unaware of things in one field of view when they perceive them in the other. For example, a child with this hemispatial neglect may draw a clock, and then label it from 12, 1, 2, ..., 6, but then stop and consider their drawing complete.
- **Akinetopsia**: The child is unable to perceive motion.
- **Apraxia**: The child is unable initiate movement in the absence of a muscular disorders.

The **ventral stream** is primarily involved with object recognition and form representation. Also described as the "what" stream, it has strong connections to the medial temporal lobe (which stores long-term memories), the limbic system (which controls emotions), and the dorsal stream (which deals with object locations and motion). Thus the ventral stream does not merely provide a description of the elements in the visual world—it also plays a crucial role in judging the significance of these elements.

Damage to the ventral stream can cause inability to recognize faces or interpret facial expression. Dorsal and ventral stream dysfunctions rarely happen in isolation. They are usually components of both.

Due to the nature of these surgeries and the connections of the occipital lobe are disconnected from other parts of the brain, visual processing difficulties noted above may result. For this reason, **comprehensive medical (including ophthalmic) and educational evaluations are critical** after surgery.

VISION EVALUATIONS

Children after hemispherectomy, TPO disconnection, and occipital lobectomy benefit from a complete evaluation from a **neuro-ophthalmologist** every year. If a neuro-ophthalmologist is unavailable in your area, an ophthalmologist (MD) or optometrist (OD) with **experience working with neurologically complicated children** may be helpful. Early diagnosis, coping strategies, and patient rehabilitation are critical after these surgeries.

Medical evaluations

A comprehensive medical evaluation should include:

- **Standard** ophthalmic eye and **functional vision examination**, including assessment of acuity, binocular vision, oculomotor assessment (including evaluation of locomotion and exploration capacities), plus a visual efficiency examination to monitor acuity, strabismus, as well as tracking and visual stamina for near activities, fusion skills (converging/diverging), and reading efficiency. The assessment should also include evaluation of contrast sensitivity, processing speed, and contour integration. These evaluations generally may be done in conjunction with a teacher of the visually impaired (TVI) whose training focuses on the functional and educational activities which involve vision. The eye care specialist should be reminded to confirm the hemianopia and provide recommendations for reading, scanning, and safety at school. This assessment should also include evaluation for nystagmus, oculomotor functions, strabismus, trouble with 1) visual fixation, 2) visual acuity, 3) visual field and possible functional/compensatory strategies. The TVI would then take this information into the classroom.

- **Objective** and **visual field perimetry**: The eye care provider should perform a **Goldmann perimetry test** or a **Humphrey threshold test**. These are challenging tests for most children. Visual fields may be measured by confrontation examination; however, confrontation only gives an estimate of the visual field loss.

- A **neuropsychological evaluation** can help determine the extent of a visual processing disorder and help determine developmental concerns or other areas of need.

School evaluations

After hemispherectomy, TPO disconnection, or occipital lobectomy, a child should receive a comprehensive educational evaluation in all areas of suspected disability, including vision. A Functional Vision Evaluation or Assessment (FVE or FVA) should be performed by a teacher of the visually impaired who is a special educator with additional training in how a visual impairment affects education. They are the bridge between the medical diagnosis and the way the child is affected in the classroom. They may be provided direct services or consultation with the classroom teachers to maximize the learning environment and suggest modifications and adaptations.

> *"It is important to note that in most school systems, the psychologists and other individuals who conduct assessment such as these have little experience with visually impaired students. There tend to be fewer of these students compared to students with other disabilities. In addition, many of the standard assessment tests and instruments that they use are not geared to the needs of children with visual impairments - for example, they may require your child to respond to pictures, or the expected results may be based on development patterns that are not typical for visually impaired children. Therefore, it's important for the teacher of students with visual impairments to be involved when these types of evaluations are conducted to provide suggestions about appropriate assessment procedures and help interpret the results. It's also important for you to remember that as a parent, you too are part of your child's educational team and can contribute information about your child if you have concerns about the assessment process."* *From American Foundation for the Blind, Family Connect*

The child's school district should perform the following assessments annually:

- **A functional vision assessment (FVA)** explores how your child uses his/her remaining vision and helps determine how the field cut impacts the child's ability to navigate the school environment and access the educational curriculum;
- **A learning media assessment (LMA)** examines the way your child uses his/her senses to obtain information and indicates the most effective ways in which she can be taught reading and other skills;
- **An orientation and mobility (O&M) assessment** determines whether your child needs training in learning how to safely and independently move through their environment;
- **An assistive technology assessment** identifies what kinds of assistive technology may be most helpful for your child.

