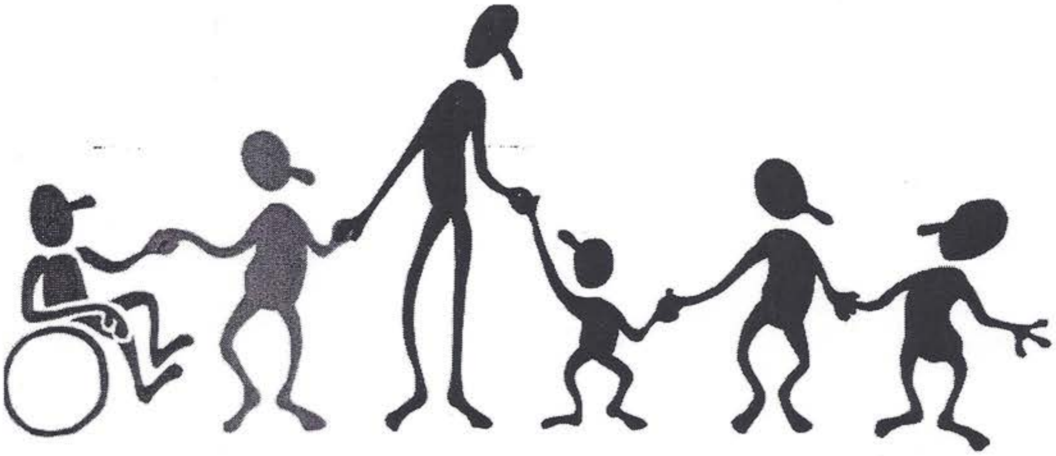
Ability Awareness: Disabilities Category Packet



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ESU → sp.ed.?
daycares...?

NICHCY Disability Fact Sheet—No. 1

Autism / PDD

✧ 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 a form of autism. As painful as this is for his parents to learn, the early intervention staff try to encourage them. 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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Disability Fact Sheet, No. 1
April 2007

✧ What is Autism / PDD? ✧

Autism/Pervasive Developmental Disorder (PDD) is a neurological disorder that affects a child's ability to communicate, understand language, play, and relate to others. PDD represents a distinct category of developmental disabilities that share many of the same characteristics.

The different diagnostic terms that fall within the broad meaning of PDD, include:

- Autistic Disorder,
- Asperger's Disorder,
- Rett's Disorder,
- Childhood Disintegrative Disorder, and
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

While there are subtle differences and degrees of severity among these conditions, treatment and educational needs can be very similar for all of them.

In the diagnostic manual used to classify mental disorders, the *DSM-IV-TR* (American Psychiatric Association, 2000), "Autistic Disorder" is listed under the heading of "Pervasive Developmental Disorders." A diagnosis of autistic disorder is made when an individual displays 6 or more of 12 symptoms across three major areas: (a) social interaction, (b) communication, and (c) behavior. When children display similar behaviors but do not meet the specific criteria for autistic disorder (or the other disorders listed above), they may receive a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified, or PDD-NOS.

Autism is one of the disabilities specifically defined in the Individuals with Disabilities Education Act (IDEA), the federal legislation under which infants, toddlers, children, and youth with disabilities receive early intervention, special education and related services. IDEA defines the disorder as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive

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activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences." See 34 *Code of Federal Regulations* §300.8(c)(1).

How Common is Autism / PDD?

Information from the National Institute of Mental Health and the Center for Disease Control and Prevention (CDC) indicates that between 2 to 6 per 1,000 children (from 1 in 500 to 1 in 150) have some form of autism/PDD. These disorders are four times more common in boys than in girls, although Rett's Disorder has only been reported and diagnosed in girls.

The causes of autism or PDD are unknown. Currently, researchers are investigating areas such as brain development, structure, genetic factors and biochemical imbalance in the brain as possible causes. These disorders are not caused by psychological factors.

What are the Signs of Autism / PDD?

Some or all of the following characteristics may be observed in mild to severe forms:

- Communication problems (e.g., using and understanding language);
- Difficulty relating to people, objects, and events;
- Unusual play with toys and other objects;
- Difficulty with changes in routine or familiar surroundings; and
- Repetitive body movements or behavior patterns.

Children with autism/PDD vary widely in abilities, intelligence, and behaviors. Some children do not speak; others have language that often includes repeated phrases or conversations. Children with more advanced language skills tend to use a small range of topics and have difficulty with abstract concepts. Repetitive play skills, a limited range of interests, and impaired social skills are generally evident as well. Unusual responses to sensory information—for example, loud noises, lights, certain textures of food or fabrics—are also common.

Early diagnosis and appropriate educational programs are very important to children with autism/PDD.

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.

Want More Info?

NICHCY's ***State Resources Sheets*** list organizations in each state related to autism, early intervention, special education, parent centers, and other disability-related issues and concerns. Help yourself!

Our ***"A to Z Topics"*** include connections to a treasure trove of links to the latest research, publications, conferences and more!

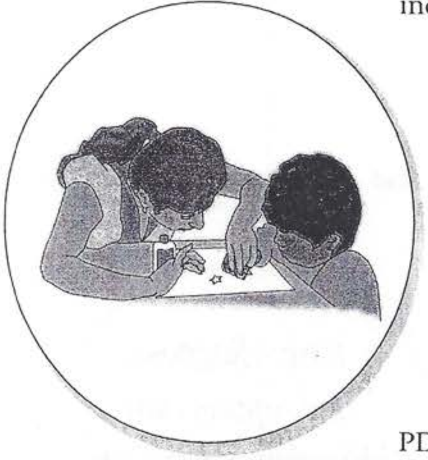
(Just two of the many resources available to you online and at no cost from NICHCY.)

✧ What Research is Being Done? ✧

Thanks to federal legislation—the Children's Health Act of 2000 and the Combating Autism Act of 2006—nearly $1 billion over the next five years (2007-2012) has been authorized to combat autism through research, screening, early detection, and early intervention. The National Institutes of Health and the CDC are the lead entities conducting and coordinating multiple research activities. On the education front, the PDA Center at the University of Washington has several sites around the country that provide training and support to schools and families for students with autism spectrum disorders. Research on instructional interventions for children with a broad range of needs is an ongoing national endeavor. Check NICHCY's Research to Practice database and OSEP's discretionary projects directories on our web site to learn more. Additional information can also be found on the web sites included in the list of Organizations at the end of this publication.

✧ What about School? ✧

Early diagnosis and intervention are very important for children with autism/PDD. Under the Individuals with Disabilities Education Act (IDEA), children with autism/PDD 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 autism/PDD (ages 3 to 22) 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 autism/PDD 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 autism/PDD, 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 autism/PDD grow to live, work, and participate fully in their communities.

✧ Tips for Parents ✧

☐ Learn about autism/PDD. The more you know, the more you can help yourself and your child. Your State's PTI can be especially helpful. You'll find resources and organizations at the end of this publication and in NICHCY's online *State Resources Sheet.*

☐ 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.

✧ Tips for Teachers ✧

☐ Learn more about autism/PDD. Check out the research on effective instructional interventions and behavior on NICHCY's web site. The resources and 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.

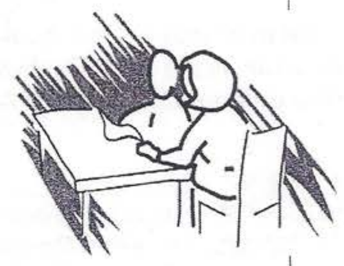
☐ Find out what the student's strengths and interests are and emphasize them. Tap into those avenues and create opportunities for success. Give positive feedback and lots of opportunities for practice.

☐ Build opportunities for the student to have social/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. Reward students for each small success.

☐ 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.



✧ Resources ✧

Baldi, H., & Detmers, D. (2000). *Embracing play: Teaching your child with autism* [Video]. Bethesda, MD: Woodbine House. (Phone: 800.843.7323; Web: www.woodbinehouse.com)

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Cafiero, J.M. (2005). *Meaningful exchanges for people with autism: An introduction to augmentative & alternative communication*. Bethesda, MD: Woodbine House. (See contact information above.)

DuCharme, R., & Gullotta, T.P. (Eds.) (2004). *Asperger syndrome: A guide for professionals and families.* New York: Springer Publishers. (Phone: 800.777.4643; Web: www.springeronline.com)

Glasberg, B. (2005). *Functional behavior assessment for people with autism: Making sense of seemingly senseless behavior.* Bethesda, MD: Woodbine House. (See contact information above.)

Journal of Autism and Developmental Disorders. New York: Springer Publishers. (See contact information above.)

Mesibov, G.B., Shea, V., & Schopler, E. (2004). *The TEACCH approach to autism spectrum disorders*. New York: Springer Publishers. (See contact information above.)

O'Brien, M., & Daggett, J.A. (2006). *Beyond the autism diagnosis: A professional's guide to helping families.* Baltimore, MD: Brookes Publishing (Phone: 800.638.3775; Web: www.brookespublishing.com)

Richman, S. (2000). *Raising a child with autism: A guide to applied behavior analysis for parents.* London: Jessica Kingsley Publishers. (Web: www.jkp.com/)

Tsai, L.Y. (1998). *Pervasive developmental disorders.* Washington, DC: NICHCY. (Available online at: www.nichcy.org/pubs/factshe/fs20txt.htm)

Volkmar, F.R., & Wiesner, L.A. (2003) *Healthcare for children on the autism spectrum: A guide to medical, nutritional, and behavioral issues.* Bethesda, MD: Woodbine House. (See contact information above.)

Wiseman, N.D. (2006). *Could it be autism?* New York: Broadway Books. (Web: www.broadwaybooks.com)

For more information, books, and videos on autism spectrum disorders, the *Autism Society of North Carolina Bookstore* has over 400 titles in their collection. (Phone: 919.743.0204; Web: www.autismbookstore.com)

✧ Organizations ✧

(★ indicates member of OSEP's Technical Assistance and Dissemination Network)

Autism Information Center at CDC
Phone: 800.311.3435
Web: www.cdc.gov/ncbddd/autism/index.htm

Autism Society of America
Phone: 800.328.8476
Web: www.autism-society.org

Autism Treatment Network
Web: www.autismtreatmentnetwork.org

★ Center on Positive Behavioral Interventions and Supports (PBIS)
Web: www.pbis.org

★ Center for Implementing Technology in Education (CITEd)
Web: www.citededucation.org

Cure Autism Now
Phone: 888.828.8476
Web: www.cureautismnow.org

★ Family Center on Technology and Disability
Web: www.fctd.info/

Indiana Resource Center for Autism
Web: www.iidc.indiana.edu/irca

Interactive Autism Network
Web: www.ianproject.org/

MAAP Services for Autism & Asperger Syndrome
Web: www.asperger.org

National Alliance for Autism Research
Phone: 888.777.6227
Web: www.naar.org/

NIH Autism Research Network
Web: www.autismresearchnetwork.org/AN/

★ NIMAS Development and Technical Assistance Centers
Web: http://nimas.cast.org

O.A.S.I.S. Online Asperger Syndrome Information and Support
Web: www.aspergersyndrome.org/

★ Professional Development in Autism Center
Web: depts.washington.edu/pdacent/

Yale Developmental Disabilities Clinic
Web: www.autism.fm

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

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AED

NICHCY Disability Fact Sheet—No. 16

Deaf-Blindness

✧ 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.

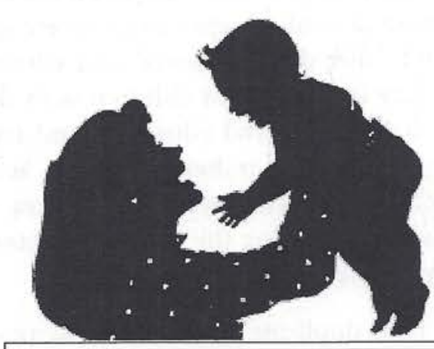
Our nation's special education law, the Individuals with Disabilities Education Act (IDEA), defines "deaf-blindness" as:

> ...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 age 3) 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



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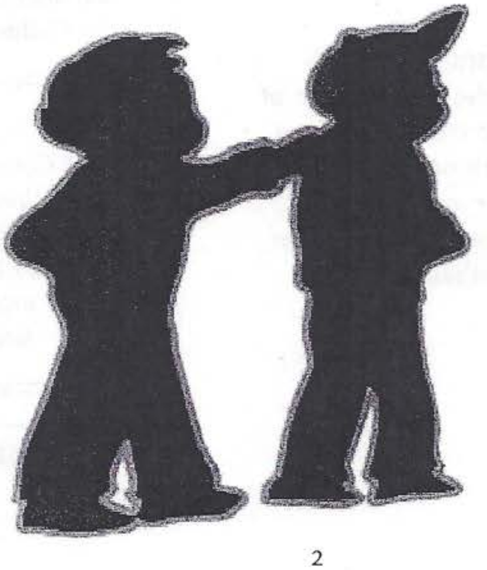
August 2009

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 your pediatrician, get in touch with the pediatric unit of a nearby hospital, or take a look at NICHCY's State Resource Sheet for your state (online at: http://www.nichcy.org/Pages/StateSpecificInfo.aspx). We list the central contact for the early intervention system in every state. This office can put you in touch with a program near you.

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 below 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.



✧ About Deaf-Blindness ✧

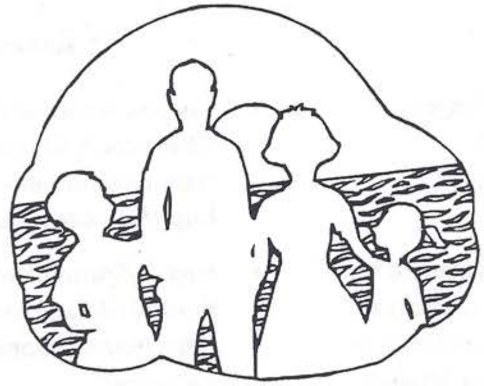
- *FAQs about deaf-blindness.* www.aadb.org/FAQ/faq_DeafBlindness.html
- *Overview of deaf-blindness.* www.nationaldb.org/NCDBProducts.php?prodID=38
- *Children who are deaf-blind.* http://www.nationaldb.org/documents/products/population.pdf
- *Information about deaf-blindness.* Personal insights and 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

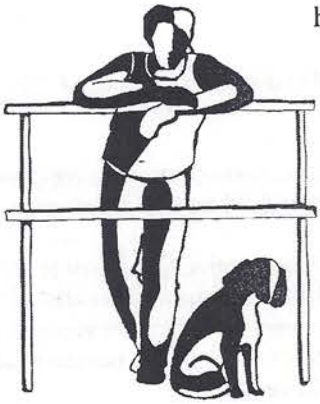
✧ The Experts on Deaf-Blindness ✧

- *National Consortium on Deaf-Blindness (NCDB)*
  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 factsheets 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://pdcorder.pepnet.org/media/1011TPSHT_Deaf_Blind.pdf
- *Deaf-blindness: Educational service guidelines.*
  This best practice guide is designed to help states, districts, schools and practitioners in supporting students who are deaf-blind and their families. Copies may be purchased at www.perkins.org/publications for $25.00 a copy.
- *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 2001 through 2006 are available in PDF. 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. 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://pdcorder.pepnet.org/media/1180LinkByLink.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

✧ References ✧

1 Gallaudet University. (2004). FAQ: *Deaf-blind in the U.S.* Retrieved February 19, 2009, from: http://library.gallaudet.edu/Library/Deaf_Research_Help/Frequently_Asked_Questions_(FAQs)/Statistics_on_Deafness/Deaf-Blind_in_the_US.html

2 National Consortium on Deaf-Blindness. (2008, September). *The 2007 national child count of children and youth who are deaf-blind.* Retrieved February 19, 2009, from: http://www.nationaldb.org/documents/products/2007-Census-Tables.pdf

3 National Consortium on Deaf-Blindness. (2007, November). *Children who are deaf-blind.* Retrieved February 19, 2009, from: www.nationaldb.org/documents/products/population.pdf

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NICHCY Disability Fact Sheet—No. 3

Deafness & Hearing Loss

✧ Definition ✧

The Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (P.L. 94-142), includes "hearing impairment" and "deafness" as two of the categories under which children with disabilities may be eligible for special education and related services programming. While the term "hearing impairment" is often used generically to describe a wide range of hearing losses, including deafness, the regulations for IDEA define hearing loss and deafness separately.

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 may be 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.

✧ Incidence ✧

Hearing loss and deafness affect individuals of all ages and may occur at any time from infancy through old age. The U.S. Department of Education (2002) reports that during the 2000-2001 school year, 70,767 students aged 6 to 21 (or 1.3% of all students with disabilities) received special education services under the category of "hearing impairment." However, the number of children with hearing loss and deaf-

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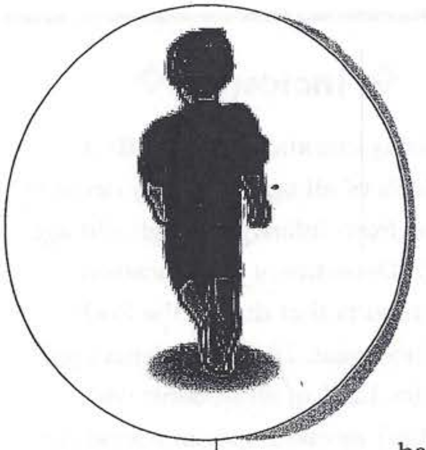
Disability Fact Sheet, No. 3
January 2004

ness is undoubtedly higher, since many of these students may have other disabilities as well and may be served under other categories.

✧ Characteristics ✧



It is 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). Impairments in hearing can occur in either or both areas, and may exist in only one ear or in both ears. 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 greatly associated with speech. Generally, only children whose hearing loss is greater than 90 decibels (dB) are considered deaf for the purposes of educational placement.

There are four types of hearing loss. *Conductive* hearing losses are caused by diseases or obstructions in the outer or middle ear (the conduction 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 which 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.

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(V/TTY)

✧ Educational Implications ✧

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn. However, children who are either 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.

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn.

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

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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.

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.

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. Dial 711 to access all TRSs anywhere in the United States. The relay service is free.

✧ Resources ✧

Luterman, D.M. (2002). *When your child is deaf: A guide for parents* (2nd ed.). Parkton, MD: York Press. (Phone: 800.962.2763. Web: www.yorkpress.com/index.html)

Medwid, D.J., & Weston, D.C. (1995). *Kid-friendly parenting with deaf and hard of hearing children: A treasury of fun activities toward better behavior.* Washington, DC: Gallaudet University Press. (Phone: 800.621.2736; 888.630.9347 (V/TTY). Web: http://gupress.gallaudet.edu)

Ogden, P.W. (1996). *The silent garden: Raising your deaf child* (Rev. ed.). Washington, DC: Gallaudet University Press. (See contact information above.)

Schwartz, S. (Ed.). (1996). *Choices in deafness: A parents' guide to communication options* (2nd ed.). Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: www.woodbinehouse.com)

So your child has a hearing loss: Next steps for parents (n.d.). (Available online at: www.agbell.org/information/brochures_parent_so.cfm)

✧ Organizations ✧

Alexander Graham Bell Association
for the Deaf and Hard of Hearing
3417 Volta Place, NW, Washington, DC 20007
202.337.5220; 202.337.5221 (TTY)
info@agbell.org
www.agbell.org

American Society for Deaf Children
P.O. Box 3355, Gettysburg, PA 17325
717.334.7922 (V/TTY); 800.942.2732 (V/TTY)
ASDC1@aol.com
www.deafchildren.org

American Speech-Language-Hearing Association
10801 Rockville Pike, Rockville, MD 20852
301.897.5700 (V/TTY)
800.638.8255 (V/TTY)
www.asha.org

Laurent Clerc National Deaf Education Center
KDES PAS-6, Gallaudet University
800 Florida Avenue N.E.
Washington, DC 20002-3695
202.651.5051 (V/TTY)
Clearinghouse.InfoToGo@gallaudet.edu
http://clerccenter.gallaudet.edu/InfoToGo

National Institute on Deafness and Other
Communication Disorders Information
Clearinghouse
1 Communication Avenue
Bethesda, MD 20892-3456
800.241.1044; 800.241.1055 (TTY)
nidcdinfo@nidcd.nih.gov
www.nidcd.nih.gov/

Self Help for Hard of Hearing People (SHHH)
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814
301.657.2248; 301.657.2249 (TTY)
info@hearingloss.org
www.hearingloss.org

FS3, January 2004

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

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AED

NICHCY Disability Fact Sheet—No.5

Emotional Disturbance

✧ Definition ✧

Many terms are used to describe emotional, behavioral, or mental disorders. Currently, students with such conditions are categorized as having an emotional disturbance, which is defined under the Individuals with Disabilities Education Act (IDEA) 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." *[Code of Federal Regulations,* Title 34, §300.7(c)(4)(i)]

As defined by IDEA at §300.7(c)(4)(ii), emotional disturbance includes schizophrenia but does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

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

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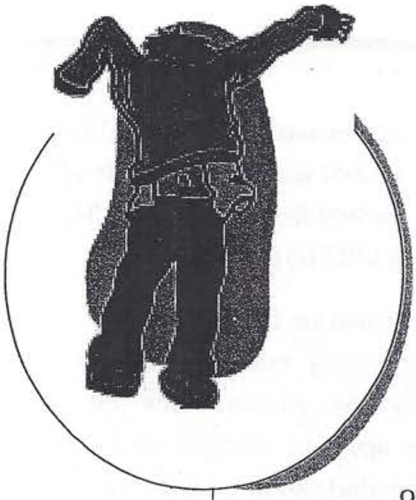
www.nichcy.org

Disability Fact Sheet, No. 5
January 2004

✧ Incidence ✧



In the 2000-2001 school year, 473,663 children and youth with emotional disturbance were provided special education and related services in the public schools (*Twenty-fourth Annual Report to Congress*, U.S. Department of Education, 2002).

✧ Characteristics ✧

The causes of emotional disturbance have not been adequately determined. Although various factors such as heredity, brain disorder, diet, stress, and family functioning have been suggested as possible causes, research has not shown any of these factors to be the direct cause of behavior or emotional problems. Some of the characteristics and behaviors seen in children who have emotional disturbances include:

- Hyperactivity (short attention span, impulsiveness);
- Aggression/self-injurious behavior (acting out, fighting);
- Withdrawal (failure to initiate interaction with others, retreat from exchanges or social interaction, 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. Some are identified as children who have severe psychosis or schizophrenia.

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.

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✧ Educational Implications ✧

The 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 list at the end of this publication 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 which are available under law and are to be provided by a qualified social worker, psychologist, guidance counselor, or other qualified personnel.
- Career education (both vocational and academic) is also a major part of secondary education and should be a part of the transition plan included in every adolescent's IEP.

There is growing recognition that families, as well as their children, need support, respite care, intensive case management, and a collaborative, multi-agency approach to services. Many communities are working toward providing these wrap-around services. There are a growing number of agencies and organizations actively involved in establishing support services in the community.

A large body of research exists regarding methods of providing students with positive behavioral support (PBS) in the school environment.

Other Helpful Things to Know

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

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✧ Other Considerations ✧

Families of children with an emotional disturbance may need help in understanding their children's condition and in learning how to work effectively with them. Parent support groups can be helpful in this regard. Organizations such as the National Mental Health Association (NMHA) and the National Alliance for the Mentally Ill (NAMI) have parent groups in every state. (See "Organizations.") Help is also available from psychiatrists, psychologists, or other mental health professionals in public or private mental health settings. Children should be provided services based on their individual needs, and all persons who are involved with these children should be aware of the care they are receiving. It is important to coordinate all services between home, school, and therapeutic community with open communication.

✧ Resources ✧

Greene, R.W. (2001). *The explosive child: A new approach for understanding and parenting easily frustrated chronically inflexible children.* New York: Harper Collins. (Phone: 212.207.7000. Web: www.harpercollins.com/hc/home.asp)

Jordan, D. (2001). *A guidebook for parents of children with emotional or behavior disorders* (3rd ed.). Minneapolis, MN: PACER. (Phone: 888.248.0822. Web: www.pacer.org)

Koplewicz, H.S. (1997). *It's nobody's fault: New hope and help for difficult children.* New York: Three Rivers Press. (To find a local or online bookseller, go to: www.randomhouse.com/reader_resources/ordering.html)

Miller, J.A. (1999). *The childhood depression sourcebook.* New York: McGraw-Hill. (Phone: 877.833.5524. Web: http://books.mcgraw-hill.com)

Papolos, D., & Papolos, J. (2002). *The bipolar child.* New York: Broadway. (To find a local or online bookseller, go to: www.randomhouse.com/reader_resources/ordering.html)

Wilen, T.E. (1998). *Straight talk about psychiatric medications for kids.* New York: Guilford. (Phone: 800.365.7006. Web: www.guilford.com)

✧ Organizations ✧

American Academy of Child and Adolescent Psychiatry, Public Information Office
3615 Wisconsin Ave., NW
Washington, DC 20016-3007
202.966.7300
www.aacap.org

Center on Positive Behavioral Interventions and Supports
5262 University of Oregon
Eugene, OR 97403-5262
541.346.2505
pbis@oregon.uregon.edu
www.pbis.org

Federation of Families for Children's Mental Health, 1101 King Street, Suite 420
Alexandria, VA 22314
703.684.7710
ffcmh@ffcmh.org
www.ffcmh.org

National Alliance for the Mentally Ill (NAMI)
Colonial Place Three, 2107 Wilson Boulevard, Suite 300, Arlington, VA 22201-3042
703.524.7600; 703.516.7227 (TTY)
800.950.6264
www.nami.org

National Mental Health Association
2001 N. Beauregard St., 12th Floor
Alexandria, VA 22311
703.684.7722; 800.969.6642
800.433.5959 (TTY)
www.nmha.org

National Mental Health Information Center
P.O. Box 42557
Washington, DC 20015
800.789.2647; 866.889.2647 (TTY)
www.mentalhealth.org

FS5, January 2004

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

AED

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Intellectual Disabilities

NICHCY Disability Fact Sheet—No. 8

✧ 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 Intellectual Disabilities? ✧

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.

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Disability Fact Sheet, No. 8
August 2009

✧ 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 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 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. Both of these are highlighted in the definition of this disability in the box on page 4. This definition comes from the Individuals with Disabilities Education Act (IDEA). The IDEA is the federal law that guides how schools provide early intervention and special education and related services to children with disabilities. In IDEA, the term *mental retardation* is used, not intellectual disabilities.

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.

✧ How Common are Intellectual Disabilities? ✧

As many as 3 out of every 100 people in the country have an intellectual disability (The Arc, 2001). Over 580,000 children ages 6 to 21 have some level of intellectual disability and need special education in school *(Twenty-seventh Annual Report to Congress,* U.S. Department of Education, 2005). In fact, 1 out of every 10 children who need special education has some form of intellectual disability.

✧ 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.

✧ Tips for Parents ✧

☐ Learn about intellectual disability. The more you know, the more you can help yourself and your child. See the list of resources and organizations on page 4 of this publication.

☐ 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 (www.nichcy.org/Pages/StateSpecificInfo.aspx) and find a parent group near you.

☐ Meet with the school and develop an educational plan 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.

✧ Tips for Teachers ✧

☐ Learn as much as you can about intellectual disability. The organizations listed on page 4 will help you identify specific 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 Individualized Education Program (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 specialists 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.

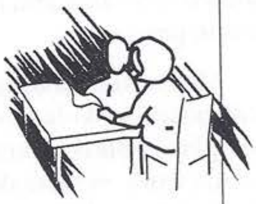
☐ Be as concrete as possible. Demonstrate what you mean rather than just giving verbal directions. Rather than just relating new information verbally, show a picture. And rather than just showing a picture, provide the student with hands-on materials and experiences and the opportunity to try things 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 educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.



About 87% of people with an intellectual disability will only be a little slower than average in learning new information and skills. When they are children, their limitations may not be obvious. They may not even be diagnosed as having an intellectual disability until they get to school. As they become adults, many people with mild intellectual disabilities can live independently. Other people may not even consider them as having an intellectual disability.

The remaining 13% of people with an intellectual disability score below 50 on IQ tests. These people will have more difficulty in school, at home, and in the community. A person with more severe intellectual disability will need more intensive support his or her entire life.

Every child with an intellectual disability is able to learn, develop, and grow. With help, all children with intellectual disabilities can live a satisfying life.

✧ What About School? ✧

A child with an intellectual disability can do well in school but is likely to need individualized help. Fortunately, states are responsible for meeting the educational needs of children with disabilities.

For children up to age three, 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. It also describes the services the child will receive to address those needs. The IFSP will emphasize the unique needs of the family, so that parents and other family members will know how to help their young child. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income. In some states, early intervention services may be at no cost to parents.

For eligible school-aged children (including preschoolers), special education and related services are made available 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. 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.

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.

Our nation's special education law, the IDEA, defines mental retardation 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 *Code of Federal Regulations* §300.7(c)(6)

Supports or changes in the classroom (called adaptations) help most students with intellectual disabilities. Some common changes that help students with intellectual disabilities are listed in the "Tips for Teachers" box on page 3. The organizations below also offer a great deal of information on ways to help children with intellectual disabilities.

✧ Organizations ✧

The Arc of the United States, 1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910. Phone: 301.565.3842; 800.433.5255. E-mail: Info@thearc.org
Web: www.thearc.org

American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation, AAMR), 501 3rd Street NW, Suite 200, Washington, D.C. 20001. Phone: 202.387.1968; 800.424.3688 (Toll Free, outside of DC). Web: www.aaidd.org/

Division on Autism and Developmental Disabilities (DADD), The Council for Exceptional Children, 1110 North Glebe Road, Suite 300, Arlington, VA 22201-5704. Phone: 703.620.3660; 866.915.5000 (TTY); 888.232.7733.
E-mail: cec@cec.sped.org Web: www.dddcec.org

NICHCY Disability Fact Sheet—No.10

Severe/Multiple Disabilities

✧ Definition ✧

People with severe disabilities are those who traditionally have been labeled as having severe or profound mental retardation. These people require ongoing extensive support in more than one major life activity in order to participate in integrated community settings and enjoy the quality of life available to people with fewer or no disabilities. They frequently have additional disabilities, including movement difficulties, sensory losses, and behavior problems.

✧ Incidence ✧

In the 2000-2001 school year, the states reported to the U.S. Department of Education that they were providing special education and related services to 122,559 students with multiple disabilities (*Twenty-fourth Annual Report to Congress*, 2002).

✧ Characteristics ✧

People with severe or multiple disabilities may exhibit a wide range of characteristics, depending on the combination and severity of disabilities, and the person's age. There are, however, some traits they may share, including:

- Limited speech or communication;
- Difficulty in basic physical mobility;
- Tendency to forget skills through disuse;
- Trouble generalizing skills from one situation to another; and
- A need for support in major life activities, e.g., domestic, leisure, community use, vocational.

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for Children with Disabilities.

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Disability Fact Sheet, No. 10
January 2004

✧ Medical Implications ✧

A variety of medical problems may accompany severe disabilities. Examples include seizures, cerebral palsy, sensory loss, hydrocephalus, and scoliosis. These conditions should be considered when establishing services. A multidisciplinary team consisting of the student's parents, educational specialists, and medical specialists in the areas in which the individual demonstrates problems should work together to plan and coordinate necessary services.

✧ Educational Implications ✧

In the past, students with severe and/or multiple disabilities were routinely excluded from public schools. Since the implementation of Public Law 94-142 (the Education of the Handicapped Act, now called the Individuals with Disabilities Education Act, or IDEA), public schools now serve large numbers of students with severe and/or multiple disabilities. Educational programming is likely to begin as early as infancy. At that time, as well as later on, the primary focus is upon increasing the child's independence.

In order to be effective, educational programs need to incorporate a variety of components to meet the considerable needs of individuals with severe and/or multiple disabilities. Programs should asseess needs in four major areas: domestic, leisure/recreational, community, and vocational. These assessments enable the identification of functional objectives (objectives which will result in the learner's increased skill and independence in dealing with the routine activities of his/her life). Instruction should include: Expression of choice; communication; functional skill development; and age-appropriate social skills training.

Related services are of great importance, and the multidisciplinary approach is crucial. Appropriate people such as speech and language therapists, physical and occupational therapists, and medical

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

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(V/TTY)

specialists need to work closely with classroom teachers and parents. Because of problems with skill generalization, related services are best offered during the natural routine in the school and community rather than removing a student from class for isolated therapy.

Frequently, classroom arrangements must take into consideration students' needs for medications, special diets, or special equipment. Adaptive aids and equipment enable students to increase their range of functioning. For example, in recent years computers have become effective communication devices. Other aids include: wheelchairs, typewriters, headsticks (head gear), clamps, modified handles on cups and silverware, and communication boards. Computerized communication equipment and specially built vocational equipment also play important roles in adapting working environments for people with serious movement limitations.

Integration with nondisabled peers is another important component of the educational setting. Attending the same school and participating in the same activities as their nondisabled peers are crucial to the development of social skills and friendships for people with severe disabilities. Integration also benefits nondisabled peers and professionals through positive attitude change.

Beginning as early as the elementary school years, community-based instruction is an important characteristic of educational programming. In order to increase the student's ability to generalize (transfer) skills to appropriate situations, this type of instruction takes place in the actual setting where the skills will be used. As students grow older, increasing time is spent in the community; high school students may spend as much as 90 percent of their day there. Programs should draw on existing adult services in the community, including group homes, vocational programs, and recreational settings.

To be effective, educational programs need to incorporate a variety of components to meet the considerable needs of individuals with severe and/or multiple disabilities.

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.

In light of the current Vocational Rehabilitation Act and the practice of supported employment, schools are now using school-to-work transition planning and working toward job placement in integrated, competitive settings rather than sheltered employment and day activity centers.

Resources

Downing, J.E. (2002). *Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers* (2nd ed.). Baltimore, MD: Paul H. Brookes. (Phone: 800.638.3775. Web: www.brookespublishing.com)

Klein, M.D., Chen, D., & Haney, M. (2002). *PLAI: A guide to communication with young children who have multiple disabilities.* Baltimore, MD: Paul H. Brookes. (See contact information above.)

Orelove, F., & Sobsey, D. (1996). *Educating children with multiple disabilities: A transdisciplinary approach* (3rd ed.). Baltimore, MD: Paul H. Brookes. (See contact information above.)

Rainforth, B., York, J., & Macdonald, C. (1997). *Collaborative teams for students with severe disabilities: Integrating therapy and educational services* (2nd ed.). Baltimore, MD: Paul H. Brookes. (See contact information above.)

TASH Newsletter. Monthly newsletter from TASH. (See contact information under "Organizations.")

Organizations

TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
410.828.8274; 410.828.1306 (TTY)
info@tash.org
www.tash.org

National Rehabilitation Information Center (NARIC)
4200 Forbes Boulevard, Suite 202
Lanham, MD 20706
301.459.5900; 800.346.2742 (Toll-free)
naricinfo@heitechservices.com
www.naric.com

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
301.565.3842
info@thearc.org;
www.thearc.org

United Cerebral Palsy Associations, Inc.
1660 L Street NW, Suite 700
Washington, DC 20036
800.872.5827 (Toll-free)
202.776.0406; 202.973.7197 (TTY)
www.ucp.org

FS10, January 2004

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

AED

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Orthopedic
Impairment

NICHCY Disability Fact Sheet—No. 2

Cerebral Palsy

✧ 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.

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Disability Fact Sheet, No. 2
January 2004

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 mental retardation. 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.

✧ How Common is CP? ✧

About 500,000 people in America have some form of CP. Each year 8,000 infants and nearly 1,500 preschool-age children are diagnosed with CP.

✧ What Are the Signs of CP? ✧

There are three 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 is the most common form of CP.

- *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.

- *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.

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.

✧ 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.

Children younger than three years old can benefit greatly from *early intervention services.* Early intervention is a system of services to support infants and toddlers with disabilities and their families. For older children, *special education and related services* are available through the public school to help each child achieve and learn.

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.

The child 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.

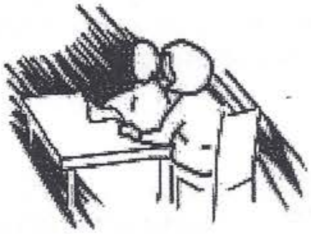
New medical treatments are being developed all the time. Sometimes surgery, Botox injections, or other medications can help lessen the effects of CP, but there is no cure for the condition.

✧ 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!

✧ 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.



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.

For children up to age three, 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 Individuals with Disabilities Education Act (IDEA) guides how early intervention services and special education and related services are provided to children with disabilities. 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 congenital anomaly (e.g. clubfoot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures)." 34 *Code of Federal Regulations* §300.7(c)(8)

Resources

Geralis, E. (1998). *Children with cerebral palsy: A parents' guide* (2nd ed.). Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: www.woodbinehouse.com)

Kelker, K.A., & Holt, R. (2000). *Family guide to assistive technology.* Cambridge, MA: Brookline Books. (Phone: 800.666.2665. Web: www.brooklinebooks.com)

Miller, F., & Bachrach, S.J. (1998). *Cerebral palsy: A complete guide for caregiving.* Baltimore, MD: Johns Hopkins University Press. (Phone: 800.537.5487. Web: www.press.jhu.edu)

Videos to rent: *My Left Foot* and *Gaby: A True Story.*

Other Web Sites

www.ninds.nih.gov—site of the National Institute of Neurological Disorders and Stroke at the National Institutes of Health

www.dreamms.org—a non-profit information clearinghouse on assistive technology

www.lburkhart.com—ideas and instructions for adapting toys for use by children with CP

Organizations

United Cerebral Palsy Associations, Inc.
1660 L Street, NW, Suite 700, Washington, DC 20036
202.776.0406; 202.973.7197 (TTY); 800.872.5827 (V/TTY)
www.ucp.org

Easter Seals—National Office
230 W. Monroe Street, Suite 1800, Chicago, IL 60606-4802
312.726.6200; 312.726.4258 (TTY); 800.221.6827
www.easter-seals.org

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Other Health Impaired.

Attention-Deficit/Hyperactivity Disorder (AD/HD)

✧ 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.

✧ 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 parents and teachers can do to help a child with AD/HD.

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✧ 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.

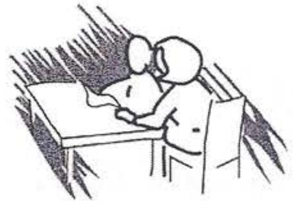
continued on page 4

✧ Tips for Parents ✧

- ☐ Learn about AD/HD. 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.
- ☐ 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 "Resources" on page 4 of this publication.
- ☐ 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.

✧ Tips for Teachers ✧

- ☐ Learn more about AD/HD. The resources and organizations at the end of 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.



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 on this page. Despite the fact that AD/HD is specifically mentioned in IDEA's definition of OHI, however, 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.

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 3. More information about helpful strategies can be found in NICHCY's briefing paper called *Attention-Deficit/Hyperactivity Disorder*. The organizations listed below will also help families and teachers learn more about ways to help children with AD/HD.

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)

Organizations

CH.A.D.D. (Children and Adults with Attention-Deficit/ Hyperactivity Disorder)
8181 Professional Place, Suite 150, Landover, MD 20785
301.306.7070; 800.233.4050
Web: www.chadd.org

Attention Deficit Information Network, Inc. (AD-IN)
475 Hillside Avenue, Needham, MA 02194
617.455.9895
Web: www.addinfonetwork.com

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NICHCY Disability Fact Sheet—No. 7

Learning Disabilities

✧ 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 (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 per-

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January 2004

son may have trouble in each 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.

The definition of "learning disability" in the box on page 4 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 with disabilities. The special help that Sara is receiving is an example of special education.

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 3 million children (ages 6 through 21) have some form of a learning disability and receive special education in school. In fact, over half of all children who receive special education have a learning disability (*Twenty-fourth Annual Report to Congress*, U.S. Department of Education, 2002).

✧ What Are the Signs of a Learning Disability? ✧

There is no *one* sign that shows a person has a learning disability. Experts look for a noticeable difference between how well a child does in school and how well he or she *could* do, given his or her intelligence or ability. There are also certain clues that may mean a child has a learning disability. We've listed a few below. Most relate to elementary school tasks, because learning disabilities tend to be identified in elementary school. 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 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.

✧ What About School? ✧

Learning disabilities tend to be diagnosed when children reach school age. This is because school focuses on the very things that may be difficult for the child—reading, writing, math, listening, speaking, reasoning. Teachers and parents notice that the child is not learning as expected. The school may ask to evaluate the child to see what is causing the problem. Parents can also ask for their child to be evaluated.

With hard work and the proper help, children with LD can learn more easily and successfully. For

✧ Tips for Parents ✧

☐ Learn about LD. 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.

☐ 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 child 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. (See resource list on page 4.)

☐ 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 learning disabilities. Parents can share practical advice and emotional support. Call NICHCY (1.800.695.0285) and ask how to find parent groups near you. Also let us put you in touch with the parent training and information (PTI) center in your state.

☐ Meet with school personnel and help develop an educational plan to address your child's needs. Plan what accommodations your child needs, and don't forget to talk about 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.

✧ Tips for Teachers ✧

☐ Learn as much as you can about the different types of LD. The resources and organizations on page 4 can help you identify specific techniques and strategies to support the student educationally.

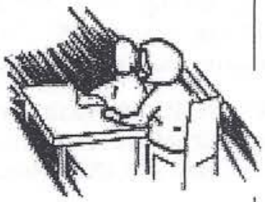
☐ Seize the opportunity to make an enormous difference in this student's life! Find out and emphasize what the student's strengths and interests are. Give the student positive feedback and lots of opportunities for practice.

☐ Review the student's evaluation records to identify where *specifically* the student has trouble. Talk to specialists in your school (e.g., special education teacher) about methods for teaching this student. Provide instruction and accommodations to address the student's special needs. Examples include:

- ✓ 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 textbooks-on-tape (available through Recording for the Blind and Dyslexic, listed on page 4);
- ✓ 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 educational plan 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.

school-aged children (including preschoolers), special education and related services are important sources of help. School staff work with the child's parents to develop an Individualized Education Program, or IEP. This document describes the child's unique needs. It also describes the special education services that will be provided to meet those needs. These services are provided at no cost to the child or family.

Supports or changes in the classroom (sometimes called *accommodations*) help most students with LD. Some common accommodations are listed in the "Tips for Teachers" box on page 3.

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).

It's important to remember that a child may need help at home as well as in school. The resources listed below will help families and teachers learn more about the many ways to help children with learning disabilities.

Our nation's special education law, the Individuals with Disabilities Education Act, defines a specific learning disability 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 an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia."

However, learning disabilities do *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 *Code of Federal Regulations* §300.7(c)(10)

✧ Resources ✧

Cronin, E.M. (1997). *Helping your dyslexic child: A step-by-step program for helping your child improve reading, writing, spelling, comprehension, and self-esteem.* Roseville, CA: Prima. (Phone: 800.726.0600. Web: www.primapublishing.com/index.pperl)

Currie, P.S., & Wadlington, E.M. (2000). *The source for learning disabilities.* East Moline, IL: LinguiSystems. (Phone: 800.776.4332. Web: www.linguisystems.com)

Hall, S., & Moats, L.C. (1998). *Straight talk about reading: How parents can make a difference during the early years.* New York: McGraw Hill/Contemporary. (Phone: 877.833.5524. Web: http://books.mcgraw-hill.com)

Harwell, J.M. (2002). *Complete learning disabilities handbook: Ready-to-use strategies and activities for teaching students with learning disabilities* (2nd ed.). West Nyack, NJ: John Wiley & Sons. (Phone: 877.762.2974. Web: www.josseybass.com)

Lerner, J.W. (2003). *Learning disabilities: Theories, diagnosis, and teaching strategies* (9th ed.). Boston: Houghton Mifflin. (Phone: 877.859.7241. Web: http://college.hmco.com/students/index.html)

Mercer, C.D., & Mercer, A.R. (2001). *Teaching students with learning problems* (6th ed.). Upper Saddle River, NJ: Prentice Hall. (Phone: 800.282.0693. Web: vig.prenhall.com)

Silver, L. (1998). *The misunderstood child: Understanding and coping with your child's learning disabilities* (3rd ed.). New York: Three Rivers Press. (To find a local or online bookseller go to: www.randomhouse.com/ reader_resources/ ordering. html)

Smith, C., & Strick, L.W. (1999). *Learning disabilities from A to Z.* New York: Simon & Schuster. (To find a local or online bookseller go to: www.simonsays.com)

Smith, S. (1995). *No easy answers* (Rev. ed.). New York: Bantam. (To find a local or online bookseller go to: www.randomhouse.com/reader_resources/ordering.html)

✧ Organizations ✧

Division for Learning Disabilities (DLD), The Council for Exceptional Children (CEC), 1110 North Glebe Road, Suite 300, Arlington, VA 22201-5704. Phone: 703.620.3660.
E-mail: cec@cec.sped.org;
Web: www.dldcec.org

International Dyslexia Association, Chester Building, Suite 382, 8600 LaSalle Road, Baltimore, MD 21286-2044.
Phone: 410.296.0232; 800.222.3123.
E-mail: info@interdys.org; Web: www.interdys.org

LDOnline - Website Only: www.ldonline.org

Learning Disabilities Association of America (LDA),
4156 Library Road, Pittsburgh, PA 15234-1349.
Phone: 412.341.1515. E-mail: info@ldaamerica.org;
Web: www.ldaamerica.org

National Center for Learning Disabilities, 381 Park Avenue South, Suite 1401, New York, NY 10016.
Phone: 212.545.7510; 888.575.7373. Web: www.ld.org

Recording for the Blind and Dyslexic, 20 Roszel Road, Princeton, NJ 08540. Phone: 609.452.0606; 866.732.3585.
E-mail: custserv@rfbd.org Web: www.rfbd.org

Schwab Learning - Website only: www.schwablearning.org

NICHCY Disability Fact Sheet—No.11

Speech & Language Impairments

✧ Definition ✧

Speech and language disorders refer to problems in communication and related areas such as oral motor function. These delays and disorders range from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech and feeding. Some causes of speech and language disorders include hearing loss, neurological disorders, brain injury, mental retardation, drug abuse, physical impairments such as cleft lip or palate, and vocal abuse or misuse. Frequently, however, the cause is unknown.

✧ Incidence ✧

More than one million of the students served in the public schools' special education programs in the 2000-2001 school year were categorized as having a speech or language impairment. This estimate does not include children who have speech/language problems secondary to other conditions such as deafness. Language disorders may be related to other disabilities such as mental retardation, autism, or cerebral palsy. It is estimated that communication disorders (including speech, language, and hearing disorders) affect one of every 10 people in the United States.

✧ Characteristics ✧

A child's communication is considered delayed when the child is noticeably behind his or her peers in the acquisition of speech and/or language skills. Sometimes a child will have greater receptive (understanding) than expressive (speaking) language skills, but this is not always the case.

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January 2004

Speech disorders refer to difficulties producing speech sounds or problems with voice quality. They might be characterized by an interruption in the flow or rhythm of speech, such as stuttering, which is called dysfluency. Speech disorders may be problems with the way sounds are formed, called articulation or phonological disorders, or they may be difficulties with the pitch, volume, or quality of the voice. There may be a combination of several problems. People with speech disorders have trouble using some speech sounds, which can also be a symptom of a delay. They may say "see" when they mean "ski" or they may have trouble using other sounds like "l" or "r." Listeners may have trouble understanding what someone with a speech disorder is trying to say. People with voice disorders may have trouble with the way their voices sound.

A language disorder is an impairment in the ability to understand and/or use words in context, both verbally and nonverbally. 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. One or a combination of these characteristics may occur in children who are affected by language learning disabilities or developmental language delay. 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.

Don't Be Shy!

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

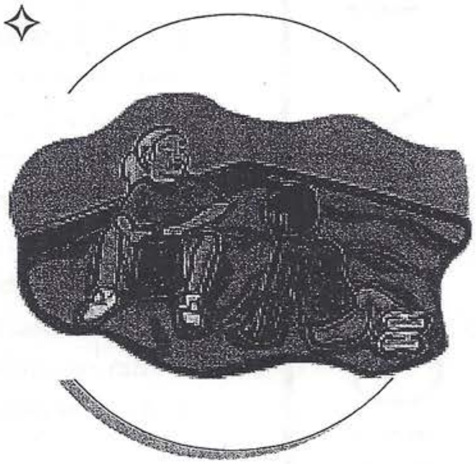
www.nichcy.org

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

nichcy@aed.org

1.800.695.0285
(V/TTY)

✧ Educational Implications ✧



Because all communication disorders carry the potential to isolate individuals from their social and educational surroundings, it is essential to find appropriate timely intervention. While many speech and language patterns can be called "baby talk" and are part of a young child's normal development, they can become problems if they are not outgrown as expected. In this way an initial delay in speech and language or an initial speech pattern can become a disorder that can cause difficulties in learning. Because of the way the brain develops, it is easier to learn language and communication skills before the age of 5. When children have muscular disorders, hearing problems, or developmental delays, their acquisition of speech, language, and related skills is often affected.

Speech-language pathologists assist children who have communication disorders in various ways. They 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. The speech-language pathologist may assist vocational teachers and counselors in establishing communication goals related to the work experiences of students and suggest strategies that are effective for the important transition from school to employment and adult life.

Technology can help children whose physical conditions make communication difficult. The use of electronic communication systems allow nonspeaking people and people with severe physical disabilities to engage in the give and take of shared thought.

Vocabulary and concept growth continues during the years children are in school. Reading and writing are taught and, as students get older, the understanding and use of language becomes more complex. Communication skills are at the heart of the education experience. 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.

Because of the way the brain develops, it is easier to learn language and communication skills before the age of 5.

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.

✧ Resources ✧

Brice, A. (2001). *Children with communication disorders* (ERIC Digest #E617). Arlington, VA: ERIC Clearinghouse on Disabilities and Gