



4th to
12th
Grade

Getting Started

A Guide for Families New to Blindness and Low Vision

APH FamilyConnect®

Welcome to Getting Started

Hello,

Welcome to Getting Started: For Families New to Blindness and Low Vision. This booklet can help support you in any stage of your journey, whether you have concerns about your child's vision, your child was recently diagnosed with an eye condition, or you're familiar with your child's eye condition.

This booklet will provide information about:

- vision in children
- various professionals who may be part of your child's team and their role
- navigating an Individual Education Plan (IEP)
- resources specific to your state
- supportive agencies and support groups
- considerations and resources for parenting a school-aged child who is blind or low vision
- technology
- additional resources

[APH FamilyConnect®](#) intends to continue to provide support beyond our Getting Started booklet. APH ConnectCenter® provides webinars, blogs, and articles with the most current information to best support your needs.

We also hope to provide opportunities for you to connect with others so you can continue to grow your support network. We want to support your needs and welcome you to reach out and provide feedback and suggestions. Contact us via the APH Information & Referral Line (800.232.5463) or at connectcenter@aph.org.

We look forward to supporting you and your child.



Your Journey: You're not alone

According to the Centers for Disease Control Vision Health Initiative's [Fast Facts About Vision Loss](#) (2020), approximately 6.8% of children under 18 in the United States have a diagnosed eye or vision condition. Nearly three percent of children under 18 are blind or have low vision, defined as having trouble seeing even when wearing glasses or contact lenses.

Though many other families have children who are blind or low vision, your story is unique to you! Learning about your child's eye condition, finding support systems and groups, and learning about specific providers and their roles in your child's growth, development, and education will help you and your child along your journey.

School-Aged Children 6 to 18 Years of Age



A child's eyes are constantly used in the classroom and at play. When their vision is not functioning correctly, it can impact their education and participation in sports.

Common demands on school-aged children include reading, writing, chalkboard/whiteboard work, and using computers. Various resources offer helpful ideas and tips to support your child in these tasks.

Resources for families and teachers include the [APH FamilyConnect](#), [Perkins Paths to Literacy](#), [Teaching Students with Visual Impairments](#), and [School-Aged Vision: 6 to 18 Years of Age](#).



The following are vision skills utilized in traditional reading and learning:

- **Eye focusing** the ability to keep objects focused as the distance from objects change
- **Eye-hand coordination** the ability to use visual information for motor planning, such as when coloring a picture or reaching for a glass of water
- **Eye tracking** the ability to use the eyes to follow an object that moves, like a rolling ball, or to move the eyes to follow something like a line (or page) of text
- **Eye teaming** the ability to use both eyes together for visual tasks
- **Visual perception** the ability to discriminate two-dimensional images on a printed page and recognize individual letters, words, and pictures and how they relate to other items on the page

Talk with your pediatrician about an evaluation from an eye care provider.

A child's vision can change frequently; they should have yearly eye exams or as recommended by your child's eye doctor.

The [American Optometric Association's School-Aged Vision: 6 to 18 Years of Age](#) provides lists of behaviors that might indicate your child has vision needs. If you suspect your child is having challenges with their vision or notice the following, talk with your child's doctor:

- If your child holds items close to their face for viewing and/or reading
- If your child says their eyes are tired and/or frequently rubs their eyes
- If your child avoids visual tasks at school
- If your child complains of blurred vision
- If your child has red or discolored eyes



- If your child turns or tilts their head or covers one eye when looking at objects or reading material up close
- If your child becomes tired after using their near vision – for example, reading, drawing, or playing handheld games
- If your child seems to see better during the day than at night
- If your child seems to have crossed or turned eyes or a squint
- If your child seems clumsy – for example, they might knock things over or trip often

Types of Eye Care Providers

Many different professionals can support eye health. It is important to make sure you are seeing the most appropriate provider for your child's needs. Ask your pediatrician and/or your eye care provider for a referral to the most appropriate specialist(s).

Types of eye care providers and specialists include:

- **Cornea specialist** a specialist who diagnoses and treats corneal eye conditions. They can perform surgeries like corneal transplantation and refractive surgery.
- **Glaucoma specialist** a specialist who treats the eye condition glaucoma—where excess fluid puts pressure on the eye, causing damage to the optic nerve
- **Neuro-ophthalmologist** an ophthalmologist who specializes in vision problems related to how the eye communicates with the brain, nerves, and muscles
- **Ophthalmologist** a professional who provides medicine and surgery. Ophthalmologists are specialized medical doctors who may choose a subspecialty.

