Having your child screened for these problems and others can prevent serious vision problems.

August is Children's Eye Health and Safety Month and the National Center for Children’s Vision and Eye Health at Prevent Blindness is teaming up with Family Voices National Center for Family Professional Partnership to offer free information on a variety of children’s eye health topics, from UV safety, the Affordable Care Act and children’s vision services, to general eye health.

- Visit the National Center for Children’s Vision and Eye Health at Prevent Blindness to learn more about:
  - Signs of Vision Problems in Children (English & Spanish)
  - First Aid for Eye Emergency
  - The Eye Patch Club
  - Selecting Sunglasses for Children
Vision and Children with Special Health Care Needs

Children with special needs, particularly those with Cerebral Palsy and Down Syndrome, have a greater risk of visual and eye health problems than their peers. In many cases, these children may not be able to respond to traditional measurements of visual acuity. Additionally, children within the Autism Spectrum may manifest sensory integration issues such as sensitivity to light, or aversion to new surroundings, and therefore can be considered difficult to examine and treat.

Children with special needs typically receive various interventions through their Individualized Education Plan (IEP) such as occupational, physical and/or speech therapy. However, in most cases, they do not receive a comprehensive eye and vision examination.

Frequently, those with special needs who have vision or eye health problems may not show obvious symptoms or may be unable to describe their symptoms. It is important for families to be aware of potential vision issues and have their child receive annual eye exams. Often, those involved with a child’s care may be the first to suspect a problem.

If your child with special needs has a vision problem, a pediatric eye care provider (pediatric ophthalmologist or pediatric optometrist) may provide the best help. Pediatric eye care providers are doctors who specialize in the eye care of children. All ophthalmologists and optometrists have training in children’s eye problems, but the pediatric providers have additional experience and expertise in examining children and the greatest knowledge of possible conditions that affect the pediatric patient. Find a pediatric provider on the American Association for Pediatric Ophthalmology and Strabismus website or the American Optometric Association website.

A teacher of students with visual impairments may also be helpful. This is a professional who has expertise in how visual impairment 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.

Signs and Symptoms of a Vision Problem in Children
- Head tilted - may be an indication that the child is avoiding double vision
- Pupil defect - if part of the iris is missing, it may be an outward sign of a defect of the inside of the eye
- Unequal pupils - may be a sign of nerve damage or tumor which is visible in one eye
- Tearing, discharge or redness - a sign of infection or tear duct blockage
- Eye turns inward or outward - could lead to loss of vision
- Dancing eyes - a sign of disease of the nervous system anywhere between the eyes and brain
- White pupil - this may indicate cataract, tumor inflammation, or detached retina
Lump, swelling, or drooping of lid - may be an inflammation which is an emergency if it happens suddenly and the lid is red and hot. May indicate muscle weakness or tumor causing blockage of vision.

Large cornea in one or both eyes - a sign of glaucoma in both the newborn and infant, especially when the child's eye waters and avoids light

One eye drifts or aims in a different direction than the other (look carefully - this can be subtle). This is significant even if it only occurs when the child is tired or stressed.

Squinting or closing of one eye

Excessive blinking or squinting

Poor visual/motor coordination skills (often called, "hand-eye coordination")

Problems judging distances while moving in space; frequently bumps into things or drops things

Becomes easily confused when in motion

Frequently loses things

While reading or doing close work your child:

Holds the reading material or object too close

Closes one eye or covers eye with hand

Twists or tilts head toward book or object so as to favor one eye

Uses finger or ruler to read

Frequently loses place and/or skips or repeats lines

Fatigues easily and/or becomes drowsy

Rubs eyes during or after periods of the reading or close work

Reports that words move on page or run together

Has a tendency to knock things over on a desk or table

Exhibits avoidance behaviors

Child demonstrates or reports:

Headaches or eyestrain

Nausea or dizziness

Motion sickness or car sickness

Double vision


Question: Help! School is starting. I want to make sure I have done my homework so this year is better than last year.

Answer: You need to view your role as your child’s “case manager.” (Learn more about "The Parent as Project Manager" in Chapter 3 of Wrightslaw: From Emotions to Advocacy). You need to be watchful, even when things appear to be going well.

Here are ten tips to help you get off to a good start at the beginning of the new school year.

1. Help Your Child Deal with Transitions.
Is your child making the transition from preschool to kindergarten, from elementary to middle school, or from middle school to high school? Plan to take your child to visit the new school or classroom before the first day of school.

2. Reread your child’s IEP.
Do you understand what the school agreed to provide? Do your child's teachers understand what they are to provide? **Is your child's IEP SMART? (Specific, measurable, action words, realistic, and time-specific)? (Review Chapter 12 about SMART IEPs from Wrightslaw: From Emotions to Advocacy).**

3. Meet with your child’s teacher(s) to discuss your child’s special needs.
Take a picture of your child to the meeting. Teachers are more likely to take a personal interest in your child and remember your child’s special needs if s/he has seen a picture of your child.

