8. Eligibility for Special Education Services

a. Fact Sheets on
    i. ADHD Fact Sheet on Disabilities from NICHCY (http://nichcy.org/disability)
    ii. Autism Spectrum Disorders Fact Sheet
    iii. Blindness/Visual Impairment Fact Sheet
    iv. Cerebral Palsy Fact Sheet
    v. Deaf-Blindness Fact Sheet
    vi. Deafness and Hearing Loss Fact Sheet
    vii. Developmental Delay Fact Sheet
    viii. Down Syndrome Fact Sheet
    ix. Emotional Disturbance Fact Sheet
    x. Epilepsy Fact Sheet
    xi. Intellectual Disabilities Fact Sheet
    xii. Learning Disabilities Fact Sheet
    xiii. Other Health Impairment Fact Sheet
    xiv. Traumatic Brain Injury Fact Sheet
b. Disability Worksheets for Eligibility for Special Education (from OSSE/DCPS)
    i. Other Health Impairment Disability Worksheet
    ii. Specific Learning Disability Worksheet
    iii. Emotional Disturbance Disability Worksheet

Attention-Deficit/ Hyperactivity Disorder

NICHCY Disability Fact Sheet #19
Updated March 2012

Mario's Story

Mario is 10 years old. When he was 7, his family learned he had AD/HD. At the time, he was driving everyone crazy. At school, he couldn't stay in his seat or keep quiet. At home, he didn't finish his homework or his chores. He did scary things, too, like climb out of his window onto the roof and run across the street without looking.

Things are much better now. Mario was tested by a trained professional to find out what he does well and what gives him trouble. His parents and teachers came up with ways to help him at school. Mario has trouble sitting still, so now he does some of his work standing up. He's also the student who tidies up the room and washes the chalkboard. His teachers break down his lessons into several parts. Then they have him do each part one at a time. This helps Mario keep his attention on his work.

At home, things have changed, too. Now his parents know why he's so active. They are careful to praise him when he does something well. They even have a reward program to encourage good behavior. He earns "good job points" that they post on a wall chart. After earning 10 points he gets to choose something fun he'd like to do. Having a child with AD/HD is still a challenge, but things are looking better.

NICHCY *is the*
National Dissemination Center for Children with Disabilities.

NICHCY
1825 Connecticut Avenue N.W.
Washington, DC 20009
1.800.695.0285 (Voice / TTY)
202.884.8200 (Voice / TTY)
nichcy@fhi360.org
http://nichcy.org

What is AD/HD?

Attention-deficit/hyperactivity disorder (AD/HD) is a condition that can make it hard for a person to sit still, control behavior, and pay attention. These difficulties usually begin before the person is 7 years old. However, these behaviors may not be noticed until the child is older.

Doctors do not know just what causes AD/HD. However, researchers who study the brain are coming closer to understanding what may cause AD/HD. They believe that some people with AD/HD do not have enough of certain chemicals (called *neurotransmitters*) in their brain. These chemicals help the brain control behavior.

Parents and teachers do not cause AD/HD. Still, there are many things that both can do to help a child with AD/HD.

How Common is AD/HD?

As many as 5 out of every 100 children in school may have AD/HD. Boys are three times more likely than girls to have AD/HD.

What Are the Signs of AD/HD?

There are three main signs, or symptoms, of AD/HD. These are:

- problems with paying attention,
- being very active (called *hyperactivity*), and
- acting before thinking (called *impulsivity*).

More information about these symptoms is listed in a book called the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), which is published by the American Psychiatric Association (2000). Based on these symptoms, three types of AD/HD have been found:

- *inattentive type,* where the person can't seem to get focused or stay focused on a task or activity;
- *hyperactive-impulsive type,* where the person is very active and often acts without thinking; and
- *combined type,* where the person is inattentive, impulsive, and too active.

Inattentive type. Many children with AD/HD have problems paying attention. Children with the inattentive type of AD/HD often:

- do not pay close attention to details;
- can't stay focused on play or school work;
- don't follow through on instructions or finish school work or chores;
- can't seem to organize tasks and activities;
- get distracted easily; and
- lose things such as toys, school work, and books. (APA, 2000, pp. 85-86)

Hyperactive-impulsive type. Being too active is probably the most visible sign of AD/HD. The hyperactive child is "always on the go." (As he or she gets older, the level of activity may go down.) These children also act before thinking (called *impulsivity*). For example, they may run across the road without looking or climb to the top of very tall trees. They may be surprised to find themselves in a dangerous situation. They may have no idea of how to get out of the situation.

Hyperactivity and impulsivity tend to go together. Children with the hyperactive-impulsive type of AD/HD often may:

- fidget and squirm;
- get out of their chairs when they're not supposed to;
- run around or climb constantly;
- have trouble playing quietly;
- talk too much;
- blurt out answers before questions have been completed;
- have trouble waiting their turn;
- interrupt others when they're talking; and
- butt in on the games others are playing. (APA, 2000, p. 86)

Combined type. Children with the combined type of AD/HD have symptoms of both of the types described above. They have problems with paying attention, with hyperactivity, and with controlling their impulses.

Of course, from time to time, all children are inattentive, impulsive, and too active. With children who have AD/HD, these behaviors are the rule, not the exception.

These behaviors can cause a child to have real problems at home, at school, and with friends. As a result, many children with AD/HD will feel anxious, unsure of themselves, and depressed. These feelings are not symptoms of AD/HD. They come from having problems again and again at home and in school.

How Do You Know if a Child Has AD/HD?

When a child shows signs of AD/HD, he or she needs to be evaluated by a trained professional. This person may work for the school system or may be a professional in private practice. A complete evaluation is the only way to know for sure if the child has AD/HD. It is also important to:

- rule out other reasons for the child's behavior, and
- find out if the child has other disabilities along with AD/HD.

What About Treatment?

There is no quick treatment for AD/HD. However, the symptoms of AD/HD can be managed. It's important that the child's family and teachers:

- find out more about AD/HD;
- learn how to help the child manage his or her behavior;
- create an educational program that fits the child's individual needs; and
- provide medication, if parents and the doctor feel this would help the child.

What About School?

School can be hard for children with AD/HD. Success in school often means being able to pay attention and control behavior and impulse. These are the areas where children with AD/HD have trouble.

There are many ways the school can help students with AD/HD. Some students may be eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA). AD/HD is specifically mentioned under the category of "Other Health Impairment" (OHI). We've included the IDEA's definition of OHI in the box below.

Despite the fact that AD/HD is specifically mentioned in IDEA's definition of OHI, some students will not be eligible for services under IDEA. Many factors go into determining eligibility, including state policies and definitions and the fact that a student's educational performance must be adversely affected. However, students who are found not eligible under IDEA may be eligible for services under a different law, Section 504 of the Rehabilitation Act of 1973.

Definition of "Other Health Impairment"

Many students with AD/HD may qualify for special education services under the "Other Health Impairment" category within the Individuals with Disabilities Education Act (IDEA). IDEA defines "other health impairment" as...

"...having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

(a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and

(b) adversely affects a child's educational performance."

34 *Code of Federal Regulations* §300.8(c)(10)

Regardless of the eligibility determination, the school and the child's parents need to meet and talk about what special help the student needs.

Most students with AD/HD are helped by supports or changes in the classroom (called *adaptations*). Some common changes that help students with AD/HD are listed in the "Tips for Teachers" box on page 5. "Tips for Parents" are given below.

Yes, it can be very helpful to read more about AD/HD. This has been just a brief overview. The *Resources for You* section (beginning on the next page) includes a range of materials you might explore—which will, of course, lead you to still more!

Tips for Parents

❑ Learn about AD/HD. The more you know, the more you can help yourself and your child. Start with the info we've listed in the *Resources for You* section, beginning on page 5.

❑ Praise your child when he or she does well. Build your child's abilities. Talk about and encourage his or her strengths and talents.

❑ Be clear, be consistent, be positive. Set clear rules for your child. Tell your child what he or she *should* do, not just what he shouldn't do. Be clear about what will happen if your child does not follow the rules. Have a reward program for good behavior. Praise your child when he or she shows the behaviors you like.

❑ Learn about strategies for managing your child's behavior. These include valuable techniques such as: charting, having a reward program, ignoring behaviors, natural consequences, logical consequences, and time-out. Using these strategies will lead to more positive behaviors and cut down on problem behaviors. You can read about these techniques in many books. See the *Resources for You* section.

❑ Talk with your doctor about whether medication will help your child.

❑ Pay attention to your child's mental health (and your own!). Be open to counseling. It can help you deal with the challenges of raising a child with AD/HD. It can help your child deal with frustration, feel better about himself or herself, and learn more about social skills.

❑ Talk to other parents whose children have AD/HD. Parents can share practical advice and emotional support. Call NICHCY to find out how to find parent groups near you.

❑ Meet with the school and develop an educational plan to address your child's needs. Both you and your child's teachers should get a written copy of this plan.

❑ Keep in touch with your child's teacher. Tell the teacher how your child is doing at home. Ask how your child is doing in school. Offer support.

Resources for You

CHADD | *Children and Adults with Attention Deficit/Hyperactivity Disorder*
1.800.233.4050
http://www.chadd.org

National Resource Center on ADHD
A program of CHADD
1.800.233.4050

- Website in English
  http://www.help4adhd.org/index.cfm?varLang=en
- Website in Spanish:
  http://www.help4adhd.org/index.cfm?varLang=es

Continued on the next page ►

Tips for Teachers

❑ Learn more about AD/HD. The resources and organizations listed in this publication will help you identify behavior support strategies and effective ways to support the student educationally. We've listed some strategies below.

❑ Figure out what specific things are hard for the student. For example, one student with AD/HD may have trouble starting a task, while another may have trouble ending one task and starting the next. Each student needs different help.

❑ Post rules, schedules, and assignments. Clear rules and routines will help a student with AD/HD. Have set times for specific tasks. Call attention to changes in the schedule.

❑ Show the student how to use an assignment book and a daily schedule. Also teach study skills and learning strategies, and reinforce these regularly.

❑ Help the student channel his or her physical activity (e.g., let the student do some work standing up or at the board). Provide regularly scheduled breaks.

❑ Make sure directions are given step by step, and that the student is following the directions. Give directions both verbally and in writing. Many students with AD/HD also benefit from doing the steps as separate tasks.

❑ Let the student do work on a computer.

❑ Work together with the student's parents to create and implement an educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at home and at school.

❑ Have high expectations for the student, but be willing to try new ways of doing things. Be patient. Maximize the student's chances for success.

Resources for You

For Parents

How do you know if your child has ADHD?
2011, U.S. Food and Drug Administration
Includes a section on "FDA-Approved Drugs to Treat ADHD in Children."
http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm269188.htm

How is parenting children with ADHD different?
http://tlc.howstuffworks.com/family/parenting-children-with-adhd.htm

Attention-deficit/hyperactivityi disorder: What should you know?
http://www.cdc.gov/ncbddd/adhd/

For Schools

How can teachers help students with AD/HD?
http://www.educationworld.com/a_issues/issues148c.shtml

Helping children with AD/HD succeed at school.
http://helpguide.org/mental/adhd_add_teaching_strategies.htm

AD/HD instructional strategies and practices.
From the U.S. Department of Education.
http://www2.ed.gov/rschstat/research/pubs/adhd/adhd-teaching-2006.pdf

How to help and support impulsive students
http://specialed.about.com/od/behavioremotiona1/p/impulsive.htm

Strategies for teaching students with attention deficit disorder.
http://www.as.wvu.edu/~scidis/add.html

NICHCY Disability Fact Sheet #9
Updated March 2012

This publication is made possible through Cooperative Agreement #H326N080003 between FHI 360 and the Office of Special Education Programs, U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Autism Spectrum Disorders

A publication of NICHCY
Disability Fact Sheet #1
June 2010

Ryan's Story

Ryan is a healthy, active two-year-old, but his parents are concerned because he doesn't seem to be doing the same things that his older sister did at this age. He's not really talking yet, although sometimes he repeats, over and over, words that he hears others say. He doesn't use words to communicate, though. It seems he just enjoys the sounds of them. Ryan spends a lot of time playing by himself. He has a few favorite toys, mostly cars, or anything with wheels on it! And sometimes, he spins himself around as fast as he does the wheels on his cars. Ryan's parents are really concerned, as he's started throwing a tantrum whenever his routine has the smallest change. More and more, his parents feel stressed, not knowing what might trigger Ryan's next upset.

Often, it seems Ryan doesn't notice or care if his family or anyone else is around. His parents just don't know how to reach their little boy, who seems so rigid and far too set in his ways for his tender young age.

After talking with their family doctor, Ryan's parents call the Early Intervention office in their community and make an appointment to have Ryan evaluated.

When the time comes, Ryan is seen by several professionals who play with him, watch him, and ask his parents a lot of questions. When they're all done, Ryan is diagnosed with autism, one of the five disorders listed under an umbrella category of "Pervasive Developmental Disorders"—a category that's often referred to as simply the "autism spectrum."

As painful as this is for his parents to learn, the early intervention staff encourage them to learn more about the autism spectrum. By getting an early diagnosis and beginning treatment, Ryan has the best chance to grow and develop. Of course, there's a long road ahead, but his parents take comfort in knowing that they aren't alone and they're getting Ryan the help he needs.

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What are the Characteristics of Autism Spectrum Disorders?

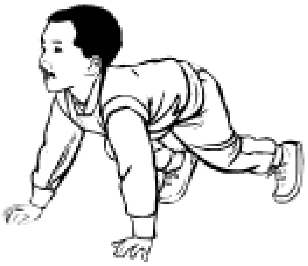
Each of the disorders on the autism spectrum is a neurological disorder that affects a child's ability to communicate, understand language, play, and relate to others. They share some or all of the following characteristics, which can vary from mild to severe:

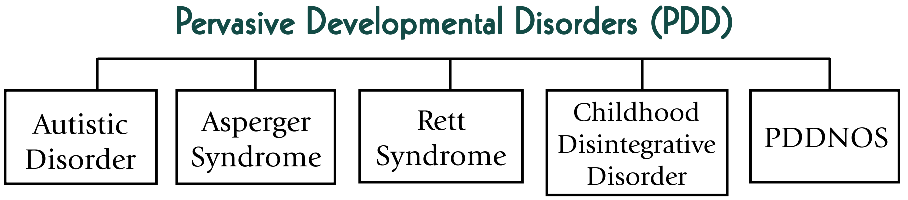
- Communication problems (for example, with the use or comprehension of language);

- Difficulty relating to people, things, and events;
- Playing with toys and objects in unusual ways;
- Difficulty adjusting to changes in routine or to familiar surroundings; and
- Repetitive body movements or behaviors.[1]

These characteristics are typically evident before the age of three.

Children with autism or one of the other disorders on the autism spectrum can differ considerably with respect to their abilities, intelligence, and behavior. Some children don't talk at all. Others use language where phrases or conversations are repeated. Children with the most advanced language skills tend to talk about a limited range of topics and to have a hard time understanding abstract concepts. Repetitive play and limited social skills are also evident. Other common symptoms of a disorder on the autism spectrum can include unusual and sometimes uncontrolled reactions to sensory information—for instance, to loud noises, bright lights, and certain textures of food or fabrics.





Current Classification Scheme in the DSM-IV-TR

What are the Specific Disorders on the Autism Spectrum?

There are five disorders classified under the umbrella category officially known as Pervasive Developmental Disorders, or PDD. As shown above, these are:

- autism;
- Asperger syndrome;
- Rett syndrome;
- childhood disintegrative disorder; and
- Pervasive Developmental Disorder Not Otherwise Specified (often referred to as PDDNOS).[2]

Although there are subtle differences and degrees of severity between these five conditions, the treatment and educational needs of a child with any of these disorders will be very similar. For that reason, the term "autism spectrum disorders"—or ASDs, as they are sometimes called— is used quite often now and is actually expected to become the official term to be used in the future (see the box on the next page).[3]

The five conditions are defined in the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (DSM-IV-TR) of the American Psychiatric Society (2000). This is also the manual used to diagnose autism and its associated disorders, as well as a wide variety of other disabilities.

At the moment, according to the 2000 edition of the *DSM-IV,* a diagnosis of autistic disorder (or "classic" autism) is made when a child displays 6 or more of 12 symptoms across three major areas:

- social interaction (such as the inability to establish or maintain relationships with peers appropriate to the level of the child's development,
- communication (such as the absence of language or delays in its development), and
- behavior (such as repetitive preoccupation with one or more areas of interest in a way that is abnormal in its intensity or focus).

When children display similar behaviors but do not meet the specific criteria for autistic disorder, they may be diagnosed as having one of the other disorders on the spectrum—Aspergers, Rett's, childhood disintegrative disorder, or PDDNOS. PDDNOS (Pervasive Developmental Disorder Not Otherwise Specified) is the least specific diagnosis and typically means that a child has displayed the least specific of autistic-like symptoms or behaviors and has not met the criteria for any of the other disorders.

Terminology used with autism spectrum disorders can be a bit confusing, especially the use of PDD and PDDNOS to refer to two different things that are similar and intertwined. Still, it's important to remember that, regardless of the specific diagnosis, treatments will be similar.

How Common are ASDs?

According to the National Institute of Mental Health (NIMH) and the Centers for Disease Control and Prevention (CDC), some form of autism affects 2 - 6 of every 1,000 children, with the most recent statistic being 1 in 110.[4] ASDs are four times more common in boys than in girls, although Rett Syndrome has only been diagnosed in girls.[5]

What Causes an ASD?

The causes of autism and the other disorders on the spectrum are not known. Researchers are currently studying such areas as neurological damage and chemical imbalances within the brain. These disorders are not due, however, to psychological factors or, as has been widely reported in the press, to childhood vaccines.[6]

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, the Individuals with Disabilities Education Act (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).

A Look at ASD Diagnoses in the Future

In early 2010, the American Psychiatric Association released draft revisions to its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and invited comments from both professionals and the general public. The final and official fifth revision of the DSM is expected to be published in May 2013.[7]

When published, the DSM-5 is expected to affect how autism and associated disorders are diagnosed. Among the proposed revisions are:

- changing the name of the diagnostic category to Autism Spectrum Disorders;
- including Asperger Syndrome, Childhood Disintegrative Disorder, and PDDNOS under the diagnosis of Autism Spectrum Disorders, rather than defining them separately and a bit differently, as is now the case;
- removing Rett Syndrome from the DSM entirely (and, thus, from the autism spectrum).[8]

All this is to say...stay tuned. The criteria for diagnoses of ASDs are in the process of changing.

Definition of "Autism" under IDEA

Under IDEA, *autism* is defined as:

> .....a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance.
>
> Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term autism does not apply if the child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in IDEA.
>
> A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied. *[34 CFR §300.8(c)(1)]*

Under IDEA, children with a disorder on the autism spectrum are usually found eligible for services under the category of "autism." In the fall of 2005, more than 160,000 school-aged children (3-21) received special education and related services in the public schools under the "autism" category.[9] IDEA specifically defines "autism" as shown in the box above.

To have a child evaluated to see if he or she has a disability, including one on the autism spectrum, *or* to access early intervention services for a child up to his or her 3rd birthday, we recommend consulting NICHCY's *State Resource Sheet* for your state (available online at: http://www.nichcy.org/families-community/states/). You'll find a listing for early intervention under the first section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To have a school-aged child evaluated for an ASD *or* to access special education services for a school-aged child, we recommend getting in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

What about School?

Early diagnosis and intervention are very important for children with an ASD. As we've mentioned, under IDEA children with an ASD may be eligible for early intervention services (birth to 3) and an educational program appropriate to their individual needs.

In addition to academic instruction, special education programs for students with ASDs focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning often require the assistance of a professional who is particularly knowledgeable in the autism field to develop and help implement a plan which can be carried out at home and school.

The classroom environment should be structured so that the program is consistent and predictable. Students with an ASD learn better and are less confused when information is presented visually as well as verbally. Interaction with nondisabled peers is also important, for these students provide models of appropriate language, social, and behavioral skills. Consistency and continuity are very important for children with an ASD, and parents should always be involved in the development of their child's program, so that learning activities, experiences, and approaches will be most effective and can be carried over into the home and community.

With educational programs designed to meet a student's individual needs and specialized adult support services in employment and living arrangements, many children and adults with a disability on the autism spectrum grow to live, work, and participate fully in their communities.

Tips for Parents

- Learn about autism spectrum disorders—especially the specific disorder of your child. The more you know, the more you can help yourself and your child. Your state's Parent Training and Information Center (PTI) can be very helpful. You'll find your PTI listed on NICHCY's online *State-Specific Information* (under "Organizations Especially for Parents"). We've also listed organizations on page 6 that can help you become knowledgeable about your child's disorder.
- Be mindful to interact with and teach your child in ways that are most likely to get a positive response. Learn what is likely to trigger a melt-down for your child, so you can try to minimize them. Remember, the earliest years are the toughest, but it does get better!
- Learn from professionals and other parents how to meet your child's special needs, but remember your son or daughter is first and foremost a child; life does not need to become a neverending round of therapies.
- If you weren't born loving highly structured, consistent schedules and routines, ask for help from other parents and professionals on how to make it second nature for you. Behavior, communication, and social skills can all be areas of concern for a child with autism and experience tells us that maintaining a solid, loving, and structured approach in caring for your child, can help greatly.
- Learn about assistive technology (AT) that can help your child. This may include a simple picture communication board to help your child express needs and desires, or may be as sophisticated as an augmentative communication device.
- Work with professionals in early intervention or in your child's school to develop an IFSP or an IEP that reflects your child's needs and abilities. Be sure to include related services, supplementary aids and services, AT, and a positive behavioral support plan, if needed.
- Be patient and stay optimistic. Your child, like every child, has a whole lifetime to learn and grow.

References

[1] Autism Society of America. (2008). *About autism*. Available online at: www.autism-society.org

[2] American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders fourth edition, text revision* (DSM-IV-TR). Arlington, VA: Author.

[3] American Psychiatric Association. (2010). *DSM-5 proposed revisions include new category of autism spectrum disorders* (press release). Available online at: www.dsm5.org/Newsroom/Documents/Autism%20Release%20FINAL%202.05.pdf

[4] Centers for Disease Control and Prevention (CDC). (2009). *Autism spectrum disorders: Data and statistics.* Available online at: www.cdc.gov/ncbddd/autism/data.html

[5] Centers for Disease Control and Prevention (CDC). (2009). *Autism spectrum disorders: Research*. Available online at: www.cdc.gov/ncbddd/autism/research.html

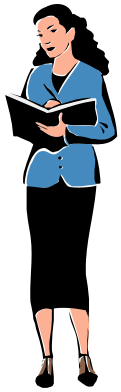
[6] Centers for Disease Control and Prevention (CDC). (2009). *Concerns about autism: CDC statement on autism and thimerosal*. Available online at: www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html

[7] American Psychiatric Association. (2009). *DSM-5 publication date moved to May 2013* (press release). Available at: www.dsm5.org/Newsroom/Documents/09-65%20DSM%20Timeline.pdf

[8] American Psychiatric Association. (2010). *Proposed revision: Autistic disorder*. Available online at: www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

[9] U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2005* (Vol. 2). Washington, DC: Author.

Tips for Teachers



- Learn more about the autism spectrum. Check out the research on effective instructional interventions and behavior on NICHCY's website. The organizations listed in this publication can also help.

- Make sure directions are given step-by- step, verbally, visually, and by providing physical supports or prompts, as needed by the student. Students with autism spectrum disorders often have trouble interpreting facial expressions, body language, and tone of voice. Be as concrete and explicit as possible in your instructions and feedback to the student.

- Find out what the student's strengths and interests are and emphasize them. Tap into those avenues and create opportunities for success. Give positive feedback and lots of opportunities for practice.

- Build opportunities for the student to have social and collaborative interactions throughout the regular school day. Provide support, structure, and lots of feedback.

- If behavior is a significant issue for the student, seek help from expert professionals (including parents) to understand the meanings of the behaviors and to develop a unified, positive approach to resolving them.

- Have consistent routines and schedules. When you know a change in routine will occur (e.g., a field trip or assembly) *prepare* the student by telling him or her what is going to be different and what to expect or do.

- Work together with the student's parents and other school personnel to create and implement an educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

Organizations: Your Gateway to Information, Connection, and Research

For incredible amounts of information on ASDs, visit the organizations listed below.

Autism Society of America
1.800.3AUTISM (1.800.328.8476)
http://www.autism-society.org/site/PageServer?pagename=about_home

First Signs
http://www.firstsigns.org

Autism Speaks
888-AUTISM2 (288-4762)
http://www.autismspeaks.org/

OASIS @ MAPP
Online Asperger Syndrome Information and Support (OASIS) and MAAP Services for Autism and Asperger Syndrome.
http://www.aspergersyndrome.org

Exploring Autism
Information in English and Spanish.
http://www.exploringautism.org/

Autism Collaboration
http://www.autism.org/

Interactive Autism Network
http://www.ianproject.org/

OAR | Organization for Autism Research
http://www.researchautism.org/

CDC | Centers for Disease Control and Prevention
Information in English and Spanish.
www.cdc.gov/ncbddd/autism/index.html

National Autism Center
1.877.313.3833
http://www.nationalautismcenter.org/index.php

NICHCY Disability Fact Sheet—No.13

Visual Impairments

✧ Definition ✧

The terms partially sighted, low vision, legally blind, and totally blind are used in the educational context to describe students with visual impairments. These terms are defined as follows:

- "Partially sighted" indicates some type of visual problem has resulted in a need for special education;
- "Low vision" generally refers to a severe visual impairment, not necessarily limited to distance vision. Low vision applies to all individuals with sight who are unable to read the newspaper at a normal viewing distance, even with the aid of eyeglasses or contact lenses. They use a combination of vision and other senses to learn, although they may require adaptations in lighting, the size of print, and, sometimes, braille;
- "Legally blind" indicates that a person has less than 20/200 vision in the better eye or a very limited field of vision (20 degrees at its widest point); and
- Totally blind students, who learn via braille or other non-visual media.

Visual impairment is the consequence of a functional loss of vision, rather than the eye disorder itself. Eye disorders which can lead to visual impairments can include retinal degeneration, albinism, cataracts, glaucoma, muscular problems that result in visual disturbances, corneal disorders, diabetic retinopathy, congenital disorders, and infection.

NICHCY *is the*
National Dissemination Center
for Children with Disabilities.

NICHCY
P.O. Box 1492
Washington, DC 20013
1.800.695.0285 (Voice / TTY)
202.884.8200 (Voice / TTY)
nichcy@aed.org
www.nichcy.org

Disability Fact Sheet, No. 13
January 2004

✧ Incidence ✧

The rate at which visual impairments occur in individuals under the age of 18 is 12.2 per 1,000. Severe visual impairments (legally or totally blind) occur at a rate of .06 per 1,000.

✧ Characteristics ✧

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appears, and overall functioning level of the child. Many children who have multiple disabilities may also have visual impairments resulting in motor, cognitive, and/or social developmental delays.

A young child with visual impairments has little reason to explore interesting objects in the environment and, thus, may miss opportunities to have experiences and to learn. This lack of exploration may continue until learning becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or under- stand nonverbal cues. Visual disabilities can create obstacles to a growing child's independence.

Don't Be Shy!

All of our publications and resource lists are online—help yourself! Visit us at:

www.nichcy.org

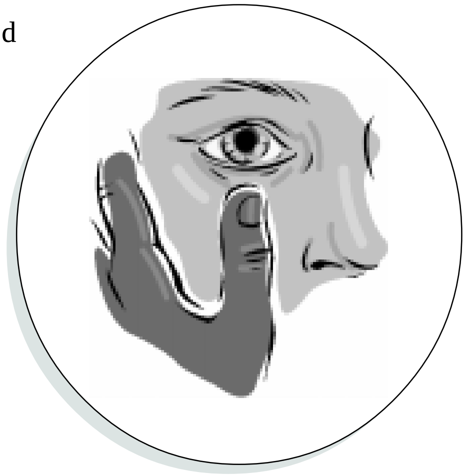
If you'd like personalized assistance, email or call us:

nichcy@aed.org

1.800.695.0285
(V/TTY)

✧ Educational Implications ✧

Children with visual impairments should be assessed early to benefit from early intervention programs, when applicable. Technology in the form of computers and low-vision optical and video aids enable many partially sighted, low vision, and blind children to participate in regular class activities. Large print materials, books on tape, and braille books are available.



Students with visual impairments may need additional help with special equipment and modifications in the regular curriculum to emphasize listening skills, communication, orientation and mobility, vocation/career options, and daily living skills. Students with low vision or those who are legally blind may need help in using their residual vision more efficiently and in working with special aids and materials. Students who have visual impairments combined with other types of disabilities have a greater need for an interdisciplinary approach and may require greater emphasis on self care and daily living skills.

✧ Resources ✧

American Foundation for the Blind. Search AFB's *Service Center* on the Internet to identify services for blind and visually impaired persons in the United States and Canada. Available: www.afb.org/services.asp

Holbrook, M.C. (Ed.). (1996). *Children with visual impairments: A parents' guide*. Bethesda, MD: Woodbine. (Phone: 800.843.7323. Web: www.woodbinehouse.com)

Lewis, S., & Allman, C.B. (2000). *Seeing eye to eye: An administrator's guide to students with low vision*. New York: American Foundation for the Blind. (Phone: 800.232.3044. Web: www.afb.org)

National Eye Institute. (2003, December). *Eye health organizations list*. (Available online at: www.nei.nih.gov/health/organizations.htm)

The terms partially sighted, low vision, legally blind, and totally blind are used in the educational context to describe students with visual impairments.

Other Helpful Things to Know

These NICHCY publications talk about topics important to parents of a child with a disability.

Parenting a Child with Special Needs

Your Child's Evaluation

Parent to Parent Support

Questions Often Asked by Parents About Special Education Services

Developing Your Child's IEP

All are available in English and in Spanish—on our Web site or by contacting us.

Organizations

American Council of the Blind
1155 15th St. N.W., Suite 1004
Washington, D.C. 20005
202.467.5081; 800.424.8666
info@acb.org
www.acb.org

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
800.232.5463 (Hotline)
For publications call: 800.232.3044
afbinfo@afb.net
www.afb.org

Blind Children's Center
4120 Marathon Street
Los Angeles, CA 90029-0159
323.664.2153; 800.222.3566
info@blindchildrenscenter.org
www.blindchildrenscenter.org

National Association for Parents of the Visually Impaired, Inc.
P.O. Box 317
Watertown, MA 02472-0317
617.972.7441; 800.562.6265
napvi@perkins.org
www.napvi.org

National Association for Visually Handicapped
22 West 21st Street, 6th Floor
New York, NY 10010
212.889.3141
staff@navh.org
www.navh.org

National Braille Association, Inc. (NBA)
3 Townline Circle
Rochester, NY 14623-2513
585.427.8260
nbaoffice@nationalbraille.org
www.nationalbraille.org/

National Braille Press
88 St. Stephen Street
Boston, MA 02115
617.266.6160; 888.965.8965
orders@nbp.org
www.nbp.org

National Eye Institute
31 Center Drive
MSC 2510
Bethesda, MD 20892-2510
301.496.5248
2020@nei.nih.gov
www.nei.nih.gov

National Federation of the Blind, Parents Division
1800 Johnson Street
Baltimore, MD 21230
410.659.9314, ext. 360
nfb@nfb.org
www.nfb.org/nopbc.htm

National Library Service for the Blind and Physically Handicapped, Library of Congress
1291 Taylor Street, N.W.
Washington, D.C. 20011
202.707.5100; 202.707.0744 (TTY);
800.424.8567
nls@loc.gov
www.loc.gov/nls

Prevent Blindness America
500 E. Remington Road
Schaumburg, IL 60173
847.843.2020; 800.331.2020
info@preventblindness.org
www.preventblindness.org

The Foundation Fighting Blindness (formerly the National Retinitis Pigmentosa Foundation)
11435 Cronhill Drive
Owings Mills, MD 21117-2220
410.568.0150; 410.363.7139 (TTY)
888.394.3937; 800.683.5551 (TTY)
info@blindness.org
www.blindness.org

FS13, January 2004

IDEAs that Work
U.S. Office of Special Education Programs

AED

Publication of this document is made possible through Cooperative Agreement #H326N030003 between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Cerebral Palsy

NICHCY Disability Fact Sheet #2
June 2010

Jennifer's Story

Jen was born 11 weeks early and weighed only 2½ pounds. The doctors were surprised to see what a strong, wiggly girl she was. But when Jen was just a few days old, she stopped breathing and was put on a ventilator. After 24 hours she was able to breathe on her own again. The doctors did a lot of tests to find out what had happened, but they couldn't find anything wrong. The rest of Jen's time in the hospital was quiet, and after two months she was able to go home. Everyone thought she would be just fine.

At home, Jen's mom noticed that Jen was really sloppy when she drank from her bottle. As the months went by, Jen's mom noticed other things she didn't remember seeing with Jen's older brother. At six months, Jen didn't hold her head up straight. She cried a lot and would go stiff with rage. When Jen went back for her six-month checkup, the doctor was concerned by what he saw and what Jen's mom told him. He suggested that Jen's mom take the little girl to a doctor who could look closely at Jen's development. Jen's mom took her to a developmental specialist who finally put a name to all the little things that hadn't seemed right with Jen—cerebral palsy.

What is CP?

Cerebral palsy—also known as CP—is a condition caused by injury to the parts of the brain that control our ability to use our muscles and bodies. *Cerebral* means having to do with the brain. *Palsy* means weakness or problems with using the muscles. Often the injury happens before birth, sometimes during delivery, or, like Jen, soon after being born.

CP can be mild, moderate, or severe. Mild CP may mean a child is clumsy. Moderate CP may mean the child walks with a limp. He or she may need a special leg brace or a cane. More severe CP can affect all parts of a child's physical abilities. A child with moderate or severe CP may have to use a wheelchair and other special equipment.

Sometimes children with CP can also have learning problems, problems with hearing or seeing (called *sensory problems*), or intellectual disabilities. Usually, the greater the injury to the brain, the more severe the CP. However, CP doesn't get worse over time, and most children with CP have a normal life span.

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How Common is CP?

Cerebral palsy occurs in approximately 2 per 1000 live births. This frequency rate hasn't changed in more than four decades, even with the significant advances in the medical care of newborns.[1]

What Are the Signs of CP?

There are four main types of CP:

• *Spastic CP* is where there is too much muscle tone or tightness. Movements are stiff, especially in the legs, arms, and/or back. Children with this form of CP move their legs awkwardly, turning in or scissoring their legs as they try to walk. This form of CP occurs in 50-75% of all cases.

• *Athetoid CP* (also called *dyskinetic CP*) can affect movements of the entire body. Typically, this form of CP involves slow, uncontrolled body movements and low muscle tone that makes it hard for the person to sit straight and walk. This form occurs in 10-20% of all cases.

• *Ataxic CP* involves poor coordination, balance, and depth perception and occurs in approximately 5-10% of all cases.

• *Mixed CP* is a combination of the symptoms listed above. A child with mixed CP has both high and low tone muscle. Some muscles are too tight, and others are too loose, creating a mix of stiffness and involuntary movements.[2]

More words used to describe the different types of CP include:

• *Diplegia*—This means only the legs are affected.

• *Hemiplegia*—This means one half of the body (such as the right arm and leg) is affected.

• *Quadriplegia*—This means both arms and legs are affected, sometimes including the facial muscles and torso.

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, the Individuals with Disabilities Education Act (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).

Under IDEA, children with CP are usually found eligible for services under the category of "Orthopedic Impairment." We've included IDEA's definition of orthopedic impairment in the box below.

To access early intervention services for a child up to his or her 3rd birthday, consult NICHCY's *State Resource Sheet* for your state

Definition of "Orthopedic Impairment" under IDEA

Under IDEA, cerebral palsy is considered an "orthopedic impairment," which is defined as:

> ...a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g.,cerebral palsy, amputations, and fractures or burns that cause contractures).
>
> *[34 CFR §300.8(c)(9)]*

(available online at: http://www.nichcy.org/families-community/states/). You'll find a listing for early intervention under the first section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To access special education services for a school-aged child, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

What About Treatment?

With early and ongoing treatment the effects of CP can be reduced. Many children learn how to get their bodies to work for them in other ways. For example, one infant whose CP keeps him from crawling may be able to get around by rolling from place to place.

Typically, children with CP may need different kinds of therapy, including:

- *Physical therapy* (PT), which helps the child develop stronger muscles such as those in the legs and trunk. Through PT, the child works on skills such as walking, sitting, and keeping his or her balance.

- *Occupational therapy* (OT), which helps the child develop fine motor skills such as dressing, feeding, writing, and other daily living tasks.

- *Speech-language pathology* (S/L), which helps the child develop his or her communication skills. The child may work in particular on speaking, which may be difficult due to problems with muscle tone of the tongue and throat.

All of these are available as related services in both early intervention programs (for very young children) and special education (for school-aged children).

Children with CP may also find a variety of special equipment helpful. For example, braces (also called AFOs) may be used to hold the foot in place when the child stands or walks. Custom splints can provide support to help a child use his or her hands. A variety of therapy equipment and adapted toys are available to help children play and have fun while they are working their bodies. Activities such as swimming or horseback riding can help strengthen weaker muscles and relax the tighter ones.

New medical treatments are being developed all the time. Sometimes surgery, Botox injections, or other medications can help lessen the effects of CP, but there is no cure for the condition. It's also important to understand that cerebral palsy is not contagious, not inherited, and not progressive.[3] The symptoms will differ from person to person and change as children and their nervous systems mature.[4]

What About School?

A child with CP can face many challenges in school and is likely to need individualized help. Fortunately, states are responsible for meeting the educational needs of children with disabilities.

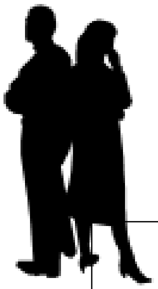
As we've said, for children up to the 3rd birthday, services are provided through an early intervention system. Staff work with the child's family to develop what is known as an Individualized Family Services Plan, or IFSP. The IFSP will describe the child's unique needs as well as the services the child will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with CP. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

For school-aged children, including preschoolers, special education and related services will be provided through the school system. School staff will work with the child's parents to develop an Individualized Education Program, or IEP. The IEP is similar to an IFSP in that it describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services, which can include PT, OT, and speech-language pathology, are provided at no cost to parents.

In addition to therapy services and special equipment, children with CP may need what is known as *assistive technology*. Examples of assistive technology include:

• *Communication devices,* which can range from the simple to the sophisticated. Communication boards, for example, have pictures, symbols, letters, or words attached. The child communicates by pointing to or gazing at the pictures or symbols. Augmentative communication devices are more sophisticated and include voice synthesizers that enable the child to "talk" with others.

• *Computer technology,* which can range from electronic toys with special switches to sophisticated computer programs operated by simple switch pads or keyboard adaptations.



The ability of the brain to find new ways of working after an injury is remarkable. Even so, it can be difficult for parents to imagine what their child's future will be like. Good therapy and handling can help, but the most important "treatment" the child can receive is love and encouragement, with lots of typical childhood

Tips for Parents

- Learn about CP. The more you know, the more you can help yourself and your child. See the list of resources and organizations at the end of this publication.
- Love and play with your child. Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.
- Learn from professionals and other parents how to meet your child's special needs, but try not to turn your lives into one round of therapy after another.
- Ask for help from family and friends. Caring for a child with CP is hard work. Teach others what to do and give them plenty of opportunities to practice while you take a break.
- Keep informed about new treatments and technologies that may help. New approaches are constantly being worked on and can make a huge difference to the quality of your child's life. However, be careful about unproven new "fads."
- Learn about assistive technology that can help your child. This may include a simple communication board to help your child express needs and desires, or may be as sophisticated as a computer with special software.
- Be patient, keep up your hope for improvement. Your child, like every child, has a whole lifetime to learn and grow.
- Work with professionals in early intervention or in your school to develop an IFSP or an IEP that reflects your child's needs and abilities. Be sure to include related services such as speech-language pathology, physical therapy, and occupational therapy if your child needs these. Don't forget about assistive technology either!

experiences, family, and friends. With the right mix of support, equipment, extra time, and accommodations, all children with CP can be successful learners and full participants in life.

Tips for Teachers

- Learn more about CP. The resources and organizations at the end of this publication will help you.
- This may seem obvious, but sometimes the "look" of CP can given the mistaken impression that a child who has CP cannot learn as much as others. Focus on the individual child and learn firsthand what needs and capabilities he or she has.
- Tap into the strategies that teachers of students with learning disabilities use for their students. Become knowledgeable about different learning styles. Then you can use the approach best suited for a particular child, based upon that child's learning abilities as well as physical abilities.
- Be inventive. Ask yourself (and others), "How can I adapt this lesson for this child to maximize *active, hands-on* learning?"
- Learn to love assistive technology. Find experts within and outside your school to help you. Assistive technology can mean the difference between independence for your student or not.
- Always remember, parents are experts, too. Talk candidly with your student's parents. They can tell you a great deal about their daughter's or son's special needs and abilities.
- Effective teamwork for the child with CP needs to bring together professionals with diverse backgrounds and expertise. The team must combine the knowledge of its members to plan, implement, and coordinate the child's services.

References

[1] eMedicine. (2009, March). *Cerebral palsy.* Available online at: http://emedicine.medscape.com/article/310740-overview

[2] United Cerebral Palsy. (2001). *General information: Cerebral palsy facts and figures*. Available online at: www.ucp.org/ucp_channeldoc.cfm/1/11/10427/10427-10427/447

[3] Healthcommunities.com. (2007, December). *Cerebral palsy.* Available online at: www.neurologychannel.com/cerebralpalsy/index.shtml

[4] *Ibid.*

Resources and *Organizations* are listed on the next page.

→

Organizations and Resources

United Cerebral Palsy
1.800.872.5827
http://www.ucp.org

Find an incredible wealth of information and connections at UCP, including the chapters working in your state and publications and resource pages for parents and professionals in English and in Spanish.

Medline
This service of the National Institutes of Health is an excellent place to learn about CP and keep on top of the latest medical treatments and therapies. Two web pages in particular to visit are:

- Medline's CP fact sheet
  www.nlm.nih.gov/medlineplus/cerebralpalsy.html
- Medline's interactive tutorial on CP
  www.nlm.nih.gov/medlineplus/tutorials/cerebralpalsy/htm/index.htm

The CDC | Centers for Disease Control and Prevention
1.800.CDC.INFO
Information in English and Spanish.
http://www.cdc.gov/ncbddd/cp/index.html

NINDS | National Institute on Neurological Disorders and Stroke
1.800.352.9424
Information in English and Spanish.
http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

4MyChild
1.800.469.2445
http://www.cerebralpalsy.org/

Woodbine House
1.800.843.7323
Visit this commercial publisher to connect with a book series on CP, including a guide for parents; a children's book; and a guide to teaching motor skills to children with CP. Read more about these resources at:
http://www.woodbinehouse.com/Cerebral-Palsy.12.0.0.2.htm

Cerebral Palsy Guide
This guide offers extensive information on CP from a medical perspective.
http://gait.aidi.udel.edu/gaitlab/cpGuide.html

FS2—June 2010

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Emotional Disturbance

NICHCY Disability Fact Sheet #5
June 2010

The mental health of our children is a natural and important concern for us all. The fact is, many mental disorders have their beginnings in childhood or adolescence, yet may go undiagnosed and untreated for years.[1]

We refer to mental disorders using different "umbrella" terms such as emotional disturbance, behavioral disorders, or mental illness. Beneath these umbrella terms, there is actually a wide range of specific conditions that differ from one another in their characteristics and treatment. These include (but are not limited to):

- anxiety disorders;
- bipolar disorder (sometimes called manic-depression);
- conduct disorders;
- eating disorders;
- obsessive-compulsive disorder (OCD); and
- psychotic disorders.

You may be reading this fact sheet with one of these specific disorders in mind, or you may be looking for information about emotional disturbances in general. In either case, keep reading to find out what different emotional distubances have in common, how they are defined in federal law, and where to find more detailed information on specific disorders.

Definition

We've chosen to use the term "emotional disturbance" in this fact sheet because that is the term used in the nation's special education law, the Individuals with Disabilities Education Act (IDEA). IDEA defines *emotional disturbance* as follows:

> "...a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:
>
> (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
>
> (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
>
> (C) Inappropriate types of behavior or feelings under normal circumstances.
>
> (D) A general pervasive mood of unhappiness or depression.
>
> (E) A tendency to develop physical symptoms or fears associated with personal or school problems."[2]

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http://nichcy.org

As defined by IDEA, emotional disturbance includes schizophrenia but does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.[3]

Characteristics

As is evident in IDEA's definition, emotional disturbances can affect an individual in areas beyond the emotional. Depending on the specific mental disorder involved, a person's physical, social, or cognitive skills may also be affected. The National Alliance on Mental Illness (NAMI) puts this very well:

> Mental illnesses are medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life.[4]

Some of the characteristics and behaviors seen in children who have an emotional disturbance include:

- Hyperactivity (short attention span, impulsiveness);
- Aggression or self-injurious behavior (acting out, fighting);
- Withdrawal (not interacting socially with others, excessive fear or anxiety);

- Immaturity (inappropriate crying, temper tantrums, poor coping skills); and
- Learning difficulties (academically performing below grade level).

Children with the most serious emotional disturbances may exhibit distorted thinking, excessive anxiety, bizarre motor acts, and abnormal mood swings.

Many children who do not have emotional disturbance may display some of these same behaviors at various times during their development. However, when children have an emotional disturbance, these behaviors continue over long periods of time. Their behavior signals that they are not coping with their environment or peers.

Causes

No one knows the actual cause or causes of emotional disturbance, although several factors—heredity, brain disorder, diet, stress, and family functioning—have been suggested and vigorously researched. A great deal of research goes on every day, but to date, researchers have not found that any of these factors are the direct cause of behavioral or emotional problems.

According to NAMI, mental illnesses can affect persons of any age, race, religion, or income. Further:

> Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Mental illnesses are treatable. Most people diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in an individual treatment plan.[5]

Frequency

According to the CDC (Centers for Disease Control and Prevention), approximately 8.3 million children (14.5%) aged 4–17 years have parents who've talked with a health care provider or school staff about the child's emotional or behavioral difficulties.[6] Nearly 2.9 million children have been prescribed medication for these difficulties.[7]

Help for School-Aged Children

IDEA requires that **special education and related services** be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, emotional disturbance, as defined by IDEA (and further specified by states). In the 2003-2004 school year, more than 484,000 children and youth with emotional disturbance received these services to address their individual needs related to emotional disturbance.[8]

Determining a child's eligibility for special education and related services begins with a full and individual evaluation of the child. Under IDEA, this evaluation is provided free of charge in public schools.

There is a lot to know about the special education process, much of which you can learn at NICHCY. We invite you to read the wide range of publications we offer on the topic, especially those listed in the box below.

A Look at Specific Emotional Disturbances

As we mentioned, emotional disturbance is a commonly used umbrella term for a number of different mental disorders. Let's take a brief look at some of the most common of these.

Anxiety Disorders

We all experience anxiety from time to time, but for many people, including children, anxiety can be excessive, persistent, seemingly uncontrollable, and overwhelming. An irrational fear of everyday situations may be involved. This high level of anxiety is a definite warning sign that a person may have an anxiety disorder.

As with the term emotional disturbance, "anxiety disorder" is an umbrella term that actually refers to several distinct disabilities that share the core characteristic of irrational fear: generalized anxiety disorder (GAD), obsessive-compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD), social anxiety disorder (also called social phobia), and specific phobias.[9]

According to the Anxiety Disorders Association of America, anxiety disorders are the most common psychiatric illnesses affecting children and adults.[10] They are also highly treatable. Unfortunately, only about 1/3 of those affected receive treatment.[11]

Bipolar Disorder

Also known as manic-depressive illness, bipolar disorder is a serious medical condition that causes dramatic mood swings from overly "high" and/or irritable to sad and hopeless, and then back again, often with periods of normal mood in between. Severe changes in energy and behavior go along with these changes in mood.[12]

For most people with bipolar disorder, these mood swings and related symptoms can be stabilized over time using an approach that combines medication and psychosocial treatment.[13]

Conduct Disorder

Conduct disorder refers to a group of behavioral and emotional problems in youngsters. Children and adolescents with this disorder have great difficulty following rules and behaving in a socially acceptable way.[14] This may include some of the following behaviors:

- aggression to people and animals;
- destruction of property;
- deceitfulness, lying, or stealing; or
- truancy or other serious violations of rules.[15]

Read More about the Special Education Process at NICHCY

- *10 Basic Steps in Special Education*
  http://nichcy.org/schoolage/steps/
- *Questions Often Asked by Parents about Special Education Services*
  http://nichcy.org/publications/lg1
- *Evaluating Children for Disability*
  http://nichcy.org/schoolage/evaluation/
- *Developing Your Child's IEP*
  http://nichcy.org/publications/pa12

Although conduct disorder is one of the most difficult behavior disorders to treat, young people often benefit from a range of services that include:

- training for parents on how to handle child or adolescent behavior;
- family therapy;
- training in problem solving skills for children or adolescents; and
- community-based services that focus on the young person within the context of family and community influences.[16]

Eating Disorders

Eating disorders are characterized by extremes in eating behavior—either too much or too little—or feelings of extreme distress or concern about body weight or shape. Females are much more likely than males to develop an eating disorder.[17]

Anorexia nervosa and bulimia nervosa are the two most common types of eating disorders. Anorexia nervosa is characterized by self-starvation and dramatic loss of weight. Bulimia nervosa involves a cycle of binge eating, then self-induced vomiting or purging. Both of these disorders are potentially life-threatening.[18]

Binge eating is also considered an eating disorder. It's characterized by eating excessive amounts of food, while feeling unable to control how much or what is eaten. Unlike with bulimia, people who binge eat usually do not purge afterward by vomiting or using laxatives.[19]

According to the National Eating Disorders Association:

> The most effective and long-lasting treatment for an eating disorder is some form of psychotherapy or counseling, coupled with careful attention to medical and nutritional needs. Some medications have been shown to be helpful. Ideally, whatever treatment is offered should be tailored to the individual, and this will vary according to both the severity of the disorder and the patient's individual problems, needs, and strengths.[20]

Obsessive-Compulsive Disorder

Often referred to as OCD, obsessive-compulsive disorder is actually considered an anxiety disorder (which was discussed earlier in this fact sheet). OCD is characterized by recurrent, unwanted thoughts (obsessions) and/or repetitive behaviors (compulsions). Repetitive behaviors (handwashing, counting, checking, or cleaning) are often performed with the hope of preventing obsessive thoughts or making them go away. Performing these so-called "rituals," however, provides only temporary relief, and *not* performing them markedly increases anxiety.[21]

A large body of scientific evidence suggests that OCD results from a chemical imbalance in the brain.[22] Treatment for most people with OCD should include one or more of the following:

- a therapist trained in behavior therapy;
- Cognitive Behavior Therapy (CBT)
- medication (usually an antidepressant).[23]

Psychotic Disorders

"Psychotic disorders" is another umbrella term used to refer to severe mental disorders that cause abnormal thinking and perceptions. Two of the main symptoms are delusions and hallucinations. *Delusions* are false beliefs, such as thinking that someone is plotting against you. *Hallucinations* are false perceptions, such as hearing, seeing, or feeling something that is not there. Schizophrenia is one type of psychotic disorder.[24] There are others as well.

Treatment for psychotic disorders will differ from person to person, depending on the specific disorder involved. Most are treated with a combination of medications and psychotherapy (a type of counseling).[25]

More about School

As mentioned, emotional disturbance is one of the categories of disability specified in IDEA. This means that a child with an emotional disturbance may be eligible for special education and related services in public school. These services can be of tremendous help to students who have an emotional disturbance.

Typically, educational programs for children with an emotional disturbance need to include attention to providing emotional and behavioral support as well as helping them to master academics, develop social skills, and increase self-awareness, self-control, and self-esteem. A large body of research exists regarding methods of providing students with positive behavioral support (PBS) in the school environment, so that problem behaviors are minimized and positive, appropriate behaviors are fostered. (See the resource section at the end of this fact sheet for more information on PBS.) It is also important to know that, within the school setting:

- For a child whose behavior impedes learning (including the learning of others), the team developing the child's Individualized Education Program (IEP) needs to consider, if appropriate, strategies to address that behavior, including positive behavioral interventions, strategies, and supports.
- Students eligible for special education services under the category of emotional disturbance may have IEPs that include psychological or counseling services. These are important related services available under IDEA and are to be provided by a qualified social worker, psychologist, guidance counselor, or other qualified personnel.

For Science Teachers and Their Students in Grades 6-8: The Science of Mental Illness

This inquiry-based curriculum from the National Institutes of Health is designed to help students in grades 6-8 gain a better understanding of the biological basis of mental illnesses and what mental illnesses are—and what they are not.

http://science.education.nih.gov/supplements/nih5/mental/default.htm

Other Considerations

Children and adolescents with an emotional disturbance should receive services based on their individual needs, and everyone involved in their education or care needs to be well-informed about the care that they are receiving. It's important to coordinate services between home, school, and community, keeping the communication channels open between all parties involved.

The Importance of Support

Families often need help in understanding their child's disability and how to address the needs that arise from the disability. Help is available from psychiatrists, psychologists, and other mental health professionals that work in the public or private sector. There is also a network of mental health support operating in every state as well as locally.

To locate systems of support in your community or state, visit the organizations we've listed in the box on the next page. They can connect you with local resources, including support groups that provide connection and understanding, information, referral, and advocacy for those living with emotional disturbance.

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[2] *Code of Federal Regulations,* Title 34, §300.8(c)(4)(i)

[3] *Code of Federal Regulations,* Title 34, §300.8(c)(4)(ii)

[4] National Alliance on Mental Illness. (2010). *What is mental illness: Mental illness facts.* Available online at: http://tinyurl.com/3ew3d

[5] *Ibid.*

Finding Support Locally

Support groups can be extremely helpful to individuals and families living with emotional disturbance. To find a state or local support group, visit:

Mental Health America | 1.800.969.6642
http://www.mentalhealthamerica.net/farcry/go/searchMHA

NAMI | National Alliance on Mental Illness | 1.800.950.NAMI
http://www.nami.org/template.cfm?section=Your_Local_Nami

National Mental Health Consumers' Self-Help Clearinghouse
1.800.553.4539 | http://www.cdsdirectory.org/

There are also support groups available from organizations that address specific mental disorders under the umbrella term of emotional disturbance. See the resources page to identify some of these groups.

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This publication is made possible through Cooperative Agreement #H326N080003 between FHI 360 and the Office of Special Education Programs, U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Resources of More Information

AACAP | American Academy of Child and Adolescent Psychiatry | AACAP offers *Facts for Families,* a series in English and Spanish that includes many briefs on specific mental disorders, including the ones mentioned in this publication.

Fact sheets in English:
http://www.aacap.org/cs/root/facts_for_families/facts_for_families_keyword_alphabetical

Fact sheets in Spanish:
http://www.aacap.org/cs/root/facts_for_families/informacion_para_la_familia

AACAP also operates different Resource Centers, which offer consumer-friendly definitions, answers to frequently asked questions, clinical resources, expert videos, *Facts for Families,* and much more. Visit the Resource Center home page if you are concerned with one of the following:

Anxiety Disorders
Autism
Bipolar Disorder
Conduct Disorder
Depression
Oppositional Defiant Disorder

Resource Center home page
http://www.aacap.org/cs/resource.centers

American Psychological Association | The APA is also a fountain of information and support on specific emotional disturbances.

- English | www.apa.org/index.aspx
- Spanish | www.apa.org/centrodeapoyo/index.aspx

National Institute of Mental Health | NIMH is clearly a source of authoritative information on specific mental disorders. Phone: 1.866.615.6464. TTY: 1.866.415.8051

- English | http://www.nimh.nih.gov/health/index.shtml
- Spanish | http://www.nimh.nih.gov/health/publications/espanol/index.shtml

National Alliance on Mental Illness (NAMI) | NAMI is an excellent source of information and connection on mental illness, including the individual disorders mentioned in this fact sheet. NAMI's website and toll-free helpline are available in English and Spanish.

Toll-free Helpline
1.800.950.6264

Website in English
http://www.nami.org

Website in Spanish
http://tinyurl.com/28rweba

SAMHSA's National Mental Health Information Center | The Center provides information and referrals on mental health services to the public through its toll-free number and website.

- Toll-free infoline | 1.800.789.2647
- Website | http://store.samhsa.gov/home

Detailed information on specific emotional disturbances, or related issues such as positive behavior supports, is also available from these sources:

Anxiety Disorders Association of America
http://www.adaa.org

Center on Positive Behavioral Interventions and Supports | The PBIS Center provides research-based information on how to provide behavioral supports to children who need them. | www.pbis.org

Conduct Disorders | A soft place to land for battle-weary parents
http://www.conductdisorders.com/

Encyclopedia of Mental Disorders
http://www.minddisorders.com/index.html

National Eating Disorders Association
1.800.931.2237 | www.nationaleatingdisorders.org

Something Fishy | (eating disorders)
1.866.690.7239 | http://www.something-fishy.org

Deaf-Blindness

NICHCY Disability Fact Sheet #16
Updated March 2012

Introduction

There are approximately 45,000 to 50,000 individuals in the U.S. who are deaf-blind.[1] According to the 2007 National Deaf-Blind Child Count, more than 10,000 are children under the age of 21.[2]

The word "deaf-blindness" may seem as if a person cannot hear or see at all. The term actually describes a person who has some degree of loss in both vision and hearing. The amount of loss in either vision or hearing will vary from person to person.

Our nation's special education law, the Individuals with Disabilities Education Act (IDEA), defines "deaf-blindness" as:

> ...concomitant [simultaneous] hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. [§300.8(c)(2)]

The National Consortium on Deaf-Blindness observes that the "key feature of deaf-blindness is that the combination of losses limits access to auditory and visual information."[3] This can severely limit an individual's natural opportunities to learn and communicate with others.

Finding Help for Children with Deaf-Blindness

Very young children (birth up to the third birthday) who are deaf-blind are typically eligible for ***early intervention services*** under the Infants and Toddlers with Disabilities program of IDEA (also called Part C).

These services are extremely important to children with deaf-blindness and their families, for the services are designed to address the child's developmental and learning needs. Parents are involved in deciding what services their child and family need to address the challenges of deaf-blindness. Services are either provided free of charge to families or on a sliding cost scale based on the family's income. To find the early intervention program in your area, ask

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your pediatrician, get in touch with the pediatric unit of a nearby hospital, or take a look at NICHCY's *State Sheet* for your state. The central contact for the early intervention system in your state is listed under "State Agencies." This office can put you in touch with a program near you. Find the State Sheet online at: http://nichcy.org/state-organization-search-by-state

Special education | When children with deaf-blindness reach the age of 3, they transition into *special education services* under Part B of IDEA. Special education services are provided free through the public school system. Even if a child with deaf-blindness is not in school yet (for example, a four-year-old), the school system is still responsible for making sure that special education and related services are available to the child. Because deaf-blindness causes severe communication and other developmental and educational needs, it's very important for children with deaf-blindness to receive special education and related services to address their individual needs. You can find out more about these services and how to access them by contacting the local elementary school in your area.

Rather than duplicate the excellent work of others, NICHCY is pleased to connect you with an array of information and assistance already available on deaf-blindness. What's listed in the rest of this fact sheet is not all that's out there, information-wise, but will certainly lead you to the founts of experience and knowledge that will be very helpful in addressing the challenges associated with deaf-blindness.

Resources for You

About Deaf-Blindness

- *FAQs about deaf-blindness.*
  www.aadb.org/FAQ/faq_DeafBlindness.html
- *Overview of deaf-blindness.*
  www.nationaldb.org/NCDBProducts.php?prodID=38
- *Children who are deaf-blind.*
  http://www.nationaldb.org/documents/products/population.pdf
- *Information about deaf-blindness.*
  Personal insights and information from an individual with deaf-blindness.
  www.deafblind.com/info-db.html
- *How do deaf-blind people communicate?*
  www.aadb.org/factsheets/db_communications.html
- *The Deafblind Manual Alphabet.*
  www.deafblind.com/card.html
- *Find what's out there on your topic.*
  Search the world's most comprehensive collection of books, articles, proceedings, videos, and other materials about deaf-blindness.
  http://www.nationaldb.org/ISLibrary.php

Finding Services

- *State deaf-blind projects.*
  Every state has a project that specializes in deaf-blindness. Find yours at the National Consortium on Deaf-Blindness.
  http://www.nationaldb.org/ppStateDBProjects.php
- *Visit the American Association of the Deaf-Blind.*
  AADB provides a listing of state and local organizations for deaf-blind people and also a listing of service and rehabilitation agencies around the country.
  http://www.aadb.org/resources/resources.html

The Experts on Deaf-Blindness

- *National Consortium on Deaf-Blindness* http://www.nationaldb.org
- *Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)* http://www.hknc.org
- *American Association of the Deaf-Blind (AADB)* http://www.aadb.org
- *Deafblind International* http://www.deafblindinternational.org/

In Children's Early Years

- *Early interactions with children who are deaf-blind.* http://www.nationaldb.org/NCDBProducts.php?prodID=34
- *Communication at home and in the community.* Helpful strategies and suggestions from parents and families with a child who is deaf-blind. http://www.nationaldb.org/documents/products/parent99.pdf
- *Communication fact sheets for parents.* http://www.nationaldb.org/documents/products/communication-a.pdf
- *Talking the language of the hands to the hands.* This publication examines the importance of hands for the person who is deaf-blind, reviews hand development, and identifies specific teaching skills that facilitate hand development and expressiveness in persons who are deaf-blind. http://www.nationaldb.org/NCDBProducts.php?prodID=47
- *The intervener in early intervention and educational settings for children with deaf-blindness.* http://www.nationaldb.org/documents/products/intervener.pdf

School Matters

- *Considerations when teaching students who are deaf-blind (NETAC Teacher Tipsheet).* http://wwwcms.hutchcc.edu/uploadedFiles/Student_Resources/Disability_Services/tpshtdb.pdf
- *Teacher packet.* A selection of articles, fact sheets, bibliographies, and state resources organized to provide information for the teacher who is new to the deaf-blind student. http://www.nationaldb.org/NCDBProducts.php?prodID=48

Transition to Adulthood for Students with Deaf-Blind

- *Transition planning for students with deaf-blindness.* http://nationaldb.org/documents/products/transition01-09.pdf
- *More on transition planning: Coaching for students, parents, and professionals.* http://centerondeafness.utk.edu/pec/transition%20planning%20for%20deafblind.pdf
- *Self-determination for students who are deaf-blind.* http://www.nationaldb.org/documents/products/self-determ.pdf
- *National Transition Follow-Up Study of Youth Identified as Deaf-blind: Parent Perspectives.* http://www.nationaldb.org/documents/products/transition.PDF

For Administrators

- *Deaf-Blind Child Counts: Issues and challenges.* http://www.projectforum.org/docs/Deaf-BlindChildCounts-IssuesandChallenges.pdf
- *National Deaf-Blind Child Counts.* The National Deaf-Blind Child Count, reported by each state's Project for Children and Youth who are Deaf-Blind, is collected annually on December 1 of each year and is a "snapshot" of the characteristics, educational

settings and living arrangements of children and youth who fit the state project's definition of being deaf-blind as of that date. The Annual Reports from 2004 through 2010 are available in PDF, at: www.nationaldb.org/TAChildCount.php#Summaries

- *Psychological evaluation of children who are deaf-blind.*
  This fact sheet provides answers to frequently asked questions about psychological evaluations for infants, children, and adults who are deaf-blind. http://www.nationaldb.org/NCDBProducts.php?prodID=40

- *Recommendations on the training of interveners for students who are deaf-blind.*
  http://www.dblink.org/pdf/intervener-train.pdf

- *Service delivery in rural areas.*
  Here's a manual or blueprint for rural agencies to develop deaf-blind services in their local areas.
  http://resources.pepnet.org/files/107_2009_5_18_18_08_PM.pdf

Resources in Spanish

- Visit the National Consortium on Deaf-Blindness, where you'll find many fact sheets and other resources available in Spanish. http://www.nationaldb.org/ISProductos.php

- *English/Spanish Specialized Deaf-Blind Glossary/Espanol Glosario Especializado En Sordoceguera.* http://www.nationaldb.org/documents/products/esgloss.pdf

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NICHCY Disability Fact Sheet #16
Updated March 2012

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Deafness and Hearing Loss

A publication of NICHCY
Disability Fact Sheet #3
June 2010

Caroline's Story

Caroline is six years old, with bright brown eyes and, at the moment, no front teeth, like so many other first graders. She also wears a hearing aid in each ear—and has done so since she was three, when she was diagnosed with a moderate hearing loss.

For Caroline's parents, there were many clues along the way. Caroline often didn't respond to her name if her back was turned. She didn't startle at noises that made other people jump. She liked the TV on loud. But it was the preschool she started attending when she was three that first put the clues together and suggested to Caroline's parents that they have her hearing checked. The most significant clue to the preschool was Caroline's unclear speech, especially the lack of consonants like "d" and "t" at the end of words.

So Caroline's parents took her to an audiologist, who collected a full medical history, examined the little girl's ears inside and out, ran a battery of hearing tests and other assessments, and eventually diagnosed that Caroline's inner ear (the cochlea) was damaged. The audiologist said she had *sensorineural hearing loss.*

Caroline was immediately fitted with hearing aids. She also began receiving special education and related services through the public school system. Now in the first grade, she regularly gets speech therapy and other services, and her speech has improved dramatically. So has her vocabulary and her attentiveness. She sits in the front row in class, an accommodation that helps her hear the teacher clearly. She's back on track, soaking up new information like a sponge, and eager for more.

NICHCY *is the*
National Dissemination Center for Children with Disabilities.

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Hearing Loss in Children

Hearing is one of our five senses. Hearing gives us access to sounds in the world around us—people's voices, their words, a car horn blown in warning or as *hello!*

When a child has a hearing loss, it is cause for immediate attention. That's because language and communication skills develop most rapidly in childhood, especially before the age of 3. When hearing loss goes undetected, children are delayed in developing these skills.[1]

Recognizing the importance of early detection, the Centers for Disease Control and Prevention (the CDC) recommends that every newborn be screened for hearing loss as early as possible, usually before they leave the hospital. Catching a hearing loss early means that treatment can start early as well and "help the child develop communication and language skills that will last a lifetime."[2]

Types of Hearing Loss

Before we describe the types of hearing loss a person may have, it's useful to know that sound is measured by:

- its loudness or intensity (measured in units called *decibels, dB*); and
- its frequency or pitch (measured in units called *hertz, Hz*).

Hearing loss is generally described as slight, mild, moderate, severe, or profound, depending upon how well a person can hear the intensities or frequencies most strongly associated with speech. Impairments in hearing can occur in either or both areas, and may exist in only one ear or in both ears. Generally, only children whose hearing loss is greater than 90 decibels (dB) are considered deaf.

There are four types of hearing loss, as follows.[3]

Conductive hearing losses are caused by diseases or obstructions in the outer or middle ear (the pathways for sound to reach the inner ear). Conductive hearing losses usually affect all frequencies of hearing evenly and do not result in severe losses. A person with a conductive hearing loss usually is able to use a hearing aid well or can be helped medically or surgically.

Sensorineural hearing losses result from damage to the delicate sensory hair cells of the inner ear or the nerves that supply it. These hearing losses can range from mild to profound. They often affect the person's ability to hear certain frequencies more than others. Thus, even with amplification to increase the sound level, a person with a sensorineural hearing loss may perceive distorted sounds, sometimes making the successful use of a hearing aid impossible.

A ***mixed hearing loss*** refers to a combination of conductive and sensorineural loss and means that a problem occurs in both the outer or middle and the inner ear.

A ***central hearing loss*** results from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself.

How Common is Hearing Loss?

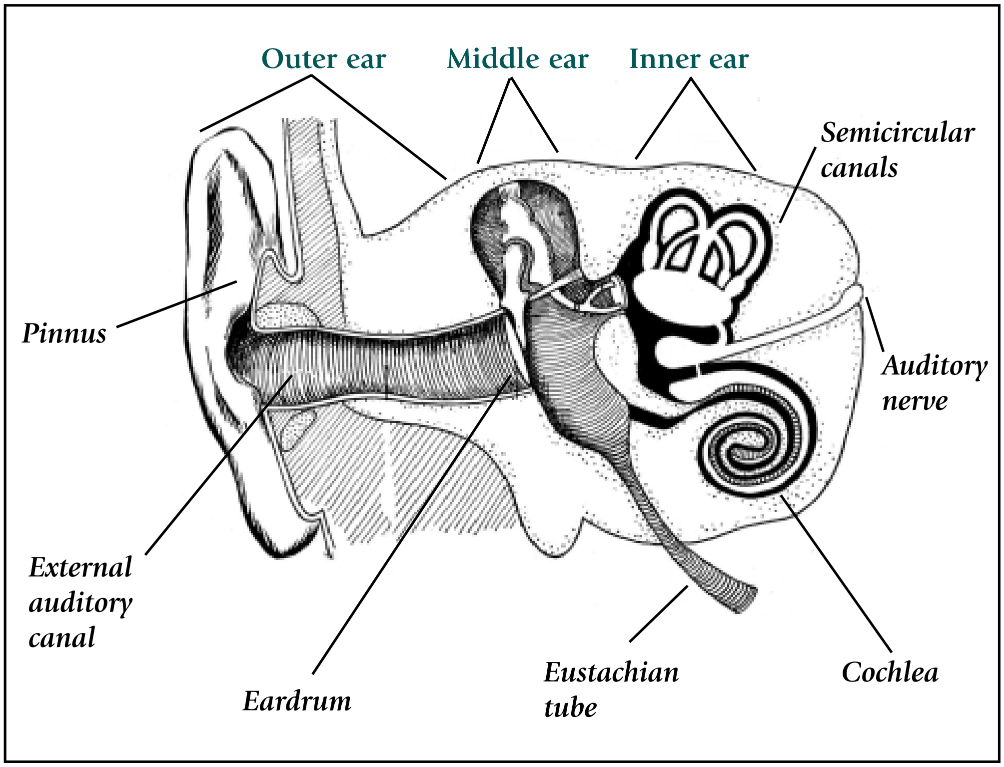
Each year in the United States, more than 12,000 babies are born with a hearing loss; often, the cause is unknown.[4] Profound deafness occurs in 4-11 per 10,000 children; in at least 50% of these cases, the cause is genetic.[5]

Through the Universal Newborn Hearing Screening program, many states now mandate that all newborns be screened for hearing loss within hours of birth.[7]

Signs of a Hearing Loss or Deafness

Just as with Caroline, our first grader, there will be signs that a child may not be hearing normally. Parents may notice that their child:

A diagram of the ear.[6]



- does not respond consistently to sounds or to his or her own name;
- asks for things to be repeated or often says "huh?"
- is delayed in developing speech or has unclear speech;
- turns the volume up loud on the TV and other electronic devices.[8]

Causes of Hearing Loss and Deafness

Hearing loss and deafness can be either:

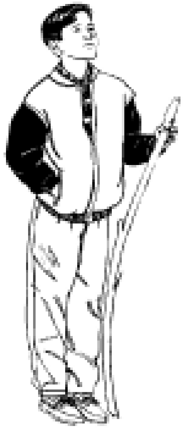
- *acquired,* meaning that the loss occurred after birth, due to illness or injury; or
- *congenital,* meaning that the hearing loss or deafness was present at birth.

The most common cause of acquired hearing loss is exposure to noise.[9] Other causes can include:

- build up of fluid behind the eardrum;
- ear infections (known as otitis media);
- childhood diseases, such as mumps, measles, or chicken pox; and
- head trauma.

Congenital causes of hearing loss and deafness include:

- a family history of hearing loss or deafness;
- infections during pregnancy (such as rubella);
- complications during pregnancy (such as the Rh factor, maternal diabetes, or toxicity).



A child's hearing loss or deafness may also be a characteristic of another disability such as Down syndrome, Usher syndrome, Treacher Collins syndrome, Crouzon syndrome, and Alport syndrome.[10]

In all cases, early detection and treatment are very important to the child's development.

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, the Individuals with Disabilities Education Act (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).

To access early intervention: To identify the EI program in your neighborhood, consult NICHCY's *State-Specific Information* for your state (online at: http://nichcy.org/state-organization-search-by-state). Early intervention is listed under the first section, State Agencies. The agency that's identified will be able to put you in contact with the early intervention program in your community. There, you can have your child evaluated free of charge and, if found eligible, your child can begin receiving early intervention services.

To access special education and related services: We recommend that you get in touch with your local public school system. Calling the elementary 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 and, if found eligible, he or she can begin receiving services specially designed to address your child's needs.

There are also special services available to low-income children through the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program, the child health component of Medicaid. To learn more about the EPSDT program, visit: http://mchb.hrsa.gov/epsdt/

More on IDEA

It's helpful to know that, while the terms "hearing impairment" and "hearing loss" are often used to describe a wide range of hearing losses, including deafness, IDEA actually defines the two terms separately, as follows:

> Hearing impairment is defined by IDEA as "an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance."
>
> Deafness is defined as "a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification."

Thus, deafness is viewed as a condition that prevents an individual from receiving sound in all or most of its forms. In contrast, a child with a hearing loss can generally respond to auditory stimuli, including speech.

The U.S. Department of Education reports that 14,787 children received audiology services in early intervention programs in the fall of 2004, while 139,643 children received speech-language pathology services.[11]

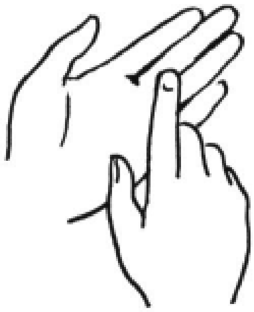
The Department also reports that, during the 2003 school year, 79,522 students aged 3 to 21 received special education services under the category of "hearing impairment."[12] However, the number of children with hearing loss and deafness is undoubtedly higher, since many of these students have other disabilities and may be served under other categories.

Educational Implications

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn. However, children who are hard of hearing or deaf generally require some form of special education services in order to receive an adequate education. Such services may include:

- regular speech, language, and auditory training from a specialist;
- amplification systems;
- services of an interpreter for those students who use sign language;
- favorable seating in the class to facilitate lip reading;
- captioned films/videos;
- assistance of a notetaker, who takes notes for the student with a hearing loss, so that the student can fully attend to instruction;
- instruction for the teacher and peers in alternate communication methods, such as sign language; and
- counseling.

Children who are hard of hearing will find it much more difficult than children who have normal hearing to learn vocabulary, grammar, word order, idiomatic expressions, and other aspects of verbal communication. For children who are deaf or have severe hearing losses, early, consistent, and conscious use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay. By age four or five, most children who are deaf are enrolled in school on a full-day basis and do special work on communication and language development.



It is important for teachers and audiologists to work together to teach the child to use his or her residual hearing to the maximum extent possible, even if the preferred means of communication is manual. Since the great majority of deaf children (over 90%) are born to hearing parents, programs should provide instruction for parents on implications of deafness within the family.

People with hearing loss use oral or manual means of communication or a combination of the two. Oral communication includes speech, lip reading, and the use of residual hearing. Manual communication involves signs and fingerspelling. Total Communication, as a method of instruction, is a combination of the oral method plus signing and fingerspelling.

Using the Relay Service

Individuals with hearing loss, including those who are deaf, now have many helpful devices available to them. Text telephones (known as TTs, TTYs, or TDDs) enable persons to type phone messages over the telephone network.

The Telecommunications Relay Service (TRS) makes it possible for TT users to communicate with virtually anyone (and vice versa) via telephone through a communications assistant. Dial 711 to access all telecommunications relay services anywhere in the United States. The relay service is free.

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Resources of Additional Information

In alphabetical order, here's a starter list of organizations providing info and guidance on deafness and hearing loss. Explore the sites below and the wealth of material they offer on types of hearing loss, newborn and early childhood screening, the EHDI program for early detection of hearing loss, guidance for parents, suggestions for educators working with children who are deaf or hard of hearing, and much more.

Organizations

Alexander Graham Bell Association for the Deaf and Hard of Hearing | www.agbell.org

American Hearing Research Foundation | www.american-hearing.org

American Society for Deaf Children |1.800.942.2732
www.deafchildren.org/

ASHA | American Speech-Language-Hearing Association
1.800.638.8255
www.asha.org/public/hearing/

Beginnings | *For parents of children who are deaf or hard of hearing*
www.ncbegin.org/index.php

Better Hearing Institute
1.800.327.9355
www.betterhearing.org

CDC | Centers for Disease Control and Prevention
1.800.CDC.INFO
http://www.cdc.gov/ncbddd/hearingloss/index.html

Deaf Culture Online
www.deaf-culture-online.com/index.html

Hands and Voices
www.handsandvoices.org/

Hearing Loss Association of America | www.hearingloss.org/

How's Your Hearing?
www.howsyourhearing.com/

Info to Go | Laurent Clerc National Deaf Education Center
202.651.5051
http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go.html

Listen Up! | www.listen-up.org

Medline Plus
www.nlm.nih.gov/medlineplus/hearingdisordersanddeafness.html

National Association of the Deaf
www.nad.org

National Center for Hearing Assessment & Management
435.797.3584
www.infanthearing.org/

NIDCD | National Institute on Deafness and Other Communication Disorders
1.800.241.1044
http://www.nidcd.nih.gov/health/hearing/Pages/Default.aspx

PEPNET | *Working to increase access to postsecondary education for persons who are deaf.*
www.pepnet.org

Helpful Readings on Specific Subjects

Your Child's Hearing Development Checklist |
www.nidcd.nih.gov/health/hearing/pages/silence.aspx

To Parents of Deaf Children |
http://www.deaf-culture-online.com/parents-of-deaf-children.html

Early Intervention
www.infanthearing.org/earlyintervention/index.html

Assistive Technology for Hearing
www.asha.org/public/hearing/treatment/assist_tech.htm

Communications Considerations A-Z |
www.handsandvoices.org/comcon/index.html

Communication Plan for a Child Who is Deaf or Hard of Hearing
www.handsandvoices.org/pdf/communication_plan.pdf

Cochlear Implants | http://www.nidcd.nih.gov/health/hearing/pages/coch.aspx

Resources for People Who Can't Afford Hearing Aids and Cochlear Implants |
www.hearingexchange.com/articles/paulas-110601.htm

Strategies for Teachers
www.as.wvu.edu/~scidis/hearing.html

Tips for Teachers
http://deafness.about.com/od/schooling/a/inclassroom.htm

Developmental Delay

NICHCY Disability Fact Sheet #9
Updated March 2012

Introduction

Think of all the skills that children have to learn when they come into the world: smiling, turning over, responding to people, communicating, eating solid food, crawling, standing, and on and on. We expect these skills to emerge naturally over time and know more or less when they should. At 3 months, Susana will probably be doing *this*, at 4 months, she'll be doing *that*. By a year, well, she'll be tottering around, getting into everything.

This timetable for skills to emerge is commonly called the *developmental milestones*. What's considered normal development is described broadly, because children don't necessarily learn skills at the same pace. Two different children born on the same day may learn the same skill months apart, and both can be considered "on schedule." It's when skills *don't* emerge as expected, more or less on that broad schedule, that parents and caregivers may become concerned.

If You're Concerned About a Child's Development

If you're reading this, perhaps you've become concerned about your child or one you care for. We're glad you're reading this, because there are many immediate things you can do to learn more and help your child. First, know that there's help available to find out just what the difficulties are, if any, and there's help available to address those difficulties. The good news is that this help is usually free, and it's available in every state.

First, you may want to talk with your pediatrician about your child's development. Don't be surprised if the pediatrician tells you not to worry, to be patient, to give your child more time to develop. Often, that's what parents hear, especially in the early stages of investigating their child's seeming delays. And it's often true. Children develop at different rates; the pediatrician is well aware that many children show sudden bursts in development rather than slow, steady growth.

On the other hand, your pediatrician may suggest that a developmental screening be conducted to see if, in fact, your child is experiencing a *developmental delay*. The screening is a quick, general measure of your child's skills

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202.884.8200 (Voice / TTY)
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http://nichcy.org

and development. It's not detailed enough to make a diagnosis, but its results indicate broadly whether or not a child should be referred for a more indepth *developmental evaluation*.

What's Involved in the Developmental Evaluation

The developmental evaluation should be conducted by a highly trained professional who can use the results to create a profile of your child's strengths and weaknesses across the range of five developmental areas. Those areas are:

- Physical development (fine motor skills, gross motor skills)
- Cognitive development (intellectual abilities)
- Communication development (speech and language)
- Social or emotional development (social skills, emotional control)
- Adaptive development (self-care skills)

The results of the developmental evaluation will be used to decide if your child needs *early intervention services* and/or a treatment plan. Early intervention services are specifically tailored to meet a child's individual needs and, as such, are a very important resource to children experiencing developmental delays.

For example, early intervention services can include:

- Assistive technology (devices a child might need)
- Audiology or hearing services
- Speech and language services
- Counseling and training for a family
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services

Things to Know

- States have a positive obligation to help children who are experiencing a developmental delay in one or more areas.
- Through the Child Find system that each state operates, developmental screenings and developmental evaluations are usually provided free of charge to families.
- If you're concerned about your child's development, talk to your child's pediatrician, who can refer you to the Child Find system in your area.
- Early intervention services are meant for children under the age of three. These services are usually provided to eligible families either free of charge or on a sliding payment scale that's determined by the family's income.
- You can find out how to access early intervention services in your area by talking to your child's pediatrician, calling a local hospital, or using NICHCY's *State Resource Sheet* for your state. All of our state sheets are available online, this moment, at: http://nichcy.org/state-organization-search-by-state

Once you've selected a state sheet to view, select "State Agencies" from the drop-down menu and click SEARCH. The contact information for the early intervention program for your state will appear in the list of state agencies you receive.

- NECTAC (the National Early Childhood Technical Assistance Center) is also a great source of this information. Use NECTAC's Contact Finder at: http://www.nectac.org/contact/contact.asp

- Special education services are meant for children over the age of three. Services are provided to eligible children free of charge through the public school system. If your child has passed his or her third birthday and you're concerned about a developmental delay or disability, call your local school (even if your child isn't enrolled there). Ask how and where to have your child evaluated under IDEA, our nation's special education law.

IDEA's Definition of Developmental Delay

As we just said, IDEA is the nation's special education law. Its full name is the Individuals with Disabilities Education Act. Through IDEA, early intervention services and special education services are made available to eligible children with developmental delays and disabilities.

Not surprisingly, IDEA includes a definition of developmental delay, which may be useful to know. Here it is:

> *Child with a disability* for children aged three through nine (or any subset of that age range, including ages three through five), may...include a child—
>
> (1) Who is experiencing developmental delays as defined by the State and as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: Physical development, cognitive development, communication development, social or emotional development, or adaptive development; and
>
> (2) Who, by reason thereof, needs special education and related services. [34 CFR §300.8(b)]

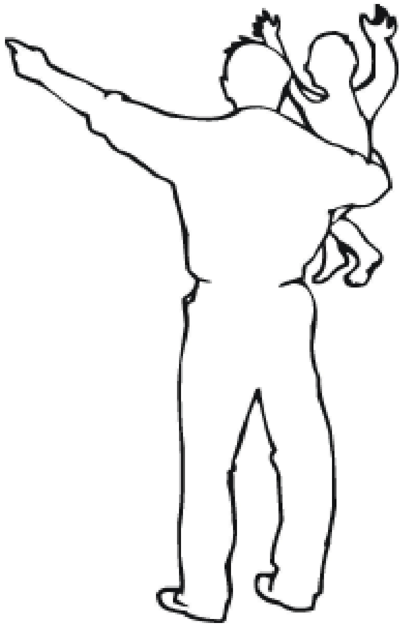
It's a good idea to find out if your state has added details to this definition of *developmental delay*. States are allowed to do so, if they choose. They also decide on the *age range of children* with whom the term may be used (3-5, 3-9, or any subset between 3-9). Your local school or early intervention program should be able to tell you the definition of developmental delay that's used in your area. You can also visit NECTAC (mentioned earlier) and find out how your state defines developmental delay, as well as the criteria of eligibility for services to young children, birth through 2 years of age, and their families. NECTAC makes this information available online at: http://www.nectac.org/~pdfs/pubs/nnotes21.pdf

It may be helpful to know that:

- your state may not *require* that your local school district also adopt and use the term developmental delay in working with children;

- if your local school district decides to use the term, it must use the same definition and age range as the state does;

- your local school district *may not* use the term at all if your state has chosen not to use the term.



Resources for You

It can be very helpful to read more about developmental delay. This has been just a brief overview, with pointers to loads of additional info and support. Below, we've identified a range of materials you can explore, which will of course lead you to still more!

- *Child development.*
  All about...from the CDC, the Centers for Disease Control and Prevention.
  http://www.cdc.gov/ncbddd/childdevelopment/index.html

- *Developmental screening.*
  From CDC, the Centers for Disease Control and Prevention.
  http://www.cdc.gov/ncbddd/childdevelopment/screening.html

- *Developmental milestones.*
  From NICHCY's own site.
  http://nichcy.org/disability/milestones/

- *What is developmental delay?*
  From How Kids Develop.
  http://www.howkidsdevelop.com/developDevDelay.html

- *Developmental delay.*
  From the Encyclopedia of Children's Health.
  http://www.healthofchildren.com/D/Developmental-Delay.html

- *Developmental delays.*
  From Keep Kids Healthy.
  http://www.keepkidshealthy.com/welcome/conditions/developmentaldelays.html

- *First Signs.*
  All about early detection of developmental delays and disabilities, especially autism.
  http://www.firstsigns.org/

- *Connect with other parents.*
  Interested in talking to other parents whose children have developmental delays? Try Parent to Parent. They'll connect you with other parents like yourself for support and exchange.
  http://www.p2pusa.org

- *Connect with the disability community and parent expertise.*
  Every state has a Parent Training and Information Center, known as the PTI. Some states have several. If you are looking to connect with state and local resources, or have questions about services and parent rights, talk to your PTI. Find the PTI for your state by visiting our State Resource Sheets, at:
  http://nichcy.org/state-organization-search-by-state

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NICHCY Disability Fact Sheet #9
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Down Syndrome

NICHCY Disability Fact Sheet #4
June 2010

Definition

Down syndrome is the most common and readily identifiable chromosomal condition associated with intellectual disabilities. It is caused by a chromosomal abnormality: for some unknown reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of intellectual disability may range from mild to severe, with the majority functioning in the mild to moderate range.

Because children with Down syndrome differ in ability, it's important that families and members of the school's education team place few limitations on potential capabilities and possible achievements. Each child with Down syndrome has his or her own talents and unique capacities, and it's important to recognize these and reinforce them. As the Family Doctor website states:

> In many important ways, children who have Down syndrome are very much the same as other children. They have the same moods and emotions, and they like to learn new things, to play and enjoy life. You can help your child by providing as many chances as possible for him or her to do these things. Read to your child and play with him or her, just as you would any other child. Help your child to have positive experiences with new people and places.[1]

Incidence of Down Syndrome

Nearly 5,000 babies are born with Down syndrome in the United States each year.[2] This means that 1 in every 733 babies is born with this condition.[3] Although parents of any age may have a child with Down syndrome, 80% are born to women under the age of 35.[4]

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Down syndrome is not a disease, nor is it contagious. Its most common forms usually do not occur more than once in a family.

Characteristics of Down Syndrome

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Every child with Down syndrome is different. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called *epicanthal folds*);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears; and
- Short neck and small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Help for Babies and Toddlers

When a baby is born with Down syndrome, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of Down syndrome is confirmed, parents will want to get in touch with the **early intervention** system in their community.

Early intervention is a system of services designed to help infants and toddlers with disabilities (before their 3rd birthday) and their families. It's mandated by federal law—the Individuals with Disabilities Education Act (IDEA), the nation's special education law. Staff work with the child's family to develop what is known as an *Individualized Family Services Plan*, or *IFSP*. The IFSP will describe the child's unique needs as well as the services he or she will receive to address those needs. The IFSP will also emphasize

the unique needs of the family, so that parents and other family members will know how to help their young child with Down syndrome. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

Help for School-Aged Children

Just as IDEA requires that early intervention be made available to babies and toddlers with disabilities, it requires that **special education and related services** be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, Down syndrome.

To Help Babies and Toddlers: Accessing the Early Intervention System in Your State

To access early intervention services for a child up to his or her 3rd birthday, consult NICHCY's *State Resource Sheet* for your state. It's available online at: http://nichcy.org/state-organization-search-by-state

There, you'll find a listing for early intervention under the first section, **State Agencies**. The agency listed will be able to put you in contact with the early intervention program in your community.

There is a lot to know about the special education process, much of which you can learn at NICHCY, which offers a wide range of publications on the topic. To begin, however, and access special education services for a school-aged child in your area, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

Health Considerations

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are common in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as *Atlanto-axial Instability*, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a tendency to become obese as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

Educating Children with Down Syndrome

When a child with Down syndrome reaches school age (after the 3rd birthday), the public school system becomes responsible for educating the child and for addressing the child's unique needs related to his or her disability. Parents and school personnel will work together to develop what is known as an Individualized Education Program (IEP) for the child. The IEP is similar to an IFSP in that it describes the child's unique needs and the services that will be provided to meet those needs. The IEP will include annual goals for learning and much more. NICHCY offers a great deal of information about the process for developing an IEP—especially our parent's guide called *Developing Your Child's IEP*—all of which can help parents learn how to participate effectively in their child's education.

Much information is also available for teachers to learn more about effective teaching practices for children with Down syndrome. It's important for teachers to take into consideration the degree of intellectual disability involved, the child's talents and interests, and the supports and services he or she needs, as specified in the IEP. Generally speaking, teachers will find it more effective to emphasize concrete concepts with a student who has Down syndrome, instead of abstract ideas. Teaching skills in a step-by-step fashion with frequent reinforcement and consistent feedback has proven successful. Other suggestions for teachers are given on the last page of this fact sheet.

Today, the majority of children with Down syndrome are educated in the regular classroom, alongside their peers without disabilities. This is in keeping with the inclusion movement of the last decade and the requirements

of IDEA, which states that each school system must ensure that:

> Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.[5]

Equally clear is this requirement of IDEA:

> A child with a disability [may not be] removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum.[6]

For High School Students with Down Syndrome

While the student is still in secondary school, parents, the IEP team, and the student himself (or herself!) will need to plan for the future and the student's life as an adult. This involves considering, for example, issues such as employment (with or without supports), independent living and self-care skills, the possibility of higher education or vocational training, and how to connect with adult service systems. Under IDEA, the process of planning for transition to adulthood should begin no later than the student's 16th birthday.[7] For adolescents with Down syndrome, it's usually important to begin earlier than that.

Adult life for individuals with Down syndrome has changed noticeably from just two decades ago. Opportunities to live and work independently in the community have greatly expanded for those with Down syndrome. This owes much to the more inclusive and comprehensive education IDEA promotes and to improved public attitudes towards disability. Today, there's a nationwide network of independent living centers, as well as apartments that are group-shared and supervised for those who need this level of support. Training, education, and assistance are also available to eligible adults with Down syndrome through service systems such as Vocational Rehabilitation and Social Security. Adult life holds many opportunities for those with Down syndrome, so it's important to plan ahead with optimism and vigor.

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[3] National Down Syndrome Society. (n.d.) *Down syndrome fact sheet*. Available online at: http://www.ndss.org/index.php?option=com_content&view=article&id=54:down-syndrome-fact-sheet&catid=35:about-down-syndrome&Itemid=74

[4] *Ibid*.

[5] 34 CFR §300.114(a)(2)(ii) of IDEA.

[6] 34 CFR §300.116(e) of IDEA.

[7] 34 CFR §300.320(b) of IDEA, Transition services.

Tips for Parents

- Learn about Down syndrome. The more you know, the more you can help yourself and your child. See the list of organizations below.
- Love and play with your child. Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.
- Encourage your child to be independent. For example, help your son or daughter learn self-care skills such as getting dressed, grooming, and doing laundry.
- Give your child chores. Keep in mind his or her age, mental capacity, attention span, and abilities. Divide tasks into small steps. Explain what your child is supposed to do, step by step, until the chore is done. Demonstrate. Offer help when it's needed and praise when things go well.
- Work with the professionals who are working with your child. Participate in team meetings where your child's education or program is being planned, share your unique knowledge of who your son or daughter is, advocate that the program address your child's needs.

- Find out what your child is learning at school. Look for ways to apply it at home. For example, if the teacher is reviewing concepts of money, take your child to the supermarket with you to help keep track of what money you're spending.
- Look for social opportunities in the community (such as Scouts) or activities offered through the department of sports and leisure. Joining in and taking part will help your child develop social skills and have fun.
- Talk with other parents whose children have Down syndrome. They can be a fountain of practical advice and emotional support. Visit the websites of the organizations listed below to see if they have a parent group nearby.
- Be patient, be hopeful. Your child, like every child, has a whole lifetime to learn and grow.
- Take pleasure in your beautiful one. He—she—is a treasure. Learn from your child, too. Those with Down syndrome have a special light within—let it shine.

Organizations

National Down Syndrome Society
1.800.221.4602 | www.ndss.org/ (English)
http://esp.ndss.org/index.php (Spanish)

NDSS offers authoritative information about Down syndrome, including a new parent video, *A Promising Future Together: A Guide for New Parents of Children with Down Syndrome*

National Down Syndrome Congress
1.800.232.6372 | www.ndsccenter.org (English)
www.ndsccenter.org/espanol/ (Spanish)

NDSC is also an authoritative source of information on Down syndrome, offering such resources as its *New Parent Package,* a collection of materials refined over years to provide new and expectant parents with an initial understanding of the challenges— and joys—of raising a child with Down syndrome.

Resource of Special Note

Woodbine House publishes an impressive collection of low-cost books and DVDs on Down syndrome, including a *Parent's Guide* (in English and Spanish) and materials for teachers. Call 1.800.843.7323 or visit: www.woodbinehouse.com/Down-Syndrome.29.0.0.2.htm

Tips for Teachers

- Learn as much as possible about Down sydrome. The organizations mentioned in this fact sheet can help you identify techniques and specific strategies to support the student's learning. We've included some additional suggestions below.

- This may seem obvious, but sometimes the appearance of Down syndrome can give the mistaken impression that the child cannot learn. Focus on the individual child and learn firsthand what needs and capabilities he or she has.

- Realize that you can make a big difference in this student's life! Use the student's abilities and interests to involve and motivate. Give lots of opportunities for the student to be successful.

- Talk candidly with your student's parents. They're experts and can tell you a great deal about their daughter's or son's special needs and abilities.

- Work with the student's parents and other school personnel to develop and implement a special educational plan (IEP) that addresses the individual needs of the student. Share information on a regular basis with parents about how things are going for the student at home and in school.