- **Optician** a technician trained to design and fit eyeglass lenses and frames, contact lenses, and other devices to correct a person's eyesight
- **Optometrist** a professional who provides primary vision care. These professionals conduct eye exams and vision tests, prescribe and dispense corrective lenses, and detect certain eye irregularities.



- **Pediatric ophthalmologist** an ophthalmologist who treats infants and children with childhood eye conditions
- **Retina specialist** a specialist who can diagnose and treat retinal eye conditions. This may involve surgically repairing torn or detached retinas.

Types of Service Providers

In addition to eye care providers, a variety of service providers can support the educational needs and functional living skills of children who are blind or have low vision. While not an exhaustive list, service providers may include the following:

- **Certified Low Vision Therapist (CLVT)** a university-trained professional with knowledge of low vision and optical devices. Like a Teacher of Students with Visual Impairments, these professionals conduct functional low vision evaluations to assess your child's visual fields, color vision, visual-motor functioning, and visual skills for activities like reading, writing, and math.



- **Low Vision Specialist** an ophthalmologist or optometrist who has completed additional training and certification in the area of low vision and can provide a clinical low vision evaluation or low vision assessment to determine if there are optical, non-optical, and/or non-visual devices that will help a child perform distant, intermediate, and near tasks more efficiently. For example, they can provide special high-magnification glasses for watching TV, prescription sunglasses, a reading stand and bold-line paper, magnifiers, monoculars, or video magnifiers.

- **Orientation and Mobility (O&M) Specialist** a university program-trained professional who teaches students who are blind or low vision the techniques for moving about the school environment and community safely, efficiently, and independently.
- **Teacher of Students with Visual Impairments (TVI)** the central figure on the educational team for your child with blindness or low vision. This is the professional with expertise in how eye conditions affect your child's development and learning, as well as the strategies and tools that can help your child learn about the world, perform everyday activities, and participate in the general curriculum and other activities in school.



- **Vision Rehabilitation Therapist (VRT)** a professional who teaches activities of daily living (i.e., cleaning and organizing clothing, cooking, household chores, etc.) with particular emphasis on adaptive skills used by people who are blind or low vision.
- **Vocational Rehabilitation Counselor (VR)** a professional who can help a student or adult obtain the services needed to find work or continue working.



Understanding Terms in Education and Services

Your child's educational team, with you as an integral member, will support your child through their schooling years. Understanding the following education terms and procedures as you plan for your child's individualized education will be helpful.

- **Clinical Low Vision Evaluation (CLVE)** assesses if your child will benefit from prescribed optical devices such as a magnifier, telescope, or electronic magnification device. This assessment may be performed by a low-vision optometrist or a university-trained professional with knowledge of low vision and optical devices. They specialize in helping individuals with limited visual abilities optimize their remaining vision.

The clinical low vision evaluation differs from the evaluation of the eye care specialist in many ways. The Low Vision

Specialist uses special charts and materials for assessment of distance and near vision acuity that are not routinely used in general eye examinations. It goes beyond the prescription of standard spectacles to provide optical, non-optical, and/or non-visual devices to help individuals meet their specific visual needs for distance, intermediate, and near activities.

- **Disabled Student Services (DSS)** an office on a post-secondary education campus that works with students to arrange for the disability-related services needed to access their education. Students are not required to use these services. Students must be proactive in working with DSS offices to determine what accommodations they will need; the process and philosophy differ greatly from that used by elementary and high schools.
- **Expanded Core Curriculum Skills (ECC)** a set of nine instructional areas designed to support children who are blind or low vision in optimizing their independence and participation in their classrooms and communities. The ECC skills include compensatory access, sensory efficiency, assistive technology, orientation and mobility, independent living, social interaction skills, recreation and leisure, career education, and self-determination.