4. Take extra copies of your child’s IEP to the meeting with the teacher(s).
Never assume that teachers have had time to read your child’s IEP before school begins. Teachers have many things to do as they prepare for the first day of school. The teacher may not understand how important the IEP is to your child’s success. Leave a copy of your child's IEP with each teacher.

5. Make a List of Important Things About Your Child.
Make a list of the five most important things that the teacher(s) need to know about your child. Explain why these things are vital to your child’s success. Leave a copy of the list with each teacher.

6. Prepare to Deal with Potential Problems Early.
If your child is in general education classes, prepare for the teacher(s) who wants to see how your child “gets along” before making any changes in the way they run their classrooms.

7. Resolve Old Concerns and Issues.
If you have concerns or issues that were not resolved during the last IEP meeting, request another IEP meeting immediately. Try to resolve these issues and concerns before your child begins to have problems this year.

8. Get a New Assessment.
Consider getting your child’s skills tested very early in the school year. Where are your child’s skills on standardized educational achievement tests? Use these scores as baseline data. You can compare these scores with scores obtained at the end of the year to measure your child’s progress. (See Chapter 8, Your Child’s Evaluations, in Wrightslaw: From Emotions to Advocacy).

9. Go to your school’s Open House.
In addition to giving you another chance to meet with your child's teachers (and make a good impression), teachers often explain their classroom rules during Open House. When you attend, you have a chance to see if your child may have trouble understanding the teachers' rules. You will also be in a better position to explain these rules to your child.

10. Get a bound notebook.
Use the notebook as a “contact log” to send messages to the teachers. Write a sentence of two to the teacher(s) every day. Do not make your child the bearer of messages about problems at school. Make an extra copy of your log often in case the notebook is lost.

Have a great school year!

By Pat Howey, Advocate
Good special education services are intensive and expensive. Resources are limited. If you have a child with special needs, you may wind up battling the school district for the services your child needs. To prevail, you need information, skills, and tools. Who can be an advocate? Anyone can advocate for another person. Here is how the dictionary defines the term “advocate”:
ad-vo-cate – Verb, transitive. To speak, plead or argue in favor of. Synonym is support.
1. One that argues for a cause; a supporter or defender; an advocate of civil rights.
2. One that pleads in another’s behalf; an intercessor; advocates for abused children and spouses.

An advocate performs several functions:
- Supports, helps, assists, and aids
- Speaks and pleads on behalf of others
- Defends and argues for people or causes

Different Types of Advocates
Special education advocates work to improve the lives of children with disabilities and their families. You are likely to meet different types of advocates.

Lay Advocates
Lay advocates use specialized knowledge and expertise to help parents resolve problems with schools. When lay advocates attend meetings, write letters, and negotiate for services, they are acting on the child’s behalf. Most lay advocates are knowledgeable about legal rights and responsibilities. In some states, lay advocates represent parents in special education due process hearings.

Educational Advocates
Educational advocates evaluate children with disabilities and make recommendations about services, supports and special education programs. When educational advocates go to eligibility and IEP meetings, they are acting on the child’s behalf. Some educational advocates negotiate for services. Others are less knowledgeable about special education law and how to use tactics and strategies.

School Personnel
Teachers and special education providers often see themselves as advocates. Teachers, administrators, and school staff often provide support to children and their families. But because they are employed by school districts, school personnel are limited in their ability to advocate for children with disabilities without endangering their jobs.

Parents
Parents are natural advocates for their children. Who is your child’s first teacher? You are. Who is your child’s most important role model? You are. Who is responsible for your child’s welfare? You are. Who has your child’s best interests at heart? You do.
You know your child better than anyone else. The school is involved with your child for a few years. You are involved with your child for life. You should play an active role in planning your child’s education. The law gives you the power to make educational decisions for your child. Do not be afraid to use your power. Use it wisely. A good education is the most important gift you can give to your child. As the parent of a child with a disability, you have two goals: To ensure that the school provides your child with a “free appropriate public education” that includes “specially designed instruction to meet the [child’s] unique needs” 20 U.S.C. §1401. To build a healthy working relationship with the school.
What Advocates Do?
Advocacy is not a mysterious process. Here is a quick overview of advocacy skills.

Gather Information
Advocates gather facts and information. As they gather information and organize documents, they learn about the child’s disability and educational history. Advocates use facts and independent documentation to resolve disagreements and disputes with the school.

Learn the Rules of the Game
- Advocates educate themselves about their local school district. They know how decisions are made and by whom.
- Advocates know about legal rights. They know that a child with a disability is entitled to an “appropriate” education, not the “best” education, nor an education that “maximizes the child’s potential.” They understand that “best” is a four-letter word that cannot be used by parents or advocates.
- Advocates know the procedures that parents must follow to protect their rights and the child’s rights.

Plan and Prepare
- Advocates know that planning prevents problems. Advocates do not expect school personnel to tell them about rights and responsibilities. Advocates read special education laws, regulations, and cases to get answers to their questions.
- Advocates learn how to use test scores to monitor a child’s progress in special education. They prepare for meetings, create agendas, write objectives, and use meeting worksheets and follow-up letters to clarify problems and nail down agreements.

Keep Written Records
Because documents are often the keys to success, advocates keep written records. They know that if a statement is not written down, it was not said. They make requests in writing and write polite follow-up letters to document events, discussions, and meetings.

Ask Questions, Listen to Answers
Advocates are not afraid to ask questions. When they ask questions, they listen carefully to answers. Advocates know how to use “Who, What, Why, Where, When, How, and Explain Questions” (5 Ws + H + E) to discover the true reasons for positions.

Identify Problems
Advocates learn to define and describe problems from all angles. They use their knowledge of interests, fears, and positions to develop strategies. Advocates are problem solvers. They do not waste valuable time and energy looking for people to blame.

Propose Solutions
Advocates know that parents negotiate with schools for special education services. As negotiators, advocates discuss issues and make offers or proposals. They seek “win-win” solutions that will satisfy the interests of parents and schools.
The IEP for Transition-Aged Students

As a parent of a student with a disability you are probably concerned about your son or daughter as he or she makes the transition from the structured environment of school to the post-school world and all of the difficult life choices that entails. The services and supports your student needed in school may continue to be needed when he or she leaves school to pursue postsecondary education, job training, work, personal and social relationships, involvement in the community, and independent living.

From the time your child begins receiving special education services, his or her Individualized Education Program (IEP) guides his or her education. During the transition years, your son or daughter's IEP must contain specific transition services defined by The Individuals with Disabilities Education Act Amendments of 1997 (IDEA) regulations. The transition plan will lay the path toward your child's young adulthood. It must reflect his or her choices, preferences, and needs in the areas of education and training, employment, adult living arrangements, and community experiences. IDEA requires that parents and students be involved in all aspects of transition planning and decision making. To participate effectively, and to ensure that your student receives appropriate educational services, it is important that you and your son or daughter become familiar with the transition requirements of IDEA. Parents, students, educators, and community service providers must work together to support the student in planning for and achieving his or her adult goals.

IDEA Transition Requirements

IDEA requires that transition planning begin at the earliest age appropriate. For each student with a disability, beginning at age 14 (or younger, if determined appropriate by the IEP team), the IEP must include a statement of the student's transition service needs that focuses on the student's course of study (such as advanced academic courses, technical training, or intensive employment preparation).
Thus, beginning at age 14, the IEP team, in identifying annual goals and services for a student, must determine what instruction and educational experiences will help the student prepare for the transition from school to adult life. For example, if a student's transition goal is to secure a job, a transition service need might be enrolling in a career development class to explore career options and specific jobs related to that career. A statement of transition service needs should relate directly to the student's goals after high school and show how planned activities are linked to these goals.

The IEP must be updated annually or more often when needed. If the student is not making expected progress toward the annual goals and in the general curriculum, the team must meet and revise the IEP. Schools must report to parents on the progress of a child with a disability at least as frequently as they report on the progress of nondisabled children. Progress reports can help determine whether or not revisions to the IEP are needed.

The law requires that the IEP team begin no later than age 14 to address the student's need for instruction that will assist him or her in preparing for transition. Beginning at age 16 (or younger, if determined appropriate by the IEP team), the IEP must contain a statement of needed transition services for the student, including, if appropriate, a statement of interagency responsibilities. This includes a coordinated set of activities with measurable outcomes that will move the student from school to post-school activities.

(a) Transition services means a coordinated set of activities for a student with a disability that:

   (1) Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
Transition Planning with IEP… continued

(2) Is based on the individual student's needs, taking into account the student's preferences and interests; and

(3) Includes-
   (i) Instruction; (ii) Related services; (iii) Community experiences; (iv) The development of employment and other post-school adult living objectives; and (v) If appropriate, acquisition of daily living skills and functional vocational evaluation.

(b) Transition services for students with disabilities may be special education, if provided as specially designed instruction, or related services, if required to assist a student with a disability to benefit from special education

The IEP Transition Team

Transition planning works best when students are actively involved. Family members and other adults also play important roles in this long-term planning. Teachers, administrators, and support agencies work with the student and family to reach the goals.

The IEP transition team relies on data from many sources to make decisions. Assessments, observation, testing, medical evaluation, and family history may be used to determine eligibility for adult services. Continued eligibility for services likewise relies on reevaluation and input from teachers and family.

All the professionals who work with the student must be knowledgeable about the student's IEP. They must understand their responsibilities and the specific accommodations, modifications, and supports that must be provided for the student in accordance with the IEP. This means that the IEP must be accessible to each of the student's teachers and all other service providers who implement any portion of the IEP, even if they do not attend the transition IEP meetings (for example, guidance counselors, vocational educators, social workers, psychologists). The IEP transition team involves the participation of several individuals, which may include the students, parents/guardians, general and special education teachers, related services personnel, counselors, administrators, adult service providers, employers, postsecondary personnel, and other personal or professional support networks. The following is a description of the roles of the key individuals involved in the transition planning process.

The Parent Brief is produced by the National Center on Secondary Education and Transition (NCSET) and PACER Center.
**State Interagency Coordinating Council (SICC)**

**Parent invitation**

**What is the SICC?** The State Interagency Coordinating Council is a federally and state mandated independent board that functions under the Governor’s Office of Community Programs in an advisory capacity to EarlySteps: Louisiana’s Early Intervention System.

Federal legislation for infants and toddlers with special needs and their families, Part C of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), calls for a comprehensive system of coordinated early intervention services. In Louisiana, this system is called EarlySteps: Louisiana’s Early Intervention System. EarlySteps is an interagency system administered through the Department of Health and Hospitals (DHH), Office for Citizens with Developmental Disabilities. The Governor designated DHH as the Lead Agency in 2004.

**Membership:** The Governor appoints members of the State Interagency Coordinating Council (SICC) to represent designated agencies and stakeholders. Our membership is as follows:

All council members are appointed by the governor and represent the population of Louisiana.

The SICC membership is composed of:

1. at least 20% parents of children with disabilities
2. at least 20% public or private providers of early intervention services
3. at least one member from the state legislature
4. at least one member representing personnel preparation
5. at least one representative from each of the state agencies involved in the provision of, or payment for, early intervention services
6. at least one member from the state education agency responsible for preschool services
7. at least one member from the agency responsible for the state governance of health insurance
8. at least one member representing a Head Start agency or program in the state
9. at least one member representing the agency responsible for child care
10. other members selected by the Governor.
Why Do We Need Parent Representatives? Your valuable input preserves the integrity of our Early Intervention system. The SICC would like to invite parents across Louisiana to apply for the position of parent representatives on the SICC. We will be accepting applications from all parents who meet the following parent representative requirements as per our statute:

♦ You are a parent of an infant(s) or toddler(s) with special needs or children with special needs age twelve or younger
♦ You are a parent with knowledge of or experience with programs for infants and toddlers with special needs.
♦ You parent of an infant or toddler with special needs or a child with special needs age six or younger
♦ To learn more about the role of the ICC, please visit our website (click on the Resources tab) for orientation materials: http://gov.state.la.us/SICC

To apply, visit the Boards and Commission website and click on State Interagency Coordinating Council. https://wwwprd.doa.louisiana.gov/boardsandcommissions/home.cfm

Once you have completed both steps, contact Christie Smith, Executive Director, at 225-219-7560 or at Christie.Smith@la.gov
What is CSHS?

Children’s Special Health Services (CSHS) is a program for children in Louisiana with special health care needs. A child with special needs is:

1. a child with a health problem that affects how the child grows, moves, and acts,
2. a child who needs more health services than most other children.

CSHS gives a child with special needs health care that is sensitive to his or her family and culture. This will help the child live a happy and more independent life.

What help does CSHS offer?

- Doctors and other health care workers who provide services for children with special needs
- Care coordination to make sure a child gets all the services he or she needs
- Hospital care
- Tests: X-ray, lab, EKG (to look at heart movement), and more
- Therapy that helps a child (1) move better, (2) speak better, and (3) build life skills
- Medicine that is ordered by CSHS doctors
- Nutrition and special diets
- Equipment: wheelchairs, braces, and more
- Parent and family support
- Help finding home care services
- Help working with schools and community groups and offices
- Help shifting to adult life and care

Who can get help from CSHS?

A child can get help from CSHS if he or she:

- lives in Louisiana
- is less than 21 years old
- has a health problem that CSHS covers
- has Medicaid or meets CSHS income rules

How do I apply?

To get help from CSHS, a parent can apply at a local parish health unit or one of the nine CSHS offices. A referral from a doctor, nurse practitioner, or audiologist is needed.

Region 3

Children Special Health Services

April Young, Parent Liaison
2535 Veterans Blvd.
Thibodaux, La. 70301
985-447-0896

Serving: Lafourche, St. Mary, Terrebonne, Assumption, St. James, St. John and St. Charles