- If you're not part of the student's IEP team, ask for a copy of this important document. The student's educational goals will be listed there, as will the services and accommodations that he or she is supposed to receive, including in your class.

- Talk to specialists in your school (for example, special educators), as necessary. They can help you identify methods that are effective for teaching a student with disabilities, ways to adapt the curriculum, and how to address the student's IEP goals in the classroom.

- Be as concrete as possible with the student. Demonstrate what you want to see happen instead of giving only verbal instructions. When you share concrete information verbally, also show a photograph. Give the student practical materials and experiences and the opportunity to touch and examine objects.

- Divide new tasks and large tasks into smaller steps. Demonstrate the steps. Have the student do the steps, one by one. Offer help when necessary.

- Give the student immediate, concrete feedback.

IDEAs that Work
U.S. Office of Special Education Programs

FS4—June 2010

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Epilepsy

NICHCY Disability Fact Sheet #6
June 2010

Jeremy's Story

When Jeremy was 4 months old, he had his first seizure. His mother Caroline knew at once that something was wrong, because she'd never seen him so stiff and pale, with his eyes rolling back.

The seizure passed quickly, although, to Caroline, it seemed to last forever. Then Jeremy took a deep breath, opened his eyes, and looked at her. Soon afterward, the baby fell into a deep sleep.

That was 15 years ago. Jeremy's a teenager now, and you wouldn't guess from his alert eyes, quick smile, or quirky sense of humor that his brain is subject sometimes to brief, strong surges of electrical activity that dramatically affect his cognition and physical functioning. It's taken a lot of doctor visits, different medications, and one brain surgery to get his epilepsy under control. He still has seizures, but they don't happen very often now, much to everyone's relief, especially his mom and dad.

This year, for the first time, Jeremy and Caroline took part in the National Walk for Epilepsy, where they joined with thousands of others to raise funds for research, education, advocacy, and services for people with epilepsy and their caregivers. The best part of the day for Jeremy and Caroline was meeting so many other people who live with epilepsy every day, just like they do themselves.

Definition

Epilepsy is a *seizure disorder*. According to the Epilepsy Foundation of America, a seizure happens when a brief, strong surge of electrical activity affects part or all of the brain.[1]

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Seizures can last from a few seconds to a few minutes. They can have different symptoms, too, from convulsions and loss of consciousness, to signs such as blank staring, lip smacking, or jerking movements of arms and legs.[2]

Some people can have a seizure and yet not have epilepsy. For example, many young children have convulsions from fevers. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. Thus, a single seizure does not mean that the person has epilepsy. Generally speaking, the diagnosis of epilepsy is made when a person has two or more unprovoked seizures.[3]

Incidence

About three million Americans have epilepsy. Of the 200,000 new cases diagnosed each year, nearly 45,000 are children and adolescents.[4]

Epilepsy affects people in all nations and of all races. Its incidence is greater in African American and socially disadvantaged populations.[5]

Characteristics

Although the symptoms listed below do not necessarily mean that a person has epilepsy, it is wise to consult a doctor if you or a member of your family experiences one or more of them:

- "Blackouts" or periods of confused memory;
- Episodes of staring or unexplained periods of unresponsiveness;
- Involuntary movement of arms and legs;
- "Fainting spells" with incontinence or followed by excessive fatigue; or
- Odd sounds, distorted perceptions, or episodic feelings of fear that cannot be explained.

Doctors have described more than 30 different types of seizures.[6] These are divided into two major categories—generalized seizures and partial seizures (also known as focal seizures).

Generalized Seizures

This type of seizure involves both sides of the brain from the beginning of the seizure. The best known subtype of generalized seizures is the **grand mal seizure.** In a grand mal seizure, the person's arms and legs stiffen (the tonic phase), and then begin to jerk (the clonic phase). That's why the grand mal seizure is also known as a generalized tonic clonic seizure.

Grand mal seizures typically last 1-2 minutes and are followed by a period of confusion and then deep sleep. The person will not remember what happened during the seizure.

You may also have heard of the **petit mal seizure**, which is an older term for another type of generalized seizure. It's now called an **absence** seizure, because during the seizure, the person stares blankly off into space and doesn't seem to be aware of his or her surroundings. The person may also blink rapidly and seem to chew. Absence seizures typically last from 2-15 seconds and may not be noticed by others. Afterwards, the person will resume whatever he or she was doing at the time of the seizure, without any memory of the event.

Partial Seizures

Partial seizures are so named because they involve only one hemisphere of the brain. They may be **simple partial seizures** (in which the person jerks and may have odd sensations and perceptions, but doesn't lose consciousness) or **complex partial seizures** (in which consciousness is impaired or lost). Complex partial seizures often involve periods of "automatic behavior" and altered consciousness. This is typified by purposeful-looking behavior, such as buttoning or unbuttoning a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not remembered afterwards.

Diagnosis

Diagnosing epilepsy is a multi-step process. According to the Epilepsy Foundation of America:

> ...the doctor's main tool...is a careful medical history with as much information as possible about what the seizures looked like and what happened just before they began. The doctor will also perform a thorough physical examination, especially of the nervous system, as well as analysis of blood and other bodily fluids.[7]

The doctor may also order an electroencephalograph (EEG) of the patient's brain activity, which may show patterns that help the doctor decide whether or not someone has epilepsy. Other tests may also be used—such as the CT (computerized tomography) or MRI (magnetic resonance imaging)—in order to look for any growths, scars, or other physical conditions in the brain that may be causing the seizures. Which tests and how many of them are ordered may vary, depending on how much each test reveals.[8]

Treatment

Anti-epileptic medication is the most common treatment for epilepsy. It's effective in stopping seizures in 70% of patients.[9]

Interestingly, it's not uncommon for doctors to wait a while before prescribing an anti-seizure medication, especially if the patient is a young child. Unless the EEG of the patient's brain is clearly abnormal, doctors may suggest waiting until a second or even third seizure occurs. Why? Because studies show that an otherwise normal child who has had a single seizure has a relatively low (15%) risk of a second one.[10]

When anti-epileptic medications are not effective in stopping a person's seizures, other treatment options may be discussed. These include:

- surgery to remove the areas of the brain that are producing the seizures;
- stimulation of the vagus nerve (a large nerve in the neck), where short bursts of electrical energy are directed into the brain via the vagus nerve; and
- a ketogenic diet (one that is very high in fats and low in carbohydrates), which makes the body burn fat for energy instead of glucose.

According to the Epilepsy Foundation of America, 10% of new patients cannot bring their seizures disorder under control despite optimal medical management.[11]

Educational and Developmental Considerations

It's not unusual for seizures to interfere with a child's development and learning. For example, if a student has the type of seizure characterized by periods of fixed staring, he or she is likely to miss parts of what the teacher is saying. If teachers—or other caregivers such as babysitters, daycare providers, preschool teachers, K-12 personnel—observe such an episode, it's important that they document and report it promptly to parents (and the school nurse, if appropriate).

Because epilepsy can affect a child's learning and development (even babies), families will want to learn more about the systems of help that are available. Much of that help comes from the nation's special education law, the Individuals with Disabilities Education Act (IDEA), which makes available these two sets of services:

- **Early intervention** | A system of services to help 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).

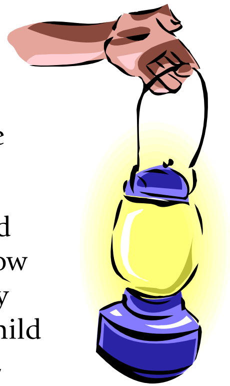
In both of these systems, eligible children receive special services designed to address the developmental, functional, and educational needs resulting from their disability.

To access *early intervention services* for a child up to his or her 3rd birthday, consult NICHCY's *State Resource Sheet* for your state (available online at: http://nichcy.org/state-organization-search-by-state). You'll find the listing for early intervention under the first section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To access s*pecial education services* for a school-aged child, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

More about Services under IDEA

The process of finding a child eligible for early intervention or special education and related services under IDEA begins with a comprehensive and individual evaluation of the child in order to:



- establish that the child does, indeed, have a disability;
- get a detailed picture of how the disability affects the child functionally, developmentally, and academically; and
- document the child's special needs related to the disability.

This evaluation is provided **free of charge** through either the early intervention system (for infants and toddlers under the age of 3) or through the local school system (for children ages 3-21). Under IDEA, children with epilepsy are usually found eligible for services under the category of "Other Health Impairment" (OHI). We've included IDEA's definition of OHI in the box below.

When a baby or toddler is found eligible for early intervention, parents meet with the early intervention staff, and together they develop what is known as an **Individualized Family Service Plan**, or **IFSP**. The IFSP will describe the child's unique needs as well as the services the child will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with epilepsy. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

When a child is found eligible for special education and related services, school staff and parents meet and develop what is known as an **Individualized Education Program**, or **IEP**. This document is very important in the educational life of a child with epilepsy, because it details the nature of the child's needs and the services that the public school system will provide free of charge to address those needs.

IDEA's Definition of "Other Health Impairment"

The nation's special education law specifically mentions ***epilepsy*** in its definition of "Other Health Impairment," a category under which children may be found eligible for special education and related services. Here's IDEA's definition.

> (9) *Other health impairment* means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—
>
> (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, **epilepsy**, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and
>
> (ii) Adversely affects a child's educational performance. *34 CFR §300.8(c)(9)*

Succeeding at School

Special education and related services can be very helpful to children with epilepsy attending public school. Because the disorder affects memory and concentration, accommodations in the classroom and during testing are key to students' academic success. Some common accommodations and services provided to students with epilepsy are listed in the box on the next page.

Related services may be every bit as important for children with epilepsy, especially *school health services* and *school nurse services*—which can provide the child's medication during school hours or give first aid instruction on seizure management to the student's teachers, for example.

Depending on the child's unique needs, other related services may also be necessary so that the student benefits from his or her special education program—for example, counseling services. Children and youth with epilepsy must deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, loss of self-control during the seizure episode, and compliance with medications. Counseling services may help students with epilepsy address the complexities of living with this disorder. The school can

also help by providing epilepsy education programs for staff and students, including information on how to recognize a seizure and what to do if a seizure occurs.

It is important that the teachers and school staff are informed about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. Most parents find that a friendly conversation with the teacher(s) at the beginning of the school year is the best way to handle the situation. Even if a child has seizures that are largely controlled by medication, it is still best to notify the school staff about the condition.

School personnel and the family should work together to monitor the effectiveness of medication as well as any side effects. If a child's physical or intellectual skills seem to change, it is important to tell the doctor. There may also be hearing or perception problems caused by changes in the brain. Written observations of both the family and school staff will be helpful in discussions with the child's doctor.

Accommodations in the Classroom

The accommodations that a child with epilepsy receives are determined by his or her IEP team (which includes the parents). Here are some possibilities to consider.[12]

To address memory deficits

- Provide written or pictorial instructions
- Use voice recordings of verbal instructions
- Have a peer buddy take notes for the student or permit tape recording
- Divide large tasks into smaller steps
- Provide a checklist of assignments and a calendar with due dates
- Decrease memory demands during classwork and testing (e.g., use recognition rather than recall tasks)

To address health concerns

- Be flexible about time missed from school to seek treatment or adjust to new medications
- Provide extra time for assignments and a modified workload (fatigue is a common side effect of seizures and medications)
- Replace fluorescent lighting with full spectrum lighting
- Provide private area to rest or recover from a seizure

References

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Resources of More Information

Epilepsy Foundation of America | Your premier source of information and guidance on epilepsy, including state and local chapters and support groups.

- English | www.epilepsyfoundation.org/ 1.800.332.1000
- Spanish | www.epilepsyfoundation.org/epilepsia/ 1.866.748.8008

epilepsy.com | A website of the Epilepsy Therapy Project, a leading source of support for translational research and new therapy projects. A wealth of information is available for families and professionals, at: http://www.epilepsy.com/

National Institute of Neurological Disorders and Stroke (NINDS) | Find detailed medical information on epilepsy, including research, clinical trials being conducted at NIH, helpful organizations, and a long list of related publications. 1.800.352.9424 | http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm

Talk About It! | A website dedicated to ending the stigma associated with epilepsy through "talking about it." Lots of info here! http://www.talkaboutit.org/flash.shtml

The Epilepsy Health Center | The Epilepsy Health Center at webmd.com has detailed, medically based information to offer on the subject. http://www.webmd.com/epilepsy/default.htm

For Families

Epilepsy Foundation eCommunities | Over 10,000 members. | http://epilepsyfoundation.ning.com/

Parent to Parent | Talk with other parents affected by epilepsy through the Parent to Parent Program in your state. | http://www.p2pusa.org/

Parent Training and Information Center | Have questions about early intervention or special education? Want to know local and state resources? Find your state's PTI for a wealth of information just for parents. | www.parentcenternetwork.org/parentcenterlisting.html

On Education

Teaching Students with Epilepsy: Strategies for Educators | http://www2.massgeneral.org/childhoodepilepsy/pdf/strategies_for_educators.pdf

How to Teach Young Students With Seizures | http://www.ehow.com/how_7714685_teach-young-students-seizures.html

Education of Kids with Epilepsy | http://www.epilepsy.com/info/family_kids_education

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Intellectual Disabilities

NICHCY Disability Fact Sheet #8
January 2011

Matthew's Story

Matt is 15 years old. Because Matt has an intellectual disability, he has been receiving special education services since elementary school. These services have helped him tremendously, because they are designed to fit his special learning needs.

Last year he started high school. He, his family, and the school took a good hard look at what he wants to do when secondary school is over. Does he want more education? A job? Does he have the skills he needs to live on his own?

Answering these questions has helped Matt and the school plan for the future. He's always been interested in the outdoors, in plants, and especially in trees. He knows all the tree names and can recognize them by their leaves and bark. So this year he's learning about jobs like forestry, landscaping, and grounds maintenance. Next year he hopes to get a part-time job. He's learning to use public transportation, so he'll be able to get to and from the job.

Having an intellectual disability makes it harder for Matt to learn new things. He needs things to be very concrete. But he's determined. He wants to work outside, maybe in the park service or in a greenhouse, and he's getting ready!

What are an Intellectual Disability?

Intellectual disability is a term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child.

Children with intellectual disabilities (sometimes called *cognitive disabilities* or *mental retardation*) may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They *will* learn, but it will take them longer. There may be some things they cannot learn.

What Causes an Intellectual Disability?

Doctors have found many causes of intellectual disabilities. The most common are:

- *Genetic conditions.* Sometimes an intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, fragile X syndrome, and phenylketonuria (PKU).
- *Problems during pregnancy.* An intellectual disability can result when the baby does not

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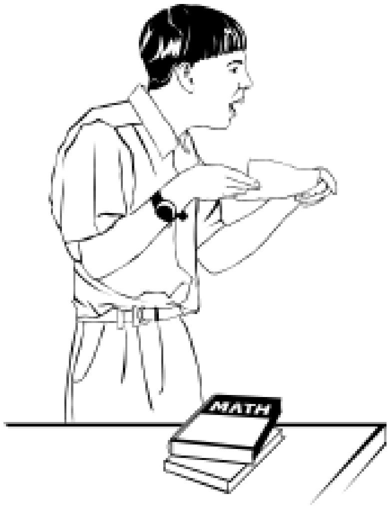

develop inside the mother properly. For example, there may be a problem with the way the baby's cells divide as it grows. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability.

- *Problems at birth.* If a baby has problems during labor and birth, such as not getting enough oxygen, he or she may have an intellectual disability.
- *Health problems.* Diseases like whooping cough, the measles, or meningitis can cause intellectual disabilities. They can also be caused by extreme malnutrition (not eating right), not getting enough medical care, or by being exposed to poisons like lead or mercury.

An intellectual disability is not a disease. You can't catch an intellectual disability from anyone. It's also not a type of mental illness, like depression. There is no cure for intellectual disabilities. However, most children with an intellectual disability can learn to do many things. It just takes them more time and effort than other children.

How Common are Intellectual Disabilities?

Intellectual disability is the most common developmental disability.[1] Approximately 6.5 million people in the United States have an intellectual disability.[2] More than 545,000 children (ages 6-21) have some level of intellectual disability and receive special education services in public school under this category in IDEA, the nation's special education law.[3] In fact, 1 in every 10 children who need special education have some form of intellectual disability.[4]

What are the Signs of Intellectual Disability?

There are many signs of an intellectual disability. For example, children with an intellectual disability may:

- sit up, crawl, or walk later than other children;
- learn to talk later, or have trouble speaking,
- find it hard to remember things,
- not understand how to pay for things,
- have trouble understanding social rules,
- have trouble seeing the consequences of their actions,
- have trouble solving problems, and/or
- have trouble thinking logically.

How are Intellectual Disabilities Diagnosed?

Intellectual disabilities are diagnosed by looking at two main things. These are:

- the ability of a person's brain to learn, think, solve problems, and make sense of the world (called IQ or *intellectual functioning*); and
- whether the person has the skills he or she needs to live independently (called *adaptive behavior*, or adaptive functioning).

Intellectual functioning, or IQ, is usually measured by a test called an IQ test. The average score is 100. People scoring below 70 to 75 are thought to have an intellectual disability. To measure adaptive behavior, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behavior. These are:

- daily living skills, such as getting dressed, going to the bathroom, and feeding one's self;
- communication skills, such as understanding what is said and being able to answer;
- social skills with peers, family members, adults, and others.

To diagnose an intellectual disability, professionals look at the person's mental abilities (IQ) and his or her adaptive skills.

Definition of "Intellectual Disability" under IDEA

Until Rosa's Law was signed into law by President Obama in October 2010, IDEA used the term "mental retardation" instead of "intellectual disability." Rosa's Law changed the term to be used in future to "intellectual disability." The definition itself, however, did not change. Accordingly, "intellectual disability" is defined as...

> "...significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance."

[34 CFR §300.8(c)(6)]

Both of these are highlighted in the definition of this disability in the box on this page. This definition comes from the Individuals with Disabilities Education Act (IDEA). IDEA is the federal law that guides how early intervention and special education services are provided to infants, toddlers, children, and youth with disbilities.

Providing services to help individuals with intellectual disabilities has led to a new understanding of how we define the term. After the initial diagnosis is made, we look at a person's strengths and weaknesses. We also look at how much support or help the person needs to get along at home, in school, and in the community. This approach gives a realistic picture of each individual. It also recognizes that the "picture" can change. As the person grows and learns, his or her ability to get along in the world grows as well.

Help for Babies and Toddlers

When a baby is born with an intellectual disability, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of ID is confirmed, parents will want to get in touch with the **early intervention** system in their community. We'll tell you how in a moment.

Early intervention is a system of services designed to help infants and toddlers with disabilities (until their 3rd birthday) and their families. It's mandated by IDEA. Staff work with the child's family to develop what is known as an *Individualized Family Services Plan*, or *IFSP*. The IFSP will describe the child's unique needs as well as the services he or she will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with intellectual disability. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

To access early intervention services in your area, consult NICHCY's *State Resource Sheet* for your state. It's available online at: http://nichcy.org/state-organization-search-by-state

There, you'll find a listing for early intervention under the first section, **State Agencies**. The agency listed will be able to put you in contact with the early intervention program in your community.

To learn more about early intervention, including how to write the IFSP, visit NICHCY at: http://nichcy.org/babies/overview/

Help for School-Aged Children

Just as IDEA requires that early intervention be made available to babies and toddlers with disabilities, it requires that **special education and related services** be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, an intellectual disability.

School staff will work with the child's parents to develop an *Individualized Education Program*, or *IEP*. The IEP is similar to an IFSP. It describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services are provided at no cost to parents.

To access special education services for a school-aged child in your area, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

There is a lot to know about the special education process, much of which you can learn at NICHCY, which offers a wide range of publications on the topic. Enter our special education information at: http://nichcy.org/schoolage/

Educational Considerations

A child with an intellectual disability can do well in school but is likely to need the individualized help that's available as special education and related services. The level of help and support that's needed will depend upon the degree of intellectual disability involved.

General education. It's important that students with intellectual disabilities be involved in, and make progress in, the general education curriculum. That's the same curriculum that's learned by those without disabilities. Be aware that IDEA does not permit a student to be removed from education in age-appropriate general education classrooms solely because he or she needs modifications to be made in the general education curriculum.

Supplementary aids and services. Given that intellectual disabilities affect learning, it's often crucial to provide supports to students with ID in the classroom. This includes making *accommodations* appropriate to the needs of the student. It also includes providing what IDEA calls "supplementary aids and services." Supplementary aids and services are supports that may include instruction, personnel, equipment, or other accommodations that enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate.

Thus, for families and teachers alike, it's important to know what changes and accommodations are helpful to students with intellectual disabilities. These need to be discussed by the IEP team and included in the IEP, if appropriate.

Some common changes that help students with intellectual disabilities are listed in the "Tips for Teachers" box on the next page. The organizations listed in the Resource Section also offer a great deal of information on ways to help children with intellectual disabilities learn and succeed in school. And you can also consult NICHCY, beginning online at: http://nichcy.org/schoolage/accommodations/

Adaptive skills. Many children with intellectual disabilities need help with adaptive skills, which are skills needed to live, work, and play in the community. Teachers and parents can help a child work on these skills at both school and home. Some of these skills include:

- communicating with others;
- taking care of personal needs (dressing, bathing, going to the bathroom);
- health and safety;
- home living (helping to set the table, cleaning the house, or cooking dinner);
- social skills (manners, knowing the rules of conversation, getting along in a group, playing a game);
- reading, writing, and basic math; and
- as they get older, skills that will help them in the workplace.

Transition planning. It's extremely important for families and schools to begin planning early for the student's transition into the world of adulthood. Because intellectual disability affects how quickly and how well an individual learns new information and skills, the sooner transition planning begins, the more can be accomplished before the student leaves secondary school.

IDEA requires that, at the latest, transition planning for students with disabilities must begin no later than the first IEP to be in effect when they turn 16. The IEP teams of many students with intellectual disabilities feel that it's important for these students to begin earlier than that. And they do.

For more information, visit NICHCY's Transition pages, beginning at: http://nichcy.org/schoolage/transitionadult/

References

[1] National Center on Birth Defects and Developmental Disabilities. (2005). *Intellectual disability*. Available online at: www.cdc.gov/ncbddd/dd/mr3.htm

[2] The Arc. (2009). *Introduction to intellectual disabilities*. Available online at: http://www.thearc.org/page.aspx?pid=2448

[3] U.S. Department of Education. (2010). *29th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2007* (Vol. 2). Washington, DC: Autor. Available online at: http://www2.ed.gov/about/reports/annual/osep/index.html

[4] *Ibid.*

Organizations

The Arc of the United States
800.433.5255 | info@thearc.org | www.thearc.org
Find a local chapter near you:
http://www.thearc.org/page.aspx?pid=2437

American Association on Intellectual and Developmental Disabilities
800.424.3688 | www.aaidd.org/
The AAIDD definition manual contains the world's most current and authoritative information on intellectual disability, including best practice guidelines on diagnosing and classifying intellectual disability and developing a system of supports for people living with an intellectual disability.

Division on Autism and Developmental Disabilities (DADD)
This division of the Council for Exceptional Children offers many publications and journals for professionals. http://daddcec.org/

"Tips for Parents" appears on the next page.

Tips for Teachers

Learn as much as you can about intellectual disability. The organizations listed on this page will help you identify techniques and strategies to support the student educationally. We've also listed some strategies below.

Recognize that you can make an enormous difference in this student's life! Find out what the student's strengths and interests are, and emphasize them. Create opportunities for success.

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. Talk to others in your school (e.g., special educators), as necessary. They can help you identify effective methods of teaching this student, ways to adapt the curriculum, and how to address the student's IEP goals in your classroom.

Be as concrete as possible. Demonstrate what you mean rather than giving verbal directions. Rather than just relating new information verbally, show a picture. And rather than just showing a picture, provide the student with hands-on materials and experiences and the opportunity to try things out.

