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Visual Impairment, Including Blindness



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Disability Fact Sheet 13 (FS13) A legacy resource from NICHCY Links updated, July 2015

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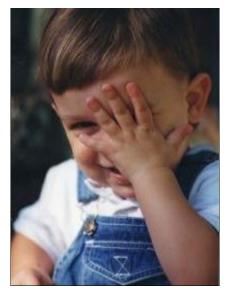
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Julian's Story

When Julian was almost two years old, he developed this adorable habit of closing one eye when he looked at you. It almost seemed as if he were winking. The possibility that Julian had a visual impairment didn't initially occur to his parents, but when Julian's right eye started crossing inward toward his nose...

Off they went to the eye doctor, who confirmed that, yes, Julian had a visual impairment—*amblyopia*, often called "lazy eye." As the most common cause of vision problems in children, amblyopia is the medical term used when vision in one eye is reduced because that eye and the brain are not working together properly. (1) Julian was also very farsighted, especially in the eye he'd taken to closing.

Soon Julian had a brand-new pair of durable glasses suited to his active two-year-old self. The eye doctor also put an eyepatch over Julian's better eye, so that he would have to *use* the weaker eye and strengthen its communication with the brain. Otherwise, the eye doctor said, the brain would begin to ignore the images sent by the weaker eye, resulting in permanent vision problems in that eye.

Julian took good care of his glasses, but he didn't take well to the patch, unfortunately. He ripped it off every time his parents put it on...and back on... and back on again. So today his eye still turns inward if he doesn't wear his glasses.

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Visual Impairments in Children

Vision is one of our five senses. Being able to see gives us tremendous access to learning about the world around us—people's faces and the subtleties of expression, what different things look like and how big they are, and the physical environments where we live and move, including approaching hazards.

When a child has a visual impairment, it is cause for immediate attention. That's because so much learning typically occurs *visually*. When vision loss goes undetected, children are delayed in developing a wide range of skills. While they can do virtually all the activities and tasks that sighted children take for granted, children who are visually impaired often need to learn to do them in a different way or using different tools or materials. (2) Central to their learning will be touching, listening, smelling, tasting, moving, and using whatever vision they have. (3) The assistance of parents, family members, friends, caregivers, and educators can be indispensable in that process. More will be said about this in a moment.

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Types of Visual Impairment

Not all visual impairments are the same, although the umbrella term "visual impairment" may be used to describe generally the *consequence* of an eye condition or disorder.

The eye has different parts that work together to create our ability to see. When a part of the eye doesn't work right or communicate well with the brain, vision is impaired.

To understand the particular visual impairment a child has, it's helpful to understand the anatomy of the eye and the functions of its different parts. Rather than go into those details here, in this general fact sheet, we're pleased to refer you to the experts for easy-to-understand explanations and diagrams of the visual system.

National Eye Institute |

Visit the Institute online for a diagram of the eye, what different parts are called, and what aspect of vision each part is responsible for. http://www.nei.nih.gov/health/eyediagram/index.asp

Most of us are familiar with visual impairments such as near-sightedness and far-sightedness. Less familiar visual impairments include:

- strabismus, where the eyes look in different directions and do not focus simultaneously on a single point;
- **congenital cataracts**, where the lens of the eye is cloudy;
- retinopathy of prematurity, which may occur in premature babies when the light-sensitive retina hasn't developed sufficiently before birth;
- **retinitis pigmentosa**, a rare inherited disease that slowly destroys the retina;
- **coloboma**, where a portion of the structure of the eye is missing;
- optic nerve hypoplasia, which is caused by underdeveloped fibers in the optic nerve and which affects depth perception, sensitivity to light, and acuity of vision; and
- cortical visual impairment (CVI), which is caused by damage to the part of the brain related to vision, not to the eyes themselves.

There are also numerous other eye conditions that can cause visual impairment. For a more comprehensive glossary of conditions, here are two resource pages you'll find helpful:

American Foundation for the Blind

http://www.afb.org/section.aspx?FolderID=2&SectionID=93

American Academy of Pediatrics

http://www.healthychildren.org/English/health-issues/conditions/eyes/pages/Specific-Eye-Problems.aspx

Because there are many different causes of visual impairment, the *degree* of impairment a child experiences can range from mild to severe (up to, and including, blindness). The degree of impairment will depend on:

- the particular eye condition a child has;
- what aspect of the visual system is affected (e.g., ability to detect light, shape, or color; ability to see things at a distance, up close, or peripherally); and
- how much correction is possible through glasses, contacts, medicine, or surgery.

The term "blindness" does not necessarily mean that a child cannot see anything at all. A child who is considered legally blind may very well be able to see light, shapes, colors, and objects (albeit indistinctly). Having such residual vision can be a valuable asset for the child in learning, movement, and life.

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Signs of a Visual Impairment

It's very important to diagnose and address visual impairment in children as soon as possible. Some vision screening may occur at birth, especially if the baby is

born prematurely or there's a family history of vision problems, but baby wellness visits as early as six months should also include basic vision screening to ensure that a little one's eyes are developing and functioning as might be expected.

That said, common signs that a child may have a visual impairment include the following.

Eyes that don't move together when following an object or a face

Crossed eyes, eyes that turn out or in, eyes that flutter from side to side or up and down, or eyes that do not seem to focus

Eyes that bulge, dance, or bounce in rapid rhythmic movements

Pupils that are unequal in size or that appear white instead of black

Repeated shutting or covering of one eye (as noticed with Julian)

Unusual degree of clumsiness, such as frequent bumping into things or knocking things over

Frequent squinting, blinking, eye-rubbing, or face crunching, especially when there's no bright light present

Sitting too close to the TV or holding toys and books too close to the face

Avoiding tasks and activities that require good vision (4)

If any of these symptoms are present, parents will want to have their child's eyes professionally examined. Early detection and treatment are very important to the child's development.

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How Common are Visual Impairments?

Very common, especially as we grow older. But there are many causes of visual impairments that have nothing to do with the aging process, and children certainly can be—and are—affected. In the U.S., there are approximately:

- 490,420 children with vision difficulty (the term "vision difficulty" refers only to children who have serious difficulty seeing even when wearing glasses and those who are blind.) (5)
- 42,000 children with a severe vision impairment (unable to see words and letters in ordinary newsprint) (6)
- 59,341 children who are legally blind (7)

Each year States must report to the U.S. Department of Education how many children with visual impairments received special education and related services in our schools under the Individuals with Disabilities Education Act (IDEA), the nation's special education law. Data reported in 2011 (for the school year 2010) indicate that the following numbers of children were served in the U.S. and its outlying areas:

- 3,447 children (ages 3-5) with visual impairment (8)
- 25,670 children (ages 6-21) with visual impairment (9)

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Understanding How Children with Visual Impairments Learn

Children with visual impairments can certainly learn and do learn well, but they lack the easy access to visual learning that sighted children have. The enormous amount of learning that takes place via vision must now be achieved using other senses and methods.

Hands are a primary information-gathering tool for children with visual impairments. So are the senses of smell, touch, taste, and hearing. Until the child holds the "thing" to be learned and explores its dimensions—let us say, a stuffed animal, a dog, a salt shaker, or a CD player —he or she cannot grasp its details. That is why **sensory learning** is so powerful for children with visual impairment and why they need to have as many opportunities as possible to experience objects directly and sensorially.

Families, friends, and others can *support sensorial learning* in many ways.

"Do you smell dinner?" appeals to the child's sense of smell.

"Listen to that bird singing outside" calls to the child's hearing. "That's a robin" gives the child a name for the bird that sings the song he or she is hearing.

"Isn't the bunny soft? And feel how long his ears are!" speaks to the child's sense of touch and helps the child build a picture of the "whole" from the many

details. (10)

Being able to see enables us to capture the "whole" of an object immediately. This isn't so for children with a visual impairment. They cannot see the "whole," they have to work from the details up to build an understanding of the whole.

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The Help Available under IDEA

If you suspect (or know) that your child has a visual impairment, you'll be pleased to know there's a lot of help available under IDEA—beginning with a *free evaluation* of your child. IDEA requires that all children suspected of having a disability be evaluated without cost to their parents to determine if they do have a disability and, because of the disability, need special services under IDEA. Those special services are:

Early intervention | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families.

Special education and related services | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).

Visual impairment, including blindness, is one of the disabilities specifically mentioned and defined in IDEA. If a child meets the definition of visual impairment in IDEA as well as the State's criteria (if any), then he or she is eligible to receive early intervention services or special education and related services under IDEA (depending on his or her age).

To identify the EI program in your neighborhood

Ask your child's pediatrician for a referral. You can also call the local hospital's maternity ward or pediatric ward, and ask for the contact information of the local early intervention program.

Accessing special education and related services

If your child is between 3 and 21 years of age, we recommend that you get in touch with your local public school system. Calling the public school in your neighborhood is an excellent place to start. The school should be able to tell you the next steps to having your child evaluated free of charge. If found eligible, your child can begin receiving services specially designed to address his or her educational needs and other needs associated with the disability.

Developing a written plan of services

In both cases—in early intervention for a baby or toddler with a visual impairment and in special education for a school-aged child, parents work together with

program professionals to develop a plan of services the child will receive based on his or her needs. In early intervention, that plan is called the *IFSP* (individualized family service plan). In special education, the plan is called the *IEP* (individualized education program). Parents are part of the team that develops their child's IFSP or IEP.

There's a lot to know about early intervention for infants and toddlers with disabilities and about special education and related services for school-aged children. Find out more about these crucial services for eligible children with visual impairments, beginning at:

- Early intervention | http://www.parentcenterhub.org/repository/babies/
- Special education and related services | http://www.parentcenterhub.org/repository/schoolage/

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How IDEA Defines Visual Impairment

IDEA provides the nation with definitions of many disabilities that can make children eligible for special education and related services in schools. *Visual impairment* is one such disability the law defines—as follows:

Visual impairment including blindness...

...means an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness. [§300.8(c)(13)]

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Working with the Medical Community

If you have a child with a visual impairment, you'll probably find yourself dealing with a variety of eye care professionals who become involved to diagnose and address your child's specific disability or eye condition. Wondering who these professionals might be, what qualifications they should have, and what kind of expertise they can bring to your child's care?

Family Connect is an excellent source of this information. Family Connect is an online, multimedia community created by the American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI). We suggest you download (or read online) Family Connect's

toolkit called *Working with Medical Professionals*. The toolkit is available online in English and Spanish, at: http://www.familyconnect.org/info/after-the-diagnosis/working-with-medical-professionals/13

Need a glossary? Becoming familiar with medical terminology relating to the visual system may also prove helpful, especially when talking to medical professionals and reading about your child's impairment. If you're baffled by the terms you hear, visit the *Glossary of Eye Terminology*, which lists common terms that eye doctors use when discussing symptoms, tests, treatments, surgery, diseases and conditions, and the anatomy of the eye. The glossary's online at: http://www.eyeglossary.net/

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Adapting the Environment

Making adaptations to the environment where a child with a visual impairment lives, works, or plays makes evident sense, but it may be difficult for families, daycare providers, or school personnel to decide *what* kinds of adaptations are necessary to ensure the child's safety while also encouraging his or her ability to do things independently.

Two resources you can consult, depending on your role in the child's life, are:

Family Connect | *Adapting Your Home* http://www.familyconnect.org/info/browse-by-age/infants-and-toddlers/parenting-and-family-life-iandt/adapting-your-home/1235

IRIS Center | Offers a professional development module for teachers called *Accommodations to the Physical Environment: Setting up a Classroom for Students with Visual Disabilities*.

http://iris.peabody.vanderbilt.edu/module/v01-clearview/

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Educational Considerations

Children with visual impairments need to learn the same subjects and academic skills as their sighted peers, although they will probably do so in adapted ways. They must also learn an expanded set of skills that are distinctly *vision*-related, including learning how to:

- **move** about safely and independently, which is known as *orientation and mobility* (O&M);
- use **assistive technologies** designed for children with visual impairments;
- use what **residual vision** they have effectively and efficiently; and
- read and write in **Braille**, if determined appropriate by the IEP team of the child after a thorough evaluation. (11)

These are just some of the skills that need to be discussed by the student's IEP team and included in the IEP, if the team decides that's appropriate. Each of the above skill areas—and more—can be addressed under the umbrella of special education and related services for a child with a visual impairment.

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Tips for Teachers

-Learn as much as you can about the **student's** *specific* **visual impairment**. What aspects of vision are affected, and how does that affect the student's ability to move about the classroom, see the board, or read a textbook? Parents (and the student!) can be an excellent source of this information.

- Learn about the many **instructional and classroom accommodations** that truly help students with visual impairments learn. We've listed a few in the resource section. Strongly support the student by making sure that needed accommodations are provided for classwork, homework, and testing. These will help the student learn successfully.

-If you are not part of the student's IEP team, **ask for a copy of his or her IEP**. The student's educational goals will be listed there, as well as the services and classroom accommodations he or she is to receive.

-Consult with others (e.g., special educators, the O&M specialist) who can help you identify strategies for teaching and supporting this student, ways to adapt the curriculum, and how to address the student's IEP goals in your classroom.

-Find out if **your state or school district** has materials or resources available to help educators address the learning needs of children with visual impairments. It's amazing how many do!

-Communicate with the student's parents. Regularly share information about how the student is doing at school and at home.

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Tips for Parents

-Learn as much as you can about your child's specific visual impairment. The more you know, the more you can help yourself and your child.

-Understand that your child is **receiving small bits of information at a time**, not all at once through vision. Help your child explore new things with his or her senses and build up a concept of the "whole." For example, your child might need to be shown a banana, help you peel it, feel the banana without its skin, have a bite of it, and then help you mash it in her bowl to understand the qualities of bananas and that bananas can be eaten in different ways. (12)

-Encourage curiosity and explore new things and places often with your child. Give lots of opportunity to touch and investigate objects, ask questions, and hear explanations of what something is, where it comes from, and so on.

-Learn how to **adapt your home**, given the range and degree of your child's visual impairment. Help your son or daughter explore the house and learn to navigate it safely.

-Encourage your child's **independence** by letting him or her do things, rather than you doing them. Teach how to do a chore by using hands-on guidance, give lots of practice opportunities with feedback. Now, your child knows the skill, too.

-Work with the early interventionists or school staff (depending on your child's age) to build a solid individualized plan of services and supports that address your child's unique developmental and educational needs.

-**Talk to other parents** of children who have visual impairments similar to your child's. They can be a great source of support and insight in the challenges and joys of raising a child with vision problems. Many of the organizations we've listed in the Resources section have state or local chapters you can contact. You can also visit **Parent to Parent**, which specializes in teaming new parents up with veteran parents of children with similar disabilities. P2P is online at: http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx

-Keep in touch with the professionals working with your child. Offer support. Demonstrate any assistive technology your child uses and provide any information teachers will need. Find out how you can augment your child's learning at home.

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Resources of More Information

In alphabetical order, here's a starter list of organizations providing info on visual impairments, including blindness. Explore the sites below and the wealth of material they offer to families, services providers, and educators. We also include helpful resources and accessible materials for those with visual impairments.

Organizations to Consult

American Council of the Blind 800.424.8666 | http://www.acb.org

American Foundation for the Blind Find services in your state right on the home page. 800.232.5463 | http://www.afb.org

American Printing House for the Blind 800.223.1839 | http://www.aph.org/

Association for Macular Diseases http://www.macula.org/

Family Connect http://www.familyconnect.org/parentsitehome.asp (English) http://www.familyconnect.org/parentsitehome.asp?lang=esp (Spanish)

Foundation Fighting Blindness Find your state chapter right on the home page. 800.683.5555 | 800.683.5551 (TTY) http://www.blindness.org/

Lighthouse Guild 800.284.4422 | http://www.lighthouseguild.org/

National Braille Association http://www.nationalbraille.org/

National Braille Press

888.965.8965 | http://www.nbp.org

National Federation of the Blind http://www.nfb.org/

National Library Service for the Blind and Physically Handicapped, Library of Congress http://www.loc.gov/nls/

National Eye Institute, National Institutes of Health http://www.nei.nih.gov/ (English) http://www.nei.nih.gov/health/espanol/index.asp (Spanish)

Prevent Blindness America 800.331.2020 | http://www.preventblindness.org

Accessible Materials

Bookshare | For those with print disabilities, including visual impairments or blindness. Offers free membership to qualified U.S. students and schools, and makes more than 169,000 titles available digitally. https://www.bookshare.org/

Learning Ally | For those cannot read standard print. Offers more than 80,000 digitally recorded textbooks and literature titles for download. Formerly Recording for the Blind and Dyslexic. 800.221.4792 | http://www.learningally.org/

LOUIS | Database of info on more than 386,000 titles in accessible formats, including braille, large print, sound recording, and electronic files. http://louis.aph.org

National Center on Accessible Educational Materials (AIM) | Excellent info for educators and families on getting AEM for students with visual impairments, blindness, or other print disabilities. http://aem.cast.org/

Other Helpful Resources

Resources for Living | Entire section of NFB's website that includes state and local connections for areas of life such as: aids and appliances, Braille, closed circuit TVs, guide dog schools, low vision, and technology. http://www.nfb.org/living

Education for Students with Blindness or Visual Impairment | Entire section of Perkins School for the Blind's website.

http://www.perkins.org/resources/scout/education/

Are You the Parent of a Blind Child? http://www.acb.org/node/392

AEM Navigator

The AEM Navigator is an interactive tool that facilitates the process of decision-making around accessible instructional materials for an individual student. http://aem.cast.org/navigating/aem-navigator.html#.Vs9ghZ5VhBc

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3 | American Foundation for the Blind. (2011). *What's different about the way visually impaired children learn?* Retrieved September 24, 2012 from the Family Connect website: http://www.familyconnect.org/parentsite.asp?SectionID=75&TopicID=351&DocumentID=3880

4 | Zundel, I.H. (n.d.). *Signs of possible vision problems in toddlers*. Retrieved September 24, 2012 from the EduGuide website: http://www.eduguide.org/library /viewarticle/932/

5 | American Foundation for the Blind. (2012, January). *Children and youth with vision loss*. New York: Author. Online at: http://www.afb.org /section.aspx?SectionID=15&TopicID=411&DocumentID=4896 6 | Lighthouse International. (n.d.). Prevalence of visual impairment. No longer available online.

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