Other Health Impairments

\diamond Introduction \diamond

"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 0H1 ♦

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:

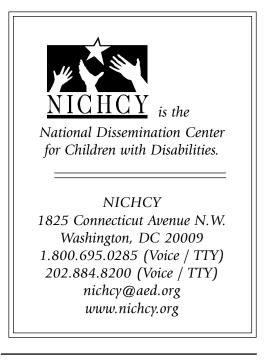
Other health impairment means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

(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)]

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.

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.

\diamond Special Help for Children \diamond

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 info 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 OH1

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 www.nichcy.org/Disabilities/ Specific/Pages/ADHD.aspx
- 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 disability, at http://www.nichcy.org/Disabilities/Specific/Pages/Epilepsy.aspx
- 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 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/
- Heart conditions in children | UAB Health System (University of Alabama at Birmingham) http://www.health.uab.edu/14561/

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 hemo-

philia. 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 http://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, pinheadsize 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 www.leukemia-lymphoma.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).



Fact Sheet on Other Health Impairments (FS15)

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/
 - http://www.sicklecellkids.org/
- American Sickle Cell Anemia Association http://www.ascaa.org/
- Información en español http://www.ascaa.org/Information_In_Spanish.asp

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, shouldershrugging) 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://espanol.ninds.nih.gov/trastornos/ sindrome_de_tourette.htm

\diamond Other Health Impairments Not Mentioned in IDEA \diamond

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, dysph-

agia, 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 wellbeing 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, physiciandirected 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: www.medicalhomeinfo.org/ index.html

Another resource you may find especially helpful in addressing the health care and medical issues associated with an OHI is a website called **Brave**



Kids. There, parents and children with chronic illnesses or life-threatening disabilities can search for helpful resources and medical information regarding their condition. While OHIs are not necessarily life-threatening, many are, and this site is rich with useful resources on many health-related topics, including: home healthcare, hospitals, lodging away from home,

financial assistance and referral, speciality centers, and support groups. You can search resources by two dropdown menus: *Resource Type* and *Condition Type*. An extra bonus comes in the form of being able to enter your zip code. Talk about easy connections! And it's right there on the home page: http://www.bravekids.org/

And last but not least, we'd also encourage you to visit the website of **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://familyvoices.org/index.php

💠 Lífe 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.

\diamond Planning for Transitions \diamond

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. Parents may wish to read a brief article from MassGeneral Hospital for Children called "After Your Child's Hospitalization." The article identifies children's common reactions to coming home from the hospital, both short-term and longer-term. It's enlightening and gives a small window into what it means from the child's perspective to have an OHI that has required a hospitalization. Find it at:

www.massgeneral.org/children/patientsandfamilies/ yourvisit/post-hospitalization.aspx



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

\diamond Finding More Info \diamond

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!



National Dissemination Center for Children with Disabilities 1.800.695.0285 (Voice/TTY) nichcy@aed.org www.nichcy.org



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