- **Individualized Education Plan (IEP)** a plan to support your child's success in a public education setting. After evaluating your child, the educational team will devise an IEP stating goals for your child, special education services and their frequency, and accommodations to set in place.
- **Individualized Service Plan (ISP)** supports access to services for children with disabilities in non-public school educational settings.
- **Pre-Employment Transition Services (Pre-ETS)** career exploration activities to help students with disabilities develop the skills and knowledge they need to succeed in the workplace. Working with your local Pre-ETS provider can help you develop a plan for your child that meets their needs and strengths. This plan can help your child get the most out of their school opportunities and transfer those skills to real-world work experiences.
- **Transition** the bridge from high school to independent living, job or employment, or further education. The team will develop goals to support your child's plan.

Transition Goals: all children with IEPs during their transition years focus on three goals:

- **Independent Living** Transition goals include preparing your child for living with as little support as necessary. Instruction may include money management, time management, cooking skills, and problem-solving skills. Independent living may also include hobbies, travel, social and technology skills.





- **Post-Secondary Education Preparation** Transition goals include helping your child prepare for future education. Your child may attend a trade school or pursue a traditional college education after high school. Your child will learn their options for post-secondary education, research different degree programs, prepare for campus life, and learn how to work with the campus office of Disabled Student Services.
- **Work Readiness** Your child will learn the skills needed to earn an income. These skills may include time management, organizational skills, social skills, discovering areas of strengths or interests, and developing work adaptations to help them be successful in a job or volunteer position.



- **Vocational Rehabilitation Services (VR)** an agency providing support to eligible individuals with disabilities, including those who are blind or low vision as well as those who have additional or multiple disabilities. They provide job training, employment resources, assistive technology, and/or other services to help individuals keep their jobs, re-enter employment in the same or different path, and provide services and training necessary for career advancement.
- **Workforce Information Opportunity Act (WIOA)** a federal law that provides funding for workforce development programs. These programs can provide a variety of services to help job seekers, including career exploration, training, and paid and unpaid work experiences.

Get Connected with Support



Your child's education team doesn't have to be your only source of support. Below are agencies and resources that can help you on your journey.

- **[American Council for the Blind](#)** You're not alone in navigating low vision and blindness. The American Council of the Blind (ACB) welcomes and accepts you. Guided by its members, ACB advocates for the equality of people who are blind or have low vision, inspires community, and connects members with education, resources, and each other to support your independence.
- **[APH FamilyConnect](#)** is a service offered by the American Printing House for the Blind (APH) to give parents and other family members of children who are blind or low vision—and professionals who work with them—a supportive place for sharing and finding resources on raising their children from birth to adulthood. Every parent wonders, "Will I do a good job raising my child?" If your child is blind or low vision, you'll have the same question...and many more.

APH FamilyConnect has answers. Whether your child has a recent diagnosis, has been living with blindness or low vision for years, or has multiple disabilities, you'll find the personal support, information, and resources you need.

- **[APH FamilyConnect ParentConnect](#)** is a family support group in partnership with The Chicago Lighthouse's Virtual Parent Support Group. APH FamilyConnect and The Chicago Lighthouse offer a virtual support group for parents and families of children who are blind or low vision. These monthly sessions allow families to connect with and learn from each other over the joys, challenges, and adventures of raising children who are blind or have low vision. Call 800-232-5463 for more information or register for the meetings [HERE](#).
- **[APH Information & Referral Hotline](#)** The I&R Line is a toll-free APH ConnectCenter phone line: 1-800-232-5463. The I&R line is staffed from 8 a.m. to 8 p.m. Eastern time. Questions emailed to are answered as quickly as possible.
- **[APH ConnectCenter Transition Hub](#)** Visit the one-stop resource for transition programs nationwide. Transition services help students with disabilities transition into adulthood. You can search for programs by state and program season (i.e., summer, fall, year-round, etc.). Additionally, you can search by whether programs are free or offered for a fee.



- **[APH CareerConnect®](#)** is an employment information resource offered by the American Printing House for the Blind. It provides employment information, career exploration tools, and job-seeking guidance for individuals who are blind or low vision and the professionals who work with them.
- **[National Organization of Parents of Blind Children](#)** Early literacy and high expectations for our children are best achieved when supported by the triad of home, community, and educator. The National Organization of Parents of Blind Children welcomes parents, relatives, educators, blind adults, and others interested in promoting opportunities for blind children.
- **[National Federation for the Blind \(NFB\)](#)** coordinates many programs, services, and resources to defend the rights of blind Americans, provide information and support to blind children and adults, and build a community that creates a future full of opportunities.

Considerations and Resources for Parenting a School-Aged Child Who is Blind or Low Vision

Chores (Cleaning, Cooking) You can help prepare your child for adult life by expecting them to help with household chores. For tips and examples of teaching a variety of household cleaning skills, please visit: [Carmen Willings' article on Teaching Students with Visual Impairments](#).

Home Adaptations Adapting your home can be overwhelming and seem like a tremendous job. Accessible home modifications make your home safer and better suited for your child’s unique needs. You and your child can modify areas of your home to ensure accessibility and safety for your child. Implementing most modifications is relatively easy and inexpensive.

Traveling with Independence Orientation and Mobility (O&M) is the area of the ECC where a child with blindness or low vision learns to travel safely and efficiently. Orientation refers to knowing where you are and where you are going. Mobility refers to moving safely and effectively through the environment. The following content will help you support your child’s O&M skills.

- [Creating a DIY Tactile Map for Your Child or Teen Who Is Blind or Low Vision](#)
- [Helping Your Child Who Is Blind or Low Vision Get Oriented to a New School Building](#)
- [Mobility Devices for Young Children](#)
- [“Never Eat Soggy Waffles”: How to Master Cardinal Directions](#)
- [Orientation and Mobility Activities for Families of Children Who Are Blind or Low Vision](#)
- [Orientation and Mobility for Blind Grade Schoolers](#)
- [Orientation and Mobility for Teenagers Who are Blind or Have Low Vision](#)
- [Orientation and Mobility for Teens with Recent Blindness or Low Vision](#)

If you’re interested in learning how O&M training is approached and how you can support your child’s development of independent travel skills, take a look at APH ConnectCenter FamilyConnect’s [O&M articles](#) by age.



Technology

Technology is ever-changing and developing at a rapid rate. The list below is a sampling of technology available for individuals who are blind or low vision. For more information, please visit the APH website.

Apps for Smartphones and/or Tablets

- [Be My Eyes](#) a free mobile app that connects individuals who are blind and low-vision with sighted volunteers and companies worldwide through a live video call. It is available for iPhone and Android. Please keep in mind that the video starts once a volunteer answers; therefore, this app is suitable for adults over 18. You may want to help your child learn how to use the resource safely.

- **BlindSquare** the most widely used accessible GPS app developed for individuals who are blind, deafblind, and low vision. BlindSquare's self-voicing app delivers detailed points of interest and intersections for safe, reliable travel both outside and inside.
- **Clew** a mobile app that records a path and guides the user back to their starting location with voice directions, sound effects, and haptic feedback. When one walks to a location, the phone keeps track of its path with a series of virtual crumbs. Available on Android and Apple Devices.
- **GoodMaps Explore** an accessible indoor and outdoor navigation app.
- **GoodMaps Outdoors** a turn-by-turn GPS app for iPhone and Android. It has all the outdoor navigation features you expect, plus unique offerings you cannot get anywhere else.
- **Key2Access** an alternative way to open the door that is truly accessible for persons who are blind or low vision with reduced mobility. OpenUp eliminates the need to touch the door or push buttons which can be difficult to find and/or reach. The user can conveniently open a door using a button on a device.
- **Lazarillo** provides guidance through voice messages. It will tell the user their location and nearby places of interest. Lazarillo will announce street intersections and key reference points as one moves through the city. It is available on iPhone and Android.
- **Lookout** provides details about objects, images, and text. The app uses the camera and sensors on the user's Android device to recognize objects and text. Available on Android only.

- **Seeing AI** an artificial intelligence application developed by Microsoft for iOS. Seeing AI uses the device's camera to identify people and objects and then audibly describes those objects.
- **STEP-HEAR: Accessibility in 1,2,3** provides users in an urban environment access to real-time information about transportation options. It is also used to contact the driver of public transportation, activate traffic lights, and much more. It can also be used to open doors and gates or to activate a wheelchair lift at the press of a button.
- **TapTapSee** a mobile camera application designed specifically for users who are blind or low vision and powered by the CloudSight Image Recognition API. TapTapSee utilizes a device's camera and VoiceOver functions to take a picture or video of anything and identify it.
- **what3words** an easy way to identify precise locations. Every 10-foot square has been given a unique combination of three words: a what3words address. The user can find, share, and navigate to precise locations using three simple words.



Resources for Audiobooks

- [Audiobooks.com](https://www.audiobooks.com) offers a Netflix-style subscription service with a twist. Rather than download the books, there is an option to stream them. Its feature allows you to go from one device to another (your laptop to your smartphone) without losing your place. Streaming uses less space on your devices.
- [BARD Mobile](https://www.bard.org) offers over 100,000 books, manuscripts, and music scores in audio format
- [Bookshare](https://www.bookshare.org) allows you to customize your reading experience with ebooks in audio, audio and highlighted text, braille, large font, and other formats. Access the largest library of textbooks, bestsellers, children's books, career resources, and more for people with reading barriers. Read on almost any device, including smartphones, tablets, Chromebooks, computers, and assistive technology devices. Get unlimited access: free for qualified U.S. students and schools, low annual fee for adults, and reduced fees in certain countries
- [OPEN CULTURE](https://www.openculture.com) brings together high-quality cultural and educational media for the worldwide lifelong learning community.



Assistive Technology Resources

- [**Humanware**](#) specializes in the design and manufacture of highly intuitive and intelligent solutions for people who are blind or low vision. Humanware creates electronic magnifiers, talking GPSs, and braille devices.
- [**Independent Living Aids**](#) offers low-vision aids, tools, and technology. Stay active, independent, and make life easier with the superb selection of low-vision aids, tools, and technology.
- [**MaxiAids**](#) a source for thousands of innovative products designed to assist blind, low vision, deaf, hard-of-hearing, seniors, children with special needs, veterans, and those with mobility issues.

National Mail Order Catalogs

- [**American Printing House for the Blind \(APH\)**](#) has been innovating products and technology to support people

who are blind and have low vision to independently live and learn since 1854. From everyday tools to high tech solutions, APH develops products for barrier breakers, dream believers, change makers, and access warriors!

- **Assistive Technology Services'** mission is to provide evaluation, consultation, spiritual guidance and assistive devices to make the quality of life better for those who need a little help.
- **Learning, Sight & Sound (LS&S) Products** specializes in products for individuals who are blind, low vision, deaf, and hard of hearing. You will find a great collection of low vision aids, hearing helpers, daily living aids, and information designed to help you or a loved one regain independence. Adjusting to life-altering changes can be difficult, but in the case of vision or hearing changes, LS&S can help you find useful products that will make a difference in your life.



Extra Tips for Success

Always use names Always use a blind or low vision person's first name when addressing them. Example: "Hi Joe, it's John, how are you today?"

Don't gesture, always verbalize Use positional and directional concepts like above/under, on top, next to, behind/in front of, etc. when talking to an individual with blindness or low vision. Avoid using words like here, over here, there, over there.

Additional Resources

[APH ConnectCenter's Directory of Services](#) -an extensive list of resources for families to access more information and local support. You can click the link to learn more or search by category for services available near you.

Websites

- [American Optometric Association](#)
- [APH FamilyConnect](#)
- [CVI NOW- Perkins School for the Blind](#)
- [Hadley School for the Blind](#)
- [National Eye Institute](#)
- [Paths to Literacy](#)
- [Teaching Students with Visual Impairments](#)

Videos

The following resources provide previously recorded webinars with valuable information:

- [APH ConnectCenter Recordings](#)
- [Career Conversations](#)
- [College Prep](#)



We look forward to continuing to support you as you parent your child who is blind or low vision!

References

- American Council for the Blind
- American Optometric Association [School-Aged Vision](#)
- APH FamilyConnect
- Centers for Disease Control Vision Health Initiative's [Fast Facts About Vision Loss](#) (2020)
- Council of State Administrators of Vocational Rehabilitation
- National Organization of Parents of Blind Children
- National Federation for the Blind
- Teaching Students with Visual Impairments
- U.S. Department of Education: [Transition of Students with Disabilities to Postsecondary Education: A Guide for High School Educators](#)
- Workforce Innovation and Opportunity Act

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1839 Frankfort Avenue
Louisville, Kentucky 40206
502-895-2405 • 800-223-1839
aph.org • info@aph.org