Functional vision assessment

The functional vision assessment will help to determine how your child uses his/her residual and useful vision in everyday life, and to identify areas of concern in safety, navigation, and reading. This is usually performed by a Teacher of the Visually Impaired (TVI) within the school district. The assessment should include a combination of formal tests and informal measures which may differ depending on your child's age. The TVI will review your child's records, spend time observing your child as she/he goes through the day, and should interview you, your child, and the classroom teacher.

The functional vision assessment should include:

- near and distance visual acuity;
- visual field;
- contrast sensitivity, or the ability of your child to detect differences in grayness and between objects and their background—that is, how clearly your child can see the elements of an image;
- color vision, or the ability to detect different colors and also hues within a color;
- light sensitivity, or response to light (sunlight or artificial light)

The school will usually want confirmation of visual acuity, eye motor control difficulties, CVI, and visual field loss, from an ophthalmologist or optometrist as well. You should have those completed assessments from your child's eye care provider completed before each school year begins.

Learning media assessment (LMA)

The learning media assessment is another key assessment conducted by the TVI. It is used to find out which senses your child uses most to get information from the environment. Some teachers of students with visual impairments combine both the functional vision assessment and learning media assessment into one process.

Regardless of what alternate media your child uses, it is important that all printed material be made accessible, including:

- textbooks and worksheets;
- information on bulletin boards, whiteboards, and chalkboards;
- maps and other pictorial material;
- standardized tests;
- lunch menus, signs, notices to students, etc.

If your child is already reading and writing, the TVI will also examine your child's literacy activities (the way in which they read and write) as part of the learning media assessment, as well as the materials (known as **literacy media**) that she uses. The teacher may also assess your child's reading speed, the degree of fatigue she may experience when reading, and how well she understands what she is reading. Based on this information, the teacher can make recommendations, such as whether your child would benefit from learning how to use a particular low vision or assistive technology device.

Orientation and mobility assessment

An orientation and mobility (O&M) assessment examines a child's ability to travel safely and independently both indoors and outdoors, and with or without assistance, in unchanging (known as **static**), changing (known as **dynamic**), and unfamiliar environments. (An example of a static environment would include your home where the arrangement of furniture is typically unchanged over time. A dynamic environment would be a playground, where children are running around at different speeds, balls are flying through the air, and games are being played.)

An O&M instructor (a professional who has specialized training in how to teach travel skills and concepts such as spatial awareness) will conduct this assessment. The assessment itself usually involves a combination of interviews and observation to see if your child would benefit from formal O&M instruction. O&M assessments are conducted for children of all ages and ability levels, including children who are not yet walking, those in wheelchairs, and those who may never travel unassisted.

Some teachers of students with visual impairments (TVIs) are also O&M instructors as and are dually certified in both areas; however, although others have some basic knowledge in the area of O&M, they are not qualified to assess your child's skills and needs for O&M instruction unless they have received specialized training and hold certificates in both special education in visual impairment and in O&M.

This assessment should be conducted in familiar, unfamiliar, and visually static (unchanging) and dynamic (changing) environments. The assessment will look at:

- Orientation skills and methods;
- Body and spatial concepts;
- Safety while traveling, with consideration of the child’s walking speed;
- Visual scanning skills;
- Ability to judge distance and depth;
- Evaluate any O&M skills has previously learned such as protective techniques, sighted (human) guide technique, trailing, and use of the long cane.

The O&M assessment should also consider functional skills such as:

- Activities of daily living: Can your child store belongings independently? Can she use money to pay the bus fare or make a purchase at a store?
- Social skills: How does your child interact with others? Does she know how to ask for assistance? When assistance is offered and she does not need it, does she know how to decline it appropriately?

- Planning: What skills does your child have when it comes to planning or mapping a route, whether it is from their classroom to music class, from your home to the neighbor's house, or across town to the public library?
- Literacy skills: How does your child make a note of information they need during travel? Does she print or audio record a list of items she wants to purchase, information about the bus schedule, or emergency telephone numbers she can call if she were to become lost?
- Use of optical aids and assistive technology: When traveling, does your child use low vision devices to gather information, such as a monocular to see a building number or a street sign, or a magnifier to read a print bus schedule?

Assistive technology assessment

Assistive technology (AT) refers to the variety of tools and devices that children with visual impairments (and other disabilities) can use to more effectively access their educational environment. An assistive technology assessment is done to identify which devices your child would most benefit from using. This can include any piece of adaptive equipment from something as low tech as a slant board to a high-tech communication device such as a Dynavox or iPad with a special app. Correction of refractive errors (need for glasses) should be carefully assessed to be sure the visual acuity is maximized for any AT.