Break longer, new tasks into small steps. Demsonstrate the steps. Have the student do the steps, one at a time. Provide assistance, as necessary.

Give the student immediate feedback.

Teach the student life skills such as daily living, social skills, and occupational awareness and exploration, as appropriate. Involve the student in group activities or clubs.

Work together with the student's parents and other school personnel to create and implement an IEP tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

Tips for Parents

- ☐ Learn about intellectual disability. The more you know, the more you can help yourself and your child. See the list of organizations on page 5.
- ☐ Be patient, be hopeful. Your child, like every child, has a whole lifetime to learn and grow.
- ☐ Encourage independence in your child. For example, help your child learn daily care skills, such as dressing, feeding him or herself, using the bathroom, and grooming.
- ☐ Give your child chores. Keep her age, attention span, and abilities in mind. Break down jobs into smaller steps. For example, if your child's job is to set the table, first ask her to get the right number of napkins. Then have her put one at each family member's place at the table. Do the same with the utensils, going one at a time. Tell her what to do, step by step, until the job is done. Demonstrate how to do the job. Help her when she needs assistance.
- ☐ Give your child frequent feedback. Praise your child when he or she does well. Build your child's abilities.
- ☐ Find out what skills your child is learning at school. Find ways for your child to apply those skills at home. For example, if the teacher is going over a lesson about money, take your child to the supermarket with you. Help him count out the money to pay for your groceries. Help him count the change.
- ☐ Find opportunities in your community for social activities, such as scouts, recreation center activities, sports, and so on. These will help your child build social skills as well as to have fun.
- ☐ Talk to other parents whose children have an intellectual disability. Parents can share practical advice and emotional support. Visit NICHCY's State-Specific Resources page and find a parent group near you. Look in the Disability-Specific section, under "intellectual disabilities." State Sheets are online at: http://nichcy.org/state-organization-search-by-state
- ☐ Meet with the school and develop an IEP to address your child's needs. Keep in touch with your child's teachers. Offer support. Find out how you can support your child's school learning at home.
- ☐ Take pleasure in your beautiful one. He—she—is a treasure. Learn from your child, too. Those with intellectual disabilities have a special light within—let it shine.

IDEAs that Work
U.S. Office of Special Education Programs

FS8—January 2011

fhi 360
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Learning Disabilities

NICHCY Disability Fact Sheet #7
January 2011

Sara's Story

When Sara was in the first grade, her teacher started teaching the students how to read. Sara's parents were really surprised when Sara had a lot of trouble. She was bright and eager, so they thought that reading would come easily to her. It didn't. She couldn't match the letters to their sounds or combine the letters to create words.

Sara's problems continued into second grade. She still wasn't reading, and she was having trouble with writing, too. The school asked Sara's mom for permission to evaluate Sara to find out what was causing her problems. Sara's mom gave permission for the evaluation.

The school conducted an evaluation and learned that Sara has a learning disability. She started getting special help in school right away.

Sara's still getting that special help. She works with a reading specialist and a resource room teacher every day. She's in the fourth grade now, and she's made real progress! She is working hard to bring her reading and writing up to grade level. With help from the school, she'll keep learning and doing well.

What are Learning Disabilities?

Learning disability is a general term that describes specific kinds of learning problems. A learning disability can cause a person to have trouble learning and using certain skills. The skills most often affected are: reading, writing, listening, speaking, reasoning, and doing math.

"Learning disabilities" is not the only term used to describe these difficulties. Others include:

- *dyslexia*—which refers to difficulties in reading;
- *dysgraphia*—which refers to difficulties in writing; and
- *dyscalcula*—which refers to difficulties in math.

All of these are considered learning disabilities.

Learning disabilities (LD) vary from person to person. One person with LD may not have the same kind of learning problems as another person with LD. Sara, in our example above, has trouble with reading and writing. Another person with LD may have problems with understanding math. Still another person may have trouble in both of these areas, as well as with understanding what people are saying.

Researchers think that learning disabilities are caused by differences in how a person's brain works and how it processes information. Children with learning disabilities are not "dumb" or "lazy." In fact, they usually have average or above average intelligence. Their brains just process information differently.

NICHCY *is the National Dissemination Center for Children with Disabilities.*

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http://nichcy.org

There is no "cure" for learning disabilities. They are life-long. However, children with LD can be high achievers and can be taught ways to get around the learning disability. With the right help, children with LD can and do learn successfully.

How Common are Learning Disabilities?

Very common! As many as 1 out of every 5 people in the United States has a learning disability. Almost 1 million children (ages 6 through 21) have some form of a learning disability and receive special education in school. In fact, one-third of all children who receive special education have a learning disability (*Twenty-Ninth Annual Report to Congress,* U.S. Department of Education, 2010).

What Are the Signs of a Learning Disability?

While there is no one "sign" that a person has a learning disability, there are certain clues. We've listed a few below. Most relate to elementary school tasks, because learning disabilities tend to be identified in elementary school. This is because school focuses on the very things that may be difficult for the child—reading, writing, math, listening, speaking, reasoning.A child probably won't show all of these signs, or even most of them. However, if a child shows a number of these problems, then parents and the teacher should consider the possibility that the child has a learning disability.

When a child has a learning disability, he or she:

- may have trouble learning the alphabet, rhyming words, or connecting letters to their sounds;
- may make many mistakes when reading aloud, and repeat and pause often;
- may not understand what he or she reads;
- may have real trouble with spelling;
- may have very messy handwriting or hold a pencil awkwardly;
- may struggle to express ideas in writing;
- may learn language late and have a limited vocabulary;
- may have trouble remembering the sounds that letters make or hearing slight differences between words;
- may have trouble understanding jokes, comic strips, and sarcasm;
- may have trouble following directions;
- may mispronounce words or use a wrong word that sounds similar;
- may have trouble organizing what he or she wants to say or not be able to think of the word he or she needs for writing or conversation;
- may not follow the social rules of conversation, such as taking turns, and may stand too close to the listener;
- may confuse math symbols and misread numbers;
- may not be able to retell a story in order (what happened first, second, third); or
- may not know where to begin a task or how to go on from there.

If a child has unexpected problems learning to read, write, listen, speak, or do math, then teachers and parents may want to investigate more. The same is true if the child is struggling to do any one of these skills. The child may need to be evaluated to see if he or she has a learning disability.

About the Evaluation Process

If you are concerned that your child may have a learning disability, contact his or her school and request that the school conduct an individualized evaluation under IDEA (the nation's special education law) to see if, in fact, a learning disability is causing your child difficulties in school. Visit NICHCY's website and read more about the evaluation process, beginning at: http://nichcy.org/schoolage/evaluation/

What if the School System Declines to Evaluate Your Child?

If the school doesn't think that your child's learning problems are caused by a learning disability, it may decline to evaluate your child. If this happens, there are specific actions you can take. These include:

- *Contact your state's Parent Training and Information Center (PTI) for assistance.* The PTI can offer you guidance and support in what to do next. Find your PTI by visiting: http://www.parentcenternetwork.org/parentcenterlisting.html
- *Consider having your child evaluated by an independent evaluator.* You may have to pay for this evaluation, or you can ask that the school pay for it. To learn more about independent evaluations, visit NICHCY at: http://nichcy.org/schoolage/parental-rights/iee
- *Ask for mediation, or use one of IDEA's other dispute resolution options.* Parents have the right to disagree with the school's decision not to evaluate their child and be heard. To find out more about dispute resolution options, visit NICHCY at: http://nichcy.org/schoolage/disputes/overview

IDEA's Definition of LD

Not surprisingly, the Individuals with Disabilities Education Act (IDEA) includes a definition of "specific learning disability." We've presented this in the box below. IDEA also lists evaluation procedures that must be used at a minimum to identify and document that a child has a specific learning disability. These will now be discussed in brief.

Additional Evaluation Procedures for LD

Now for the confusing part! The ways in which children are identified as having a learning disability have changed over the years. Until recently, the most common approach was to use a "severe discrepancy" formula. This referred to the gap, or discrepancy, between the child's intelligence or aptitude and his or her actual performance.

However, in the 2004 reauthorization of IDEA, how LD is determined has been expanded. IDEA now requires that states adopt criteria that:

- ***must not require*** the use of a severe discrepancy between intellectual ability and achievement in determining whether a child has a specific learning disability;

IDEA's Definition of "Specific Learning Disability"

The nation's special education law specifically defines the term "specific learning disability," as follows:

> (10) *Specific learning disability* —(i) *General.* Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.
>
> (ii) *Disorders not included.* Specific learning disability does not include learning problems that are primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

34 CFR §300.8(c)(10)

- ***must permit*** local educational agencies (LEAs) to use a process based on the child's response to scientific, research-based intervention; and
- ***may permit*** the use of other alternative research-based procedures for determining whether a child has a specific learning disability.

Basically, what this means is that, instead of using a severe discrepancy approach to determining LD, school systems may provide the student with a research-based intervention and keep close track of the student's performance. Analyzing the student's response to that intervention (RTI) may then be considered by school districts in the process of identifying that a child has a learning disability.

There are also other aspects required when evaluating children for LD. These include observing the student in his or her learning environment (including the regular education setting) to document academic performance and behavior in the areas of difficulty.

This entire fact sheet could be devoted to what IDEA requires when children are evaluated for a learning disability. Instead, let us refer you to a training module on the subject. It's quite detailed, but if you would like to know those details, read through Module 11 of NICHCY's *Building the Legacy* curriculum on IDEA 2004. It's available online, at: http://nichcy.org/laws/idea/legacy/module11

Moving on, let us suppose that the student *has* been diagnosed with a specific learning disability. What next?

What About School?

Once a child is evaluated and found eligible for special education and related services, school staff and parents meet and develop what is known as an **Individualized Education Program**, or **IEP**. This document is very important in the educational life of a child with learning disabilities. It describes the child's needs and the services that the public school system will provide free of charge to address those needs. Learn more about the IEP, what it includes, and how it is developed, at: http://nichcy.org/schoolage/iep

Supports or changes in the classroom (called *accommodations*) help most students with LD. Common accommodations are listed in the "Tips for Teachers" box on the next page. Accessible instructional materials (AIM) are among the most helpful to students whose LD affects their ability to read and process printed language. Thanks to IDEA 2004, there are numerous places to turn now for AIMs. We've listed one central source in "Resources Especially for Teachers" on the next page.

Assistive technology can also help many students work around their learning disabilities. Assistive technology can range from "low-tech" equipment such as tape recorders to "high-tech" tools such as reading machines (which read books aloud) and voice recognition systems (which allow the student to "write" by talking to the computer). To learn more about AT for students who have learning disabilities, visit LD Online's Technology section, at: http://www.ldonline.org/indepth/technology

What About Home?

A child with learning disabilities may need help at home as well as in school. Some suggestions are given in under "Tips for Parents" (see page 6) where you'll find other relevant items listed, too.

Conclusion

Learning disabilities clearly affect some of the key skills in life—reading, writing, doing math. Because many people have learning disabilities, there is a great deal of expertise and support available. Take advantage of the many organizations focused on LD. Their materials and their work are intended solely to help families, students, educators, and others understand LD and address it in ways that have long-lasting impact.

Tips for Teachers

Learn as much as you can about the different types of LD. The resources and organizations listed below can help you identify specific techniques and strategies to support the student educationally.

Seize the opportunity to make an enormous difference in this student's life! Find out and emphasize what the student's strengths and interests are. Give the student positive feedback and lots of opportunities for practice.

Provide instruction and accommodations to address the student's special needs. Examples:

- breaking tasks into smaller steps, and giving directions verbally and in writing;
- giving the student more time to finish schoolwork or take tests;
- letting the student with reading problems use instructional materials that are accessible to those with print disabilities;
- letting the student with listening difficulties borrow notes from a classmate or use a tape recorder; and
- letting the student with writing difficulties use a computer with specialized software that spell checks, grammar checks, or recognizes speech.

Learn about the different testing modifications that can really help a student with LD show what he or she has learned.

Teach organizational skills, study skills, and learning strategies. These help all students but are particularly helpful to those with LD.

Work with the student's parents to create an IEP tailored to meet the student's needs.

Establish a positive working relationship with the student's parents. Through regular communication, exchange information about the student's progress at school.

Resources Especially *for* Teachers

LD Online | **For Educators**
http://www.ldonline.org/educators

LD Online | **Teaching and Instruction**
http://www.ldonline.org/indepth/teaching

National Center for Learning Disabilities |
Especially for Teachers
http://www.ncld.org/at-school/especially-for-teachers

TeachingLD | A service of the Division for Learning Disabilities (DLD) of the Council for Exceptional Children
http://teachingld.org/

Learning Disabilities Association of America |
For Teachers
http://www.ldanatl.org/aboutld/teachers/index.asp

National Center for Accessible Instructional Materials |
Find AIM in your state!
http://aim.cast.org/

Reading Rockets | **For Teachers**
http://www.readingrockets.org/audience/teachers

Tips for Parents

Learn about LD. The more you know, the more you can help yourself and your child.

Praise your child when he or she does well. Children with LD are often very good at a variety of things. Find out what your child really enjoys doing, such as dancing, playing soccer, or working with computers. Give your child plenty of opportunities to pursue his or her strengths and talents.

Find out the ways your child learns best. Does he or she learn by hands-on practice, looking, or listening? Help your child learn through his or her areas of strength.

Let your son or daughter help with household chores. These can build self-confidence and concrete skills. Keep instructions simple, break down tasks into smaller steps, and reward your child's efforts with praise.

Make homework a priority. Read more about how to help your child be a success at homework in the resources listed below.

Pay attention to your child's mental health (and your own!). Be open to counseling, which can help your child deal with frustration, feel better about himself or herself, and learn more about social skills.

Talk to other parents whose children have LD. Parents can share practical advice and emotional support. You can identify parent groups in your area via NICHCY's State Resource Sheets. Go to the section entitled "Disability-Specific Agencies" and scroll down until you reach "learning disabilities."

Meet with school personnel and help develop an IEP to address your child's needs. Plan what accommodations your child needs, and don't forget to talk about AIM or assistive technology!

Establish a positive working relationship with your child's teacher. Through regular communication, exchange information about your child's progress at home and at school.

Resources Especially *for* Parents

LD Online | For Parents
http://www.ldonline.org/parents

LD Online | Parenting and Family
http://www.ldonline.org/indepth/parenting

National Center for Learning Disabilities | In the Home
http://www.ncld.org/in-the-home

Learning Disabilities Association of America | For Parents
http://www.ldanatl.org/aboutld/parents/index.asp

Reading Rockets | For Parents
http://www.readingrockets.org/audience/parents

NICHCY Disability Fact Sheet #7
January 2011

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Other Health Impairment

A publication of NICHCY
Disability Fact Sheet #15
March 2012

Introduction

"Other Health Impairment" is one of the 14 categories of disability listed in our nation's special education law, the Individuals with Disabilities Education Act (IDEA). Under IDEA, a child who has an "other health impairment" is likely to be eligible for special services to help the child address his or her educational, developmental, and functional needs resulting from the disability.

IDEA's Definition of OHI

Before we talk about how to access those special services, let's look at how IDEA defines "other health impairment." This definition, in combination with a state's policies, is a very important factor in whether or not a child is found eligible for services. IDEA states that:

> *Other health impairment* means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—
>
> (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and
>
> (ii) Adversely affects a child's educational performance. [§300.8(c)(9)]

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What's immediately clear from this definition is that there are quite a few disabilities and disorders that fall under the umbrella of "other health impairment." And those disabilities are very different from one another. This makes it difficult for us to summarize "other health impairment" and connect you with more information and guidance on the subject.

And that is why we will break this discussion down into brief looks at each of the disabilities listed.

We'd also like to point out that IDEA's definition uses the phrase *"such as…"* That's significant. It means that the disabilities listed are not the *only* ones that may be considered when a child's eligibility for special services under IDEA is decided. A child with another health impairment (one *not* listed in IDEA's definition) may be found eligible for special services and assistance. What's central to all the disabilities falling under "Other Health Impairment" is that the child must have:

- limited strength, vitality, or alertness due to chronic health problems; and
- an educational performance that is negatively affected as a result.

Special Help for Children

Two systems of help are available immediately to help eligible children with OHI. These divide out by age, as follows:

- *Early intervention services* are for children under the age of 3. Known as Part C of IDEA, the early intervention program exists in every state and includes free evaluation of the baby or toddler to see what the problem is. The child's needs (and the family's) are identified in the evaluation. The parents and early interventionists then write an individualized family service plan (IFSP) to address the child's (and family's) unique needs.
- *Special education and related services* are for children from 3 to 21, sometimes older. These services include specially designed instruction and a wide range of supports to address the student's individual needs that result from his or her disability. Special education and related services are available to eligible children, free of charge, through the public school system. This includes a comprehensive and individual evaluation of the child to determine his or her eligibility, unique needs, and the services and supports that are approrpriate to address those needs.

If your child has a health impairment, especially one listed in IDEA, you will want to find out all you can about these service systems. They can be incredibly helpful for your child. A lot of information is available on NICHCY's website, and we encourage you to visit, read the summaries of early intervention and special education and related services, and use the active links to connect directly with those systems of help in your area.

The Specific Disabilities Mentioned in IDEA's Definition of OHI

What are the characteristics of the different disabilities mentioned in IDEA's definition of Other Health Impairment? Let's take a very brief look.

ADD and AH/HD. ADD stands for attention deficit disorder. AD/HD stands for attention-deficit/hyperactivity disorder. The only difference between these two is whether the child has hyperactivity with the attention disorder. Both ADD and AD/HD can make it hard for a person to sit still, control behavior, and pay attention. These difficulties usually begin before the person is 7 years old, but may not be noticed until the child is older.

For more information on ADD and AD/HD:

- Read NICHCY's stand-alone fact sheet on the disability, at http://nichcy.org/disability/specific/adhd/
- Visit Children and Adults with Attention Deficit Disorder (CHADD) | www.chadd.org

Diabetes is a disease in which the body does not produce or use insulin properly. Insulin is a hormone our bodies use to convert sugar, starches, and other food into the energy we need. There are 23.6 million children and adults in the United States with diabetes. This is about 7.8% of the population.

Symptoms of diabetes include: frequent urination, excessive thirst, extreme hunger, weight loss, fatigue, irritability, and blurry vision. If your child has these symptoms, see the doctor immediately and investigate the possibility of diabetes.

For more information on diabetes in both English and Spanish, contact:

- American Diabetes Association (ADA)
  (800) 342-2383 | http://www.diabetes.org
- National Diabetes Information Clearinghouse
  (800) 860–8747 | www.diabetes.niddk.nih.gov

Epilepsy. According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures. Epilepsy affects people in all nations and of all races.

Symptoms include: "blackouts" or periods of confused memory; episodes of staring or unexplained unresponsiveness; involuntary movement of arms and legs; fainting spells with incontinence or followed by excessive fatigue; or odd sounds, distorted perceptions, and feelings of fear that cannot be explained.

For information on epilepsy in English and Spanish:

- Read NICHCY's stand-alone fact sheet on the epilepsy, at http://nichcy.org/disability/specific/epilepsy/
- Visit the Epilepsy Foundation http://www.epilepsyfoundation.org

Heart conditions. It is nearly impossible to give a summary of heart conditions that may cause a "chronic or acute health condition" as defined within IDEA. There are many resources, however, that you can use to learn more about the specific condition of concern or interest to you. We've listed several below to get you started.

- American Heart Association
  (800)AHA-USA1
  http://www.americanheart.org
- National Heart, Lung, and Blood Institute
  http://www.nhlbi.nih.gov/health/public/heart/index.htm
- Mayo Clinic | Look under *Diseases and Conditions* for comprehensive guides to hundreds of different conditions, not just those related to the heart. http://mayoclinic.com/

Hemophilia is a rare, inherited disorder in which your blood doesn't clot properly. As a result, people with hemophilia may bleed after an injury for a longer time than those without the disorder. It's a myth that persons with hemophilia bleed to death from even minor injuries. In truth, the condition ranges mild to severe. Symptoms include: excessive bleeding, excessive bruising, easy bleeding, nose bleeds, and abnormal menstrual bleeding. Bleeding can also be internal, especially in the knees, ankles, and elbows.

With very few exceptions, this disorder usually occurs only in males. Each year, about 400 children are born with hemophilia. Approximately 18,000 people in the U.S. have hemophilia.

For more information on hemophilia in English and Spanish, contact the National Hemophilia Foundation, at (800) 42-HANDI and www.hemophilia.org

Lead poisoning. Lead can build up in the body over a period of months or years. Even a small amount of lead in the body can cause serious problems—hence, the term *lead poisoning*. Being exposed to lead-based paint or paint dust is the most common avenue to lead poisoning.

Children under the age of six are especially vulnerable, because their mental and physical abilities are still developing. Signs of lead poisoning are rather nonspecific, sometimes making diagnosis more difficult. Symptoms include: irritability, loss of appetite, weight loss, sluggishness, abdominal pain, vomiting, constipation, unusual paleness from anemia, and learning difficulties.

For more information in English and Spanish on lead poisoning, contact the National Lead Information Center, at (800) 424-LEAD (5323) and www.epa.gov/lead/nlic.htm

Leukemia. Normally, the bone marrow in our bodies produces white blood cells to defend against infections. Leukemia develops when the marrow produces too many white blood cells and what's produced are abnormal. Leukemia is considered a cancer of the bone marrow and blood. There

are four types. According to the Leukemia & Lymphoma Society , the most common type in children under 19 years of age is Acute Lymphocytic Leukemia (ALL).

Symptoms of ALL include: tiredness or no energy, shortness of breath during physical activity, pale skin, mild fever or night sweats, slow healing of cuts and excess bleeding, black-and-blue marks (bruises) for no clear reason, pinhead-size red spots under the skin, aches in bones or joints (for example, knees, hips or shoulders), and low white cell counts. A child showing any such symptoms should visit a healthcare professional for examination, to identify the cause.

For more information in English and Spanish on leukemia, contact the Leukemia & Lymphoma Society, at (800) 955-4572 and http://www.lls.org/

Nephritis means that one or both of a person's kidneys are inflamed. The kidneys are very important organs in the body, because they clean the blood by filtering out excess water, salt, and waste products from the food we eat. Nephritis may be due to infection, but it's more commonly associated with autoimmune disorders that affect the major organs of the body. Individuals with lupus, for example, are at much higher risk for developing nephritis.

You may also hear the term *nephrotic syndrome* used. In itself, nephrotic syndrome is not a disease, but it may be the first signs of kidney disease that makes it difficult for the body to produce urine. In children, nephrotic syndrome is most common between the ages of 1½ and 5 years, and seems to affect boys more often than girls. Symptoms include: high levels protein in the blood or, paradoxically, low levels; swelling, when salt and water build up in the tissues; less frequent urination; and weight gain from water retention. Diagnosing childhood nephrotic syndrome involves taking a urine sample to test for protein.

For more information in English and Spanish on your kidneys and nephritis, contact:

- American Kidney Fund | (800) 638–8299
  www.kidneyfund.org
- American Society of Pediatric Nephrology
  www.aspneph.com
- National Kidney Foundation | (800) 622–9010
  www.kidney.org

Rheumatic fever can develop as a complication of untreated or poorly treated strep throat or scarlet fever. It's not common in the United States, although it is fairly common worldwide. Symptoms include: fever; pain in one joint that moves to another joint; red, hot, or swollen joints; small, painless nodules beneath the skin; rapid, fluttering, or pounding heartbeats (palpitations); shortness of breath; a painless rash with a ragged edge; jerky, uncontrollable body movements, most often in the hands, feet, and face; and unusual behavior, such as crying or inappropriate laughing.

It's very important to treat rheumatic fever, because it can cause permanent damage to the heart, especially the valves. Diagnosing the condition usually involves a physical exam by the doctor, who will look for signs of tender or swollen joints, the tell-tale rash, and abnormal heart rhythm. Typically, the doctor will also do a blood test for strep throat. Antibiotics are the usual treatment for rheumatic fever, to eliminate the strep bacteria from the system. It's not unusual for a person to take low-dose antibiotics continually for years (especially the first 3 -5 years after the first episode) to prevent rheumatic fever from coming back.

For more information on rheumatic fever, read the Mayo Clinics article, at: http://www.mayoclinic.com/health/rheumatic-fever/DS00250

Sickle cell anemia. Anemia, in general, is a condition where an individual's blood has less than a normal number of red blood cells or the red blood cells themselves don't have enough hemoglobin (which carries oxygen throughout the body). Sickle cell anemia is one type of anemia where the hemoglobin is abnormal and the red blood cells often become shaped like the letter C, making them sickle-shaped (like a crescent). This shape makes it hard for the red blood cells to pass through small blood vessels, causing pain and damaging organs.

Literally millions of people worldwide are affected by sickle cell anemia. The disease is inherited and primarily affects people of African descent. Symptoms include chronic anemia and periodic episodes of pain (in the arms, legs, chest, and abdomen).

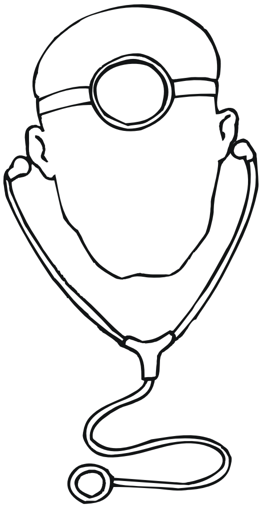
For more information on sickle cell anemia, check out these resources:

- Sickle Cell Disease Association of America, Inc.
  (800) 421-8453 | http://www.sicklecelldisease.org/
- SickleCellKids.org
  A fun, educational website for kids with sickle cell anemnia.
  http://www.sicklecellkids.org/
- American Sickle Cell Anemia Association
  http://www.ascaa.org/
- Información en español
  http://www.ascaa.org/espanol.php

Tourette syndrome is a disorder characterized by tics (involuntary, rapid, sudden movements) and/or vocal outbursts that occur repeatedly. The tics can range from simple (e.g., rapid eye-blinking, facial grimacing, shoulder-shrugging) to complex (involving several muscle groups, such as hopping, bending, or twisting). Vocalizations can also range from simple (throat-clearing, sniffing, grunting) to complex (involving words or phrases).

Tourette syndrome is an inherited disorder that is first noticed in childhood, usually between the ages of 7 and 10. The syndrome occurs in boys four times more than in girls. It's estimated that 2% of the population has Tourette syndrome. This may be a conservative estimate, since many people with very mild tics are unaware of them and never seek medical attention. However, effective medications are available for those whose symptoms interfere with functioning.

Are children with Tourette syndrome automatically eligible for special education and related services? The plain answer is: No. Eligibility will depend on several factors and a careful study of the evaluation results. As IDEA's definition of OHI indicates, the child's educational performance must be adversely affected as a result of the syndrome.



Interestingly, Tourette syndrome was explicitly added to the OHI category in the 2004 Amendments to IDEA. According to the U.S. Department of Education, the syndrome was specifically named in the definition of "other health impairment" because:

> …Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs. (71 Fed. Reg. at 46550)

For more information on Tourette syndrome:

- National Tourette Syndrome Association
  http://tsa-usa.org/
- Tourette Syndrome "Plus"
  http://www.tourettesyndrome.net/
- Información en español
  http://tsa-usa.org/aTSA_Espanol/bienvenidos.html

Other Health Impairments *Not* Mentioned in IDEA

As we said earlier, there are other health impairments that can fall under the umbrella of IDEA's OHI category besides the ones specifically mentioned in the law. The U.S. Department of Education mentions specific other disorders or conditions that may qualify a child for services under IDEA, in combination with other factors—for example: fetal alcohol syndrome (FAS), bipolar disorders, dysphagia, and other organic neurological disorders.

Why aren't these other disorders specifically mentioned in IDEA's regulations? According to the Department:

> ...because these conditions are commonly understood to be health impairments...The list of acute or chronic health conditions in the definition of other health impairment is not exhaustive, but rather provides examples of problems that children have that could make them eligible for special education and related services under the category of other health impairment. (71 Fed. Reg. at 46550)

Note that the Department uses the phase "could make them eligible"—*could*, not *does*. Other aspects (adversely affected educational performance, a child's evaluation results, state policies) are considered in determining eligibility for services under IDEA, not solely the existence of the disability or condition.

Addressing Medical Issues

By their very nature, other health impairments involve medical care and medical concerns. The amount of time that must be devoted to doctor visits, medical appointments, hospitalization, and seeing to the child's well-being will depend greatly on the nature and severity of the child's health impairment. For many families, the actual medical care of their child can be a daily, weekly, monthly challenge.

How to deal with the medical side of things? This section of our OHI fact sheet will connect you with resources and wisdom within the health care and parent communities both.

The Concept of a Medical Home

Recently, the term "medical home" has entered the lexicon of health care. A medical home is not a house, office, or hospital. It's a team-partnership approach to providing comprehensive primary care. The principles of a medical home are well stated by the American Academy of Pediatrics (2007): personal physician, physician-directed medical practice, whole person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment.

To find out more about this approach to health care, and to connect with resources in your state, visit the website of the **National Center for Medical Home Initiatives for Children with Special Needs**. You'll find the site full of information and tools for health care providers and families, including a national medical home training curriculum and links to medical home projects and activities in every state. There are also materials in other languages for addressing health care issues (Cambodian, Chinese, Korean, Laotian, Russian, Spanish, Vietnamese). Enter the site at: http://www.medicalhomeinfo.org/

Another resource you may find especially helpful in addressing the health care and medical issues associated with an OHI is **Family Voices**. Family Voices concerns itself proactively with the health care of children with special health care needs. Through a network of state chapters, Family-to-Family Health Information Centers, and political advocacy, Family Voices offers tools and informed guidance to professionals and families alike. Visit FV at: http://www.familyvoices.org/

Life at School

Health impairments can affect a student's educational performance. In fact, for a child to qualify for special education services in the public schools under the category of OHI, the health impairment *must* affect the child's educational performance.

When a child is found to be eligible for special education, he or she will also be eligible to receive **related services** in school. Related services are provided as required to enable children with disabilities to benefit from their special education. Three related services in particular come to mind for children who have an OHI:

- *medical services,* which are provided for diagnostic and evaluative purposes only, and which are defined as "…services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services" [34 CFR §300.34(c)(5)];
- *school health services* and *school nurse services,* which are defined by IDEA as "…health services that are designed to enable a child with a disability to receive FAPE as described in the child's IEP.

School nurse services are services provided by a qualified school nurse. School health services are services that may be provided by either a qualified school nurse or other qualified person [34 CFR §300.34(c)(13)]. Many children with disabilities, especially those who are medically fragile, could not attend school without these supportive services. Over the years, the number and type of the health-related services provided in schools have grown, as might be expected when you consider medical advances in the last decade alone. States and local school districts often have guidelines that address school health services and school nurse services. These may include providing such health-related support as:

- special feedings;
- clean intermittent catheterization;
- suctioning;
- the management of a tracheostomy;
- administering and/or dispensing medications;
- planning for the safety of a child in school;
- ensuring that care is given while at school and at school functions to prevent injury (e.g., changing a child's position frequently to prevent pressure sores);
- chronic disease management; and
- conducting and/or promoting education and skills training for all (including the child) who serve as caregivers in the school setting.

Determining what related services a child needs is the responsibility of the child's IEP team, the group that develops the child's individualized education program. Key information will be available from the evaluation process, since a child must be assessed in all areas related to his or her suspected disability. The IEP team must look carefully at the evaluation results, which show the child's areas of strength and need, and decide which related services are appropriate for the child. The school must then provide these services as part of the child's education program.

When Health Affects School Attendance

It's not uncommon for a child with an OHI to be absent from school, sometimes even for long periods of time, especially if a hospitalization is necessary. During these times, the public school remains responsible for providing educational and related services to the eligible child with OHI. Because IDEA specifically says that special education can be provided in a range of settings, including the home or the hospital, states and school districts will have policies and approaches for addressing children's individualized needs and circumstances.

This makes the school the best source of information about local policies on making sure that services are provided to children with OHI who are home-bound or hospitalized. When the child is at home, the school may arrange for a homebound instructor to bring assignments from school to home and help the student complete those assignments. When the child is hospitalized, services may be provided by the hospital, through arrangement with the school, although this will vary according to local policies. (In any event, the hospital is likely to have policies and procedures of its own, and it's important for the family to find out what those are.) The hospital may want to review the child's IEP and may, with the parent's permission, modify it during the child's hospitalization. Then, after the child is discharged, the hospital will share a summary of the child's progress with the school, in keeping with whatever local school policies are.

Planning for Transitions

After a child has been out of school for an extended period of time, it's important for parents and school staff to plan carefully for his or her return to school and the activities that go on there. Planning for a child's transition isn't just about when he or she returns to school, though. It needs to include moves from:

- hospital to home
- home to school
- school to school
- hospital to school
- school to work or college
- pediatric to adult health care (Pola-Money, 2005).

That's a tall order, isn't it? Fortunately, there are numerous resources available that can help families, schools, and health care providers plan for each of these types of transition. Here are several to start, and they will likely lead you to more:

- *Transition issues.*
  Medical Home Portal.
  http://www.medicalhomeportal.org/living-with-child/transition-issues
- *Transitioning from pediatric to adult health care.*
  The Adolescent Health Transition Project.
  http://depts.washington.edu/healthtr/
- *Transitions for youth with health care needs.*
  Healthy & Ready to Work (HRTW) National Resource Center.
  http://www.hrtw.org/index.html

Finding More Info

In closing, we hope that this information is helpful to you. We encourage you to learn more through the many resources we've listed in this factsheet *and* by visiting our website. Every page on our website has a SEARCH box in the upper right corner. What OHI are you interested in? Type the name of that OHI into the SEARCH box, press the SEARCH button (alongside), and you'll get a list of search results. Those results will connect you with products and organizations related to your OHI of interest. Good luck!

FS15—Updated March 2012

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Speech & Language Impairments

NICHCY Disability Fact Sheet #11
January 2011

A Day in the Life of an SLP

Christina is a speech-language pathologist. She works with children and adults who have impairments in their speech, voice, or language skills. These impairments can take many forms, as her schedule today shows.

First comes Robbie. He's a cutie pie in the first grade and has recently been diagnosed with childhood apraxia of speech—or CAS. CAS is a speech disorder marked by choppy speech. Robbie also talks in a monotone, making odd pauses as he tries to form words. Sometimes she can see him struggle. It's not that the muscles of his tongue, lips, and jaw are weak. The difficulty lies in the brain and how it communicates to the muscles involved in producing speech. The muscles need to move in precise ways for speech to be intelligible. And that's what she and Robbie are working on.

Next, Christina goes down the hall and meets with Pearl in her third grade classroom. While the other students are reading in small groups, she works with Pearl one on one, using the same storybook. Pearl has a speech disorder, too, but hers is called dysarthria. It causes Pearl's speech to be slurred, very soft, breathy, and slow. Here, the cause *is* weak muscles of the tongue, lips, palate, and jaw. So that's what Christina and Pearl work on—strengthening the muscles used to form sounds, words, and sentences, and improving Pearl's articulation.

One more student to see—4th grader Mario, who has a stutter. She's helping Mario learn to slow down his speech and control his breathing as he talks. Christina already sees improvement in his fluency.

Tomorrow she'll go to a different school, and meet with different students. But for today, her day is...Robbie, Pearl, and Mario.

Definition

There are many kinds of speech and language disorders that can affect children. In this fact sheet, we'll talk about four major areas in which these impairments occur. These are the areas of:

- **Articulation** | speech impairments where the child produces sounds incorrectly (e.g., lisp, difficulty articulating certain sounds, such as "l" or "r");
- **Fluency** | speech impairments where a child's flow of speech is disrupted by sounds, syllables, and words that are repeated, prolonged, or avoided and where there may be silent blocks or inappropriate inhalation, exhalation, or phonation patterns;
- **Voice** | speech impairments where the child's voice has an abnormal quality to its pitch, resonance, or loudness; and

NICHCY *is the National Dissemination Center for Children with Disabilities.*

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- **Language** | language impairments where the child has problems expressing needs, ideas, or information, and/or in understanding what others say.[1]

These areas are reflected in how "speech or language impairment" is defined by the nation's special education law, the Individuals with Disabilities Education Act (IDEA's definition is given in the box to the right). IDEA is the law that makes early intervention services available to infants and toddlers with disabilities, and special education available to school-aged children with disabilities.

Development of Speech and Language Skills in Childhood

Speech and language skills develop in childhood according to fairly well-defined milestones (see the box below). Parents and other caregivers may become concerned if a child's language seems noticeably behind (or different from) the language of same-aged peers. This may motivate parents to investigate further and, eventually, to have the child evaluated by a professional.

More on the Milestones of Language Development

What *are* the milestones of typical speech-language development? What level of communication skill does a typical 8-month-old baby have, or a 18-month-old, or a child who's just celebrated his or her fourth birthday?

You'll find these expertly described in *How Does Your Child Hear and Talk?*, a series of resource pages available online at the American Speech-Language-Hearing Association (ASHA):

http://www.asha.org/public/speech/development/chart.htm

Definition of "Speech or Language Impairment" under IDEA

The Individuals with Disabilities Education Act, or IDEA, defines the term "speech or language impairment" as follows:

> "(11) *Speech or language impairment* means a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, that adversely affects a child's educational performance."

[34 CFR §300.8(c)(11]

Having the child's hearing checked is a critical first step. The child may not have a speech or language impairment at all but, rather, a hearing impairment that is interfering with his or her development of language.

It's important to realize that a *language delay* isn't the same thing as a speech or language impairment. Language delay is a very common developmental problem—in fact, *the* most common, affecting 5-10% of children in preschool.[2] With language delay, children's language is developing in the expected sequence, only at a slower rate. In contrast, *speech and language disorder* refers to abnormal language development.[3] Distinguishing between the two is most reliably done by a certified speech-language pathologist such as Christina, the SLP in our opening story.

Characteristics of Speech or Language Impairments

The characteristics of speech or language impairments will vary depending upon the type of impairment involved. There may also be a combination of several problems.

When a child has an **articulation disorder**, he or she has difficulty making certain sounds. These sounds may be left off, added, changed, or distorted, which makes it hard for people to understand the child.

Leaving out or changing certain sounds is common when young children are learning to talk, of course. A good example of this is saying "wabbit" for "rabbit." The incorrect articulation isn't necessarily a cause for concern unless it continues past the age where children are expected to produce such sounds correctly.[4] (ASHA's milestone resource pages, mentioned above, are useful here.)

Fluency refers to the flow of speech. A **fluency disorder** means that something is disrupting the rhythmic and forward flow of speech—usually, a stutter. As a result, the child's speech contains an "abnormal number of repetitions, hesitations, prolongations, or disturbances. Tension may also be seen in the face, neck, shoulders, or fists."[5]

Voice is the sound that's produced when air from the lungs pushes through the voice box in the throat (also called the larnyx), making the vocal folds within vibrate. From there, the sound generated travels up through the spaces of the throat, nose, and mouth, and emerges as our "voice." A **voice disorder** involves problems with the pitch, loudness, resonance, or quality of the voice.[6] The voice may be hoarse, raspy, or harsh. For some, it may sound quite nasal; others might seem as if they are "stuffed up." People with voice problems often notice changes in pitch, loss of voice, loss of endurance, and sometimes a sharp or dull pain associated with voice use.[7]

Language has to do with meanings, rather than sounds.[8] A **language disorder** refers to an impaired ability to understand and/or use words in context.[9] A child may have an *expressive* language disorder (difficulty in expressing ideas or needs), a *receptive* language disorder (difficulty in understanding what others are saying), or a *mixed* language disorder (which involves both).

Some characteristics of language disorders include:

- improper use of words and their meanings,
- inability to express ideas,
- inappropriate grammatical patterns,
- reduced vocabulary, and
- inability to follow directions.[10]

Children may hear or see a word but not be able to understand its meaning. They may have trouble getting others to understand what they are trying to communicate. These symptoms can easily be mistaken for other disabilities such as autism or learning disabilities, so it's very important to ensure that the child receives a thorough evaluation by a certified speech-language pathologist.

What Causes Speech and Language Disorders?

Some causes of speech and language disorders include hearing loss, neurological disorders, brain injury, intellectual disabilities, drug abuse, physical impairments such as cleft lip or palate, and vocal abuse or misuse. Frequently, however, the cause is unknown.

Incidence

Of the 6.1 million children with disabilities who received special education under IDEA in public schools in the 2005-2006 school year, **more than 1.1 million** were served under the category of speech or language impairment.[11]

This estimate does not include children who have speech/language problems secondary to other conditions such as deafness, intellectual disability, autism, or cerebral palsy. Because many disabilities do impact the individual's ability to communicate, the actual incidence of children with speech-language impairment is undoubtedly much higher.

Finding Help

Because all communication disorders carry the potential to isolate individuals from their social and educational surroundings, it is essential to provide help and support as soon as a problem is identified. While many speech and language patterns can be called "baby talk" and are part of children's normal development, they can become problems if they are not outgrown as expected.

Therefore, it's important to take action if you suspect that your child has a speech or language impairment (or other disability or delay). The next two sections in this fact sheet will tell you how to find this help.

Help for Babies and Toddlers

Since we begin learning communication skills in infancy, it's not surprising that parents are often the first to notice—and worry about—problems or delays in their child's ability to communicate or understand. Parents should know that there is a lot of help available to address concerns that their young child may be delayed or impaired in developing communication skills. Of particular note is the the **early intervention** system that's available in every state.

Early intervention is a system of services designed to help infants and toddlers with disabilities (until their 3rd birthday) and their families. It's mandated by the IDEA. Through early intervention, parents can have their young one evaluated free of charge, to identify developmental delays or disabilities, including speech and language impairments.

If a child is found to have a delay or disability, staff work with the child's family to develop what is known as an *Individualized Family Services Plan*, or *IFSP*. The IFSP will describe the child's unique needs as well as the services he or she will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to support their young child's needs. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

To access early intervention services in your area
Consult NICHCY's
State Resource Sheet
for your state.
●●●●●●●
http://nichcy.org/state-organization-search-by-state

There, you'll find a listing for early intervention under the first section, **State Agencies**. The agency listed will be able to put you in contact with the early intervention program in your community.

To learn more about early intervention, including how to write the IFSP, visit NICHCY at: http://nichcy.org/babies/overview/

Help for School-Aged Children

Just as IDEA requires that early intervention be made available to babies and toddlers with disabilities, it requires that **special education and related services** be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, a speech or language impairment.

Many children are identified as having a speech or language impairment after they enter the public school system. A teacher may notice difficulties in a child's speech or communication skills and refer the child for evaluation. Parents may ask to have their child evaluated. This evaluation is provided free by the public school system.

If the child is found to have a disability under IDEA—such as a speech-language impairment—school staff will work with his or her parents to develop an *Individualized Education Program*, or *IEP*. The IEP is similar to an IFSP. It describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services are provided at no cost to parents.

There is a lot to know about the special education process, much of which you can learn at NICHCY, which offers a wide range of publications on the topic. Enter our special education information at: http://nichcy.org/schoolage/

Educational Considerations

Communication skills are at the heart of the education experience. Eligible students with speech or language impairments will want to take advantage of special education and related services that are available in public schools.

The types of supports and services provided can vary a great deal from student to student, just as speech-language impairments do. Special education and related services are planned and delivered based on *each student's individualized educational and developmental needs*.

Most, if not all, students with a speech or language impairment will need **speech-language pathology services**. This related service is defined by IDEA as follows:

(15) *Speech-language pathology services* includes—

(i) Identification of children with speech or language impairments;

(ii) Diagnosis and appraisal of specific speech or language impairments;

(iii) Referral for medical or other professional attention necessary for the habilitation of speech or language impairments;

(iv) Provision of speech and language services for the habilitation or prevention of communicative impairments; and

(v) Counseling and guidance of parents, children, and teachers regarding speech and language impairments. [34 CFR §300.34(c)(15)]

Thus, in addition to diagnosing the nature of a child's speech-language difficulties, speech-language pathologists also provide:

- individual therapy for the child;
- consult with the child's teacher about the most effective ways to facilitate the child's communication in the class setting; and
- work closely with the family to develop goals and techniques for effective therapy in class and at home.

Speech and/or language therapy may continue throughout a student's school years either in the form of direct therapy or on a consultant basis.

Assistive technology (AT) can also be very helpful to students, especially those whose physical conditions make communication difficult. Each student's IEP team will need to consider if the student would benefit from AT such as an electronic communication system or other device. AT is often the key that helps students engage in the give and take of shared thought, complete school work, and demonstrate their learning.

References

1| Minnesota Department of Education. (2010). *Speech or language impairments.* Online at: http://education.state.mn.us/MDE/Learning_Support/Special_Education/Categorical_Disability_Information/Speech_or_Language_Impairments/index.html

2| Boyse, K. (2008). *Speech and language delay and disorder*. Retrieved from the University of Michigan Health System website: http://www.med.umich.edu/yourchild/topics/speech.htm

3| *Ibid.*

Tips for Teachers

—Learn as much as you can about the student's *specific* disability. Speech-language impairments differ considerably from one another, so it's important to know the specific impairment and how it affects the student's communication abilities.

—Recognize that you can make an enormous difference in this student's life! Find out what the student's strengths and interests are, and emphasize them. Create opportunities for success.

—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.

—Make sure that needed accommodations are provided for classwork, homework, and testing. These will help the student learn successfully.

—Consult with others (e.g., special educators, the SLP) 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 speech or language 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.

Tips for Parents

—Learn the specifics of your child's speech or language impairment. The more you know, the more you can help yourself and your child.

—Be patient. Your child, like every child, has a whole lifetime to learn and grow.

—Meet with the school and develop an IEP to address your child's needs. Be your child's advocate. You know your son or daughter best, share what you know.

—Be well informed about the speech-language therapy your son or daughter is receiving. Talk with the SLP, find out how to augment and enrich the therapy at home and in other environments. Also find out what *not* to do!

—Give your child chores. Chores build confidence and ability. Keep your child's age, attention span, and abilities in mind. Break down jobs into smaller steps. Explain what to do, step by step, until the job is done. Demonstrate. Provide help when it's needed. Praise a job (or part of a job) well done.

—Listen to your child. Don't rush to fill gaps or make corrections. Conversely, don't force your child to speak. Be aware of the other ways in which communication takes place between people.

—Talk to other parents whose children have a similar speech or language impairment. Parents can share practical advice and emotional support. Visit NICHCY's State Sheets and find a parent group near you. Look in the Disability-Specific section, under "speech-language." State Sheets are online at: http://nichcy.org/state-organization-search-by-state

—Keep in touch with your child's teachers. 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 school learning at home.