A comprehensive assistive technology assessment should review the need for any assistive technology **devices** or **services** (low tech to high tech) needed for the student to benefit from education, including the use of such devices in the student's home or in other settings. This helps reduce the academic demands on the child via these resources if possible so as to free up cognitive resources for richer learning.

A child after hemispherectomy, TPO disconnection, or occipital lobectomy should receive an AT assessment **in conjunction with** any other visual and communication evaluations. During these evaluations there should be a consideration and understanding of the significant visual field loss and other impairments which result from the surgery and also the underlying brain malformation or condition which caused the seizure disorder. This ensures that the other evaluators use assistive technologies such as a stand/mount to position equipment in the optimal visual field, preferred colors, or reducing competing sensory information through their evaluations.

Consider consulting with the child's **occupational therapist** when exploring assistive technology tools to take into account any motor challenges (such as hemiparesis after hemispherectomy.) Consideration should be made for the fact that the child only uses one hand to manage devices. How is the student going to access their AT tools in multiple classrooms when seated at a different desk? Is there a plan to have student carry equipment from place to place and set it up independently in each classroom, if possible, or will support staff be provided to do so?

The child should be assessed in a **quiet room without interruption**. Because some of these procedure may be combined with others that remove or disconnect one auditory cortex (located in the temporal lobe and responsible for processing hearing and listening), children post-surgically almost always struggle with proper processing of sounds and words in noisy environments. A quiet room ensures they will not be distracted by environmental noise and give the best opportunity for accurate assessment.

The most successful AT assessments come with hands-on training for both staff and student, learning strategies, a viable implementation plan (with technology 'cheat sheets' if needed until tools become familiar), and AT goals that align with IEP goals.

A note about legal blindness

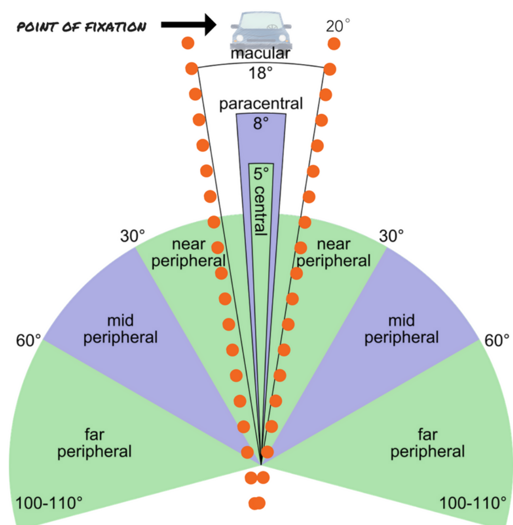
The phrase "**legal blindness**" is a definition used by various state and federal agencies to determine eligibility for vocational training, rehabilitation, schooling, disability benefits, low vision devices, and tax exemption programs.

Many people think that legal blindness means an almost total lack of sight. **This is not true**. A person may have intact vision, but is considered *legally blind* if they meet certain criteria. Overall, the phrase "legal blindness" does not tell us very much at all about what a person can and cannot see.

Social Security Benefits

In the United States, the federal social security administration defines **legal** (statutory) **blindness** to include a visual field (the total area an individual can see without moving the eyes from side to side) of no more than 20 degrees **from the point of fixation** (ten degrees on the left, ten degrees on the right) in the better eye.

> *"To determine statutory blindness based on visual field loss in your better eye (102.03A), we need the results of a visual field test that measures the central 24 to 30 degrees of your visual field; that is, the area measuring 24 to 30 degrees from the point of fixation."*
>
> From the U.S. Social Security Administration's Programs Operations Manual System, DI 34005.102 Special Senses and Speech - Child, § 102.03 Contraction of the visual field in the better eye.



This means that a child or adult with homonymous hemianopia, who typically has only a 10 degree visual field from the point of fixation (because half the central visual field is gone), is considered legally blind for purposes of social security disability insurance and supplementary income benefits.

Statutory blindness alone triggers benefits, subject to other income and age qualifications and other calculations. The monthly earnings limit for an adult who is legally blind is **higher** than the limit that applies to non-blind disabled workers. In 2018, the monthly earnings limit for legally blind workers is $1,970.

Education

The federal **Individual with Disabilities in Education Act** ("IDEA") does not use the phrase legal blindness anywhere in the law. Instead, it defines visual impairment broadly as "...an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness." Because homonymous hemianopia can have a profound effect on a child's educational performance, including as described in this guide, children with homonymous hemianopia should be identified as visually impaired under the IDEA.

For purposes of receiving educational materials, the **Federal Act to Promote the Education of the Blind** was enacted by Congress in 1879. This act provides adapted educational materials to eligible students who meet the definition of blindness under that law. It requires the student to register annually so that the government can determine a per capita amount of money designated for the purchase of educational materials produced by the American Printing House for the Blind.

To register, the child's eye care provider must designate that the child meets the definition of blindness under the act or functions at the definition of blindness. To meet the definition of blindness, the peripheral field must so contracted that the widest diameter of such field subtends an angular distance no greater than 20 degrees. To function at the definition of blindness, the child's visual performance reduced by brain injury or dysfunction when visual function meets the definition of blindness as determined by an eye care specialist or neurologist. Both designations are appropriate for a child with homonymous hemianopia. More information, including forms for the eye care professional, are available at federal quota information page of the American Printing House for the Blind's website at http://www.aph.org/federal-quota.

Driving

Each state's driving laws define visual impairment in different ways. Approximately half the states in the U.S. prohibit a person with homonymous hemianopia from driving and many countries outlaw it altogether. This is primarily due to the **importance of a wide field of view** when driving, particularly at intersections. Although persons with homonymous hemianopia may scan their missing visual field, research has shown that they often **do not scan far enough** to detect pedestrians or cars entering the intersection. Check your department of motor vehicle's website for further information.

HELPFUL PRODUCTS AND RESOURCES

E.Z.C. Reader Strips™ – feature a tinted transparent "window" that helps pop print into view. Dark area helps block distractions surrounding targeted words, so eyes are easily guided to the desired print.

Hemianopsia.net: Comprehensive online resource to understand hemianopia and related challenges.

Highlight reading strips – flexible, transparent colored strips that highlight the line the student is reading while blocking out the line below.

Rummel Hemianopsia Buttons– Worn on clothing, the buttons remind anyone interacting with the child that they have challenges with their right or left side.

Rummel Hemianopsia Guides – Helps increase reading speed and comprehension. Without the guide, those with field loss or neglect will often leave off part of a line and miss or change the meaning of the sentence. With the guide, one reads until coming to the stop or returns back until the go barrier.

The Little Room® is an environment for babies and small children with multiple disabilities, including visual impairments, that allows the child to play and explore without distraction or interference. You can order a Little Room online or build one yourself. Activelearningspace.org and www.liliworks.org

Books, Websites, and Guides

Vision and the Brain: Understanding Cortical Vision Impairment In Children by Amanda Hall Lueck and Gordon N. Dutton is a unique and comprehensive sourcebook geared especially to professionals in the field of visual impairment, educators, and families who need to know more about the causes and types of cortical vision impairment and the best practices for working with affected children. Expert contributors from many countries represent education, occupational therapy, orientation and mobility, ophthalmology, optometry, neuropsychology, psychology, and vision science, and include parents of children with CVI.

Bookshare is a website with accessible e-books for people with print disabilities.

Hemianopsia.net is a great website with extensive information about homonymous hemianopia and coping mechanisms.

American Foundation for the Blind enables access, promotes and delivers technological solutions, and collaborate with the vision loss community to provide resources that inform and enlighten.

Lighthouse Guild is the leading not-for-profit vision and healthcare organization, with a long-standing heritage of addressing the needs of people who are blind or visually impaired, including those with multiple disabilities or chronic medical conditions.

LIlliworks is a website which sells Active Learning toys for children with multiple, significant disabilities including deaf blindness. Includes **The Little Room** and **Resonance Board** which offer.

Perkins School for the Blind E Learning is an excellent online resource with information for parents, educators, and aligned professionals who work with children with visual impairments.

Professional Organizations

Association for the Education and Rehabilitation of the Blind and Visually Impaired is the professional organization for TVIs, orientation and mobility specialists, and all other professionals providing instruction and supports for students with visual impairments.

North American Neuro-Ophthalmology Society is a professional organization of more than 600 members who are fully trained ophthalmologists or neurologists. It seeks to promote the field of neuro-ophthalmology by supporting all forms of education, encouraging research, fostering clinical expertise and maintaining cordial exchanges. You can search for a neuro-ophthalmologist in your area on this website.

College of Optometrists In Vision Development provides board certification for optometrists and vision therapists who are prepared to offer state-of-the-art services in behavioral and developmental vision care, vision therapy, and neuro-optometric rehabilitation.

American Association for Pediatric Ophthalmology and Strabismus is a professional organization. “Find a Doctor” can help you locate a pediatric ophthalmologist in your area. www.aapos.org

Pediatric Cortical Visual Impairment Society is a group of professionals and parents of children with cortical vision impairment. www.pediatriccvisociety.org

Texas School for the Blind and Visually Impaired - Low vision service provider directory list of clinical low vision service providers for the US and Canada. www.tsbvi.edu

Eye Wiki is a website where ophthalmologists, other physicians, patients and the public can view articles written by ophthalmologists covering the vast spectrum of eye disease, diagnosis and treatment.

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