4| American Speech-Language-Hearing Association. (n.d.). *Speech sound disorders: Articulation and phonological processes.* Online at: http://www.asha.org/public/speech/disorders/speechsounddisorders.htm

5| Cincinnati Children's Hospital. (n.d.). *Speech conditions and diagnoses*. Online at: http://www.cincinnatichildrens.org/health/info/speech/diagnose/speech-disorder.htm

6| National Institute on Deafness and Other Communication Disorders. (2002). *What is voice? What is speech? What is language?* Online at: http://www.nidcd.nih.gov/health/voice/whatis_vsl.htm

7| American Academy of Otolaryngology — Head and Neck Surgery. (n.d.). *Fact sheet: About your voice.* Online at: http://www.entnet.org/HealthInformation/aboutVoice.cfm

8| Boyse, K. (2008). *Speech and language delay and disorder*. Retrieved from the University of Michigan Health System website: http://www.med.umich.edu/yourchild/topics/speech.htm

9| Encyclopedia of Nursing & Allied Health. (n.d.). *Language disorders.* Online at: http://www.enotes.com/nursing-encyclopedia/language-disorders

10| *Ibid.*

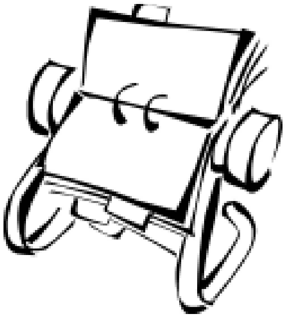
11| U.S. Department of Education. (2010, December). *Twenty-ninth annual report to Congress on the Implementation of the Individuals with Disabilities Education Act: 2007*. Online at: http://www2.ed.gov/about/reports/annual/osep/2007/parts-b-c/index.html

Readings and Articles

We urge you to read the articles identified in the References section. Each provides detailed and expert information on speech or language impairments. Additionally, we'd also recommend:

- Speech-Language Impairment: How to Identify the Most Common and Least Diagnosed Disability of Childhood | http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2491683/
- Speech and Language (Communication) Disorders | NOAH-Health | http://www.noah-health.org/en/bns/disorders/speech/

Organizations to Consult



ASHA | American Speech-Language-Hearing Association
Information in Spanish | Información en español.
1.800.638.8255 | actioncenter@asha.org | www.asha.org

NIDCD | National Institute on Deafness and Other Communication Disorders
1.800.241.1044 (Voice) | 1.800.241.1055 (TTY)
nidcdinfo@nidcd.nih.gov | http://www.nidcd.nih.gov/Pages/default.aspx

Cleft Palate Foundation | 1.800.242.5338 | http://www.cleftline.org

Childhood Apraxia of Speech Association of North America | CASANA
http://www.apraxia-kids.org

National Stuttering Foundation | 1.800.937.8888 | info@WeStutter.org | http://www.nsastutter.org/

Stuttering Foundation | 1.800.992.9392 | info@stutteringhelp.org | http://www.stuttersfa.org/

If there is a primary condition that is associated with the speech-language impairment, such as autism or learning disabilities, we'd recommend visiting NICHCY and using the "search" box to identify organizations that specialize in that primary condition.

IDEAs that Work
U.S. Office of Special Education Programs

FS11—January 2011

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THE SCIENCE OF IMPROVING LIVES

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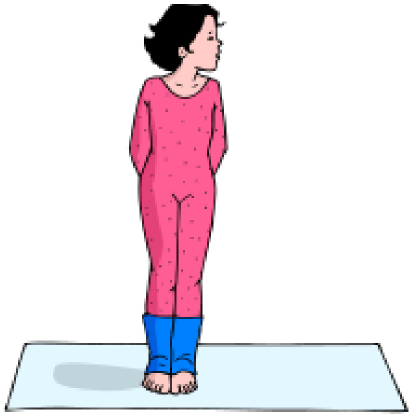

Traumatic Brain Injury

NICHCY Disability Fact Sheet #18
Resources updated, March 2011

Susan's Story

Susan was 7 years old when she was hit by a car while riding her bike. She broke her arm and leg. She also hit her head very hard. The doctors say she sustained a traumatic brain injury. When she came home from the hospital, she needed lots of help, but now she looks fine.

In fact, that's part of the problem, especially at school. Her friends and teachers think her brain has healed because her broken bones have. But there are changes in Susan that are hard to understand. It takes Susan longer to do things. She has trouble remembering things. She can't always find the words she wants to use. Reading is hard for her now. It's going to take time before people really understand the changes they see in her.

What is TBI?

A traumatic brain injury (TBI) is an injury to the brain caused by the head being hit by something or shaken violently. (The exact definition of TBI, according to special education law, is given in the box on the next page.) This injury can change how the person acts, moves, and thinks. A traumatic brain injury can also change how a student learns and acts in school. The term TBI is used for head injuries that can cause changes in one or more areas, such as:

- thinking and reasoning,
- understanding words,
- remembering things,
- paying attention,
- solving problems,
- thinking abstractly,
- talking,
- behaving,
- walking and other physical activities,
- seeing and/or hearing, and
- learning.

The term TBI is not used for a person who is born with a brain injury. It also is not used for brain injuries that happen during birth.

NICHCY *is the*
National Dissemination Center for Children with Disabilities.

NICHCY
1825 Connecticut Avenue N.W.
Washington, DC 20009
1.800.695.0285 (Voice / TTY)
202.884.8200 (Voice / TTY)
nichcy@fhi360.org
http://nichcy.org

The definition of TBI in the box to the right comes from the Individuals with Disabilities Education Act (IDEA). The IDEA is the federal law that guides how schools provide special education and related services to children and youth with disabilities.

Definition of "Traumatic Brain Injury" under IDEA

Our nation's special education law, the Individuals with Disabilities Education Act (IDEA), defines traumatic brain injury as. . .

> *Traumatic brain injury* means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. Traumatic brain injury applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. Traumatic brain injury does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma. [34 *Code of Federal Regulations* §300.8(c)(12)]

How Common is TBI?

Approximately 1.4 million people receive traumatic brain injuries every year.[1] Of children 0-14 years old, TBI results in 435,000 trips to the emergency room annually, 37,000 hospitalizations, and nearly 2,700 deaths.[2]

What Are the Signs of TBI?

The signs of brain injury can be very different depending on where the brain is injured and how severely. Children with TBI may have one or more difficulties, including:

- *Physical disabilities:* Individuals with TBI may have problems speaking, seeing, hearing, and using their other senses. They may have headaches and feel tired a lot. They may also have trouble with skills such as writing or drawing. Their muscles may suddenly contract or tighten (this is called spasticity). They may also have seizures. Their balance and walking may also be affected. They may be partly or completely paralyzed on one side of the body, or both sides.

- *Difficulties with thinking:* Because the brain has been injured, it is common that the person's ability to use the brain changes. For example, children with TBI may have trouble with short-term memory (being able to remember something from one minute to the next, like what the teacher just said). They may also have trouble with their long-term memory (being able to remember information from a while ago, like facts learned last month). People with TBI may have trouble concentrating and only be able to focus their attention for a short time. They may think slowly. They may have trouble talking and listening to others. They may also have difficulty with reading and writing, planning, understanding the order in which events happen (called sequencing), and judgment.

- *Social, behavioral, or emotional problems:* These difficulties may include sudden changes in mood, anxiety, and depression. Children with TBI may have trouble relating to others. They may be restless and may laugh or cry a lot. They may not have much motivation or much control over their emotions.

A child with TBI may not have all of the above difficulties. Brain injuries can range from mild to severe, and so can the changes that result from the injury. This means that it's hard to predict how an individual will recover from the injury. Early and ongoing help can make a big difference in how the child recovers. This help can include physical or occupational therapy, counseling, and special education.

It's also important to know that, as the child grows and develops, parents and teachers may notice new problems. This is because, as students grow, they are expected to use their brain in new and different ways. The damage to the brain from the earlier injury can make it hard for the student to learn new skills that come with getting older. Sometimes parents and educators may not even realize that the student's difficulty comes from the earlier injury.

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, 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).

To access early intervention: To identify the EI program in your neighborhood, consult NICHCY's *State Resource Sheet* for your state (it's available online on NICHCY's website). Early intervention is listed under the first section, State Agencies. The agency that's identified will be able to put you in contact with the early intervention program in your community. There, you can have your child evaluated free of charge and, if found eligible, your child can begin receiving early intervention services.

To access special education and related services: We recommend that you get in touch with your local public school system. Calling the elementary 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, he or she can begin receiving services specially designed to address your child's needs. In the fall of 2007, nearly 25,000 school-aged children (ages 3-21) received special education and related services in our public schools under the category of "traumatic brain injury."[3]

What About School?

Although TBI is very common, many medical and education professionals may not realize that some difficulties can be caused by a childhood brain injury. Often, students with TBI are thought to have a learning disability, emotional disturbance, or an intellectual disability. As a result, they don't receive the type of educational help and support they really need.

When children with TBI return to school, their educational and emotional needs are often very different than before the injury. Their disability has happened suddenly and traumatically. They can often remember how they were before the brain injury. This can bring on many emotional and social changes. The child's family, friends, and teachers also recall what the child was like before the injury. These other people in the child's life may have trouble changing or adjusting their expectations of the child.

Therefore, it is extremely important to plan carefully for the child's return to school. Parents will want to find out ahead of time about special education services at the school. This information is usually available from the school's principal or special education teacher. The school will need to evaluate the child thoroughly. This evaluation will let the school and parents know what the student's educational needs are. The school and parents will then develop an Individualized Education Program (IEP) that addresses those educational needs.

It's important to remember that the IEP is a *flexible* plan. It can be changed as the parents, the school, and the student learn more about what the student needs at school.

References

[1] National Center for Injury Prevention and Control. (2009). *What is traumatic brain injury?* Available online at the Centers for Disease Prevention and Control (CDC) website: http://www.cdc.gov/ncipc/tbi/TBI.htm

[2] *Ibid.*

[3] Data Accountability Center. (2009). *Data tables for OSEP state reported data.* Available online at:

- http://www.ideadata.org/TABLES31ST/AR_1-2.htm
- http://www.ideadata.org/TABLES31ST/AR_1-3.htm

Tips for Parents

- Learn about TBI. The more you know, the more you can help yourself and your child. The resources and organizations listed in this fact sheet offer a great deal of information about TBI.
- Work with the medical team to understand your child's injury and treatment plan. Don't be shy about asking questions. Tell them what you know or think. Make suggestions.
- Keep track of your child's treatment. A 3-ring binder or a box can help you store this history. As your child recovers, you may meet with many doctors, nurses, and others. Write down what they say. Put any paperwork they give you in the notebook or throw it in the box. You can't remember all this! Also, if you need to share any of this paperwork with someone else, make a copy. Don't give away your original!
- Talk to other parents whose children have TBI. There are parent groups all over the U.S. Parents can share practical advice and emotional support. Email NICHCY (nichcy@fhi360.org) or use NICHCY's *State Resource Sheet* to locate parent groups near you. Look under the heading "Organizations for Parents." Find your state sheet at: http://nichcy.org/state-organization-search-by-state
- If your child was in school before the injury, plan for his or her return to school. Get in touch with the school. Ask the principal about special education services. Have the medical team share information with the school.
- When your child returns to school, ask the school to test your child as soon as possible to identify his or her special education needs. Meet with the school and help develop a plan for your child called an Individualized Education Program (IEP).
- Keep in touch with your child's teacher. Tell the teacher about how your child is doing at home. Ask how your child is doing in school.

Tips for Teachers

- Find out as much as you can about the child's injury and his or her present needs. Find out more about TBI through the resources and organizations listed in this fact sheet. These can help you identify specific techniques and strategies to support the student educationally.
- Recognize that you can make an enormous difference in this student's life! Find out what the student's strengths and interests are, and emphasize them. Create opportunities for success.
- 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.
- Make sure that needed accommodations are provided for classwork, homework, and testing. These will help the student learn successfully.
- Show the student how to perform new tasks. Give directions one step at a time. For tasks with many steps, it helps to give the student written directions.
- Check to make sure that the student has actually learned the new skill. Give the student lots of opportunities to practice the new skill.

- Give the student more time to finish schoolwork and tests.
- Have consistent routines. This helps the student know what to expect. If the routine is going to change, let the student know ahead of time.
- Show the student how to use an assignment book and a daily schedule. This helps the student get organized.
- Realize that the student may get tired quickly. Let the student rest as needed. Reduce distractions.
- Keep in touch with the student's parents. Share information about how the student is doing at home and at school.

Basic Readings

American Academy of Family Physicians. (2010). *Traumatic brain injury.* Online at: http://familydoctor.org/familydoctor/en/diseases-conditions/traumatic-brain-injury.html

CDC | Centers for Disease Control and Prevention. (2010). *Traumatic brain injury.* Online at: www.cdc.gov/TraumaticBrainInjury/

National Institute of Neurological Disorders and Stroke. (2011, January). *NINDS traumatic brain injury information page.* Online at: http://www.ninds.nih.gov/disorders/tbi/tbi.htm

Organizations

Brain Injury Association of America |

- Main website: http://www.biausa.org/
- Find your state BIA affiliate: www.biausa.org/state-affiliates.htm
- National Brain Injury Information Center *(brain injury information only)* 1.800.444.6443

National Resource Center for Traumatic Brain Injury (NRCTBI)
http://www.neuro.pmr.vcu.edu/

Brainline
Information available in English and Spanish.
info@BrainLine.org
http://www.brainline.org/

The Perspectives Network, Inc.
TPN@tbi.org
http://www.tbi.org

Family Caregiver Alliance
Information in English, Spanish, and Chinese.
http://www.caregiver.org/caregiver/jsp/home.jsp

TBI Recovery Center
http://www.tbirecoverycenter.org/

FS18—Resources updated, March 2011

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Maya Angelou PCS Shaw Campus
1851 9th Street, NW 5600
Washington, DC,

Student Information

Student Name: [redacted] **Student ID:** [redacted] **Date of Birth:** 04/13/1994 **Student Grade:** 11th Grade

School Information

School Name: Maya Angelou PCS Shaw Campus **Case Manager:** Jennifer T. Troya

Disability Worksheet

Teams should use the following checklist as a tool to facilitate discussion about the determination of eligibility for a specific disability. Teams are expected to use evidence including evaluation information and other existing data to confirm or deny each criterion in order to make a differential determination of eligibility.

Other Health Impairment

State Policy Definition: Having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, resulting in limited alertness with respect to the educational environment, and adversely affecting a child's education performance, due to chronic or acute health problems.

Federal and State regulation reference: ***34 CFR §300.8(c)(9), DCMR 3001.1***

Requirements of eligibility determination: The student must meet each numbered criterion (and have documentation to support decision) in order to be considered eligible as a student with the disability named above.

Directions: Check the box below if the team has evidence to show that the student meets the following criteria.

Eligibility Criteria

	1. The impairment is due to chronic or acute health problems such as asthma, attention deficit disorder, attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; Identify specific diagnosis or diagnoses: Attention Deficit Hyper-Activity Disorder (Psychological Report 6/28/10)
✓	**2. The impairment adversely affects a student's educational performance.**
✓	**3. Impact on developmental or academic functioning is not primarily the result of behavior.**

Decision

The team reviewed all relevant evaluation and other existing data and determined that:

__✓__ The student meets all of the criteria for the specified disability

_____ The student does not meet all of the required criteria for the specified disability

Date of Decision: 8.31.2010

Student Information			
Student Name: [redacted]	**Student ID:** 9258646	**Date of Birth:** 04/13/1994	**Student Grade:** 11th Grade
School Information			
School Name: Maya Angelou PCS Shaw Campus		**Case Manager:** Jennifer T. Troya	

Disability Worksheet

Teams should use the following checklist as a tool to facilitate discussion about the determination of eligibility for a specific disability. Teams are expected to use evidence including evaluation information and other existing data to confirm or deny each criterion in order to make a differential determination of eligibility.

Specific Learning Disability

State Policy Definition: IDEA 2004 defines a specific learning disability (SLD) as a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. SLD may include conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. However, SLD may not include learning problems that are primarily the result of: visual, hearing, or motor disabilities; intellectual disability (known as mental retardation); emotional disturbance; cultural, factors; environmental or economic disadvantage; or limited English proficiency. The District of Columbia Municipal Regulations adopt the federal definition of SLD. Federal and State regulation reference: ***34 CFR §300.8(c)(10), DCMR 3001.1***

Requirements of eligibility determination: Part I: The student must meet all of the criteria for either option A-Discrepancy Model OR Option B-Scientific Research-Based Interventions Model. Additionally, the team must complete all of the required documentation associated with Parts II and III.

Directions: Use the information below to guide discussion and as a worksheet to document evidence to support criteria for SLD. ***Note: If found eligible for SLD, this information must be entered into EasyIEP in order to meet the specific requirements for SLD determination 34 CFR §300.311.***

Part I: SLD Identification Model (Team must discuss and record decisions related ALL of the requirements of EITHER the **Discrepancy Model** OR the **Scientific Research-Based Interventions Model**)

Option A: Discrepancy Model	
Criterion 1: The student does not achieve adequately and/or does not make sufficient progress to meet age or State-approved grade-level standards in one or more of the following areas, when provided with learning experiences and instruction appropriate for the student's age or State-approved grade-level standards (At least one of the following must be marked in order to meet the requirement): ☐ Oral expression ☐ Listening comprehension ☐ Written expression ☐ Basic reading skill ☐ Reading fluency skills ☐ Reading comprehension ☑ Mathematics calculation ☑ Mathematics problem solving Basis for determination: Psychological / Psychoeducational Evaluation 6.18.10	
[✓ Yes] ___ No	**Criterion 2: The student demonstrates a discrepancy between achievement (as measured by the academic evaluation) and measured ability (as measured by the intellectual evaluation) of two years below a student's chronological age and/or at least two standard deviations below the student's cognitive ability as measured by appropriate standardized diagnostic instruments and procedures.** (Must be yes in order to meet the requirement)
Criterion 3: Is the impact on the student's achievement level the result of: (All of the following must be no in order to meet the requirement)	
___ Yes [✓ No]	Lack of appropriate instruction in reading, to include the essential components of reading instruction (phonemic awareness, phonics, fluency, vocabulary and comprehension)
___ Yes [✓ No]	Lack of appropriate instruction in math
___ Yes [✓ No]	Lack of appropriate instruction in writing
___ Yes [✓ No]	A visual, hearing, or motor disability
___ Yes [✓ No]	Intellectual disability (known as mental retardation)
___ Yes [✓ No]	Emotional disturbance
___ Yes [✓ No]	Cultural factors
___ Yes [✓ No]	Environmental or economic disadvantage
___ Yes [✓ No]	Limited English Proficiency

Option B: Scientific Research-Based Interventions Model	
___ Yes ___ No	**Criterion 1: The student must meet 1a AND 1b OR 1c AND 1d in order to satisfy the criterion.** **Criterion 1a: The student's response to scientific research based interventions indicates that the student is not achieving adequately for their age or to meet age or State-approved grade-level standards in one or more of the following areas, when provided with learning experiences and instruction appropriate for the student's age or state-approved grade-level standards:** ☐ Oral expression ☐ Listening comprehension ☐ Written expression ☐ Basic reading skill ☐ Reading fluency skills ☐ Reading comprehension ☐ Mathematics calculation ☐ Mathematics problem solving **AND**
___ Yes ___ No	**Criterion 1b: The student does not make sufficient progress to meet age or District of Columbia Learning Standards in one or more of the areas identified above when using a process based on the student's response to scientific, research-based intervention**
[✓ Yes] ___ No	**Criterion 1c: The student exhibits a pattern of strengths and weaknesses in performance, achievement, or both, relative to age, District of Columbia Learning Standards, or intellectual development, that is determined by the group to be relevant to the identification of a specific learning disability, using appropriate assessments** **AND**
[✓ Yes] ___ No	**Criterion 1d: The student exhibits characteristics of specific learning disabilities consistent with the definition.**

Criterion 2: Is the impact on the student's achievement level the result of :	
___ Yes [✓ No]	Lack of appropriate instruction in reading, to include the essential components of reading instruction (phonemic awareness, phonics, fluency, vocabulary and comprehension)
___ Yes [✓ No]	Lack of appropriate instruction in math
___ Yes [✓ No]	Lack of appropriate instruction in writing
___ Yes [✓ No]	A visual, hearing, or motor disability
___ Yes [✓ No]	Intellectual Disability
___ Yes [✓ No]	Emotional disturbance
___ Yes [✓ No]	Cultural factors
___ Yes [✓ No]	Environmental or economic disadvantage
___ Yes [✓ No]	Limited English Proficiency

Document interventions or instructional strategies and student-centered data collected **(At least 2 interventions required)**

Intervention/Strategy	Progress Monitoring Tool	Outcome
Use of Calculator	- Teacher Observations - Work Samples	Student benefits from calculator - she uses the calculator to check work and when doing multi step problems.
Extended time on assignments and assessment	Teacher observations - Work Samples	~~The~~ student cannot perform given time constraints - Sarah continues to need extended time as an accomodation

Were parents notified of all the following? **(Response to all must be yes in order to meet the requirement)**	
[✓ Yes] ___ No	The State's policies regarding the amount and nature of student performance data that would be collected and the general education services that would be provided;
[✓ Yes] ___ No	Strategies for increasing the student's rate of learning
[✓ Yes] ___ No	The parents' right to request an evaluation

Part II: Documentation of Other Factors

Documentation of Other Factors

Describe the relevant behavior, if any, noted during the observation of the student and the relationship of that behavior to the student's academic functioning

Student's area of weakness is Mathematics; she struggles with manipulating information – which Results in Sarah having difficulty with Math Reasoning.

Describe the educationally relevant medical findings, if any;

Student has also been diagnosed with ADHD and other emotional disorders

Part III: SLD Decision

Decision

The team reviewed all relevant evaluation and other existing data and determined that:

__✓__ The student meets all of the criteria for the specified disability

______ The student does not meet all of the required criteria for the specified disability

✓ Yes __ No	All team members documented their agreement or disagreement with the report conclusions on the eligibility determination form. (Team members in disagreement with the determination must submit a written statement documenting their decision).

Date of Decision: 8.31.2010

Maya Angelou PCS Shaw Campus
1851 9th Street, NW 5600
Washington, DC,

Student Information			
Student Name: [redacted]	**Student ID:** [redacted]	**Date of Birth:** 04/13/1994	**Student Grade:** 11th Grade
School Information			
School Name: Maya Angelou PCS Shaw Campus		**Case Manager:** Jennifer T. Troya	

Disability Worksheet

Teams should use the following checklist as a tool to facilitate discussion about the determination of eligibility for a specific disability. Teams are expected to use evidence including evaluation information and other existing data to confirm or deny each criterion in order to make a differential determination of eligibility.

Emotional Disturbance

State Policy Definition: Emotional Disturbance (ED) is defined as an inability to learn that cannot be explained by intellectual, sensory, or health factors and exists over a long period of time and to a marked degree, and that adversely affects a child's educational performance. Emotional Disturbance includes schizophrenia.
Federal and State regulation reference: ***34 CFR §300.8(c)(4), DCMR 3001.1***

Requirements of eligibility determination: The student must meet each numbered criterion (and have documentation to support decision) in order to be considered eligible as a student with the disability named above.

Directions: Check the box below if the team has evidence to show that the student meets the following criteria.

Eligibility Criteria

	1. The student exhibits one or more of the following characteristics over a long period of time that is not generally accepted as age appropriate and/or ethnic or cultural norms AND adversely affects the student in at least one of the following areas: (Check all that apply)	
		Academic progress
	✓	Social relationships
	✓	Personal adjustment
	✓	Classroom adjustment
		Self-care
		Vocational skills
		Other: Specify ______________
✓	**2. Behaviors are severe, chronic and frequent.**	
✓	**3. Adversely impacts the student's educational performance to the extent that the student requires specially designed instruction.**	
✓	**4. Behaviors occur at school and at least one other setting.**	
✓	**5. Team reviewed and/or conducted two scientific research-based interventions to address behavioral/emotional skill deficiency.**	
	6. Team documented the results of the intervention, including progress monitoring documentation.	
	7. The student displays at least one of the following (Check all that apply)	
	✓	An inability to build or maintain satisfactory interpersonal relationships with peers and teachers
	✓	Inappropriate types of behavior or feelings under normal circumstances
	✓	Pervasive unhappiness, depression or anxiety
	✓	Physical symptoms, pains or fears associated with personal or school problems
	✓	Inability to learn that cannot be explained by intellectual, sensory or health factors

Decision

The team reviewed all relevant evaluation and other existing data and determined that:

✓ The student meets all of the criteria for the specified disability

☐ The student does not meet all of the required criteria for the specified disability

Date of Decision: 8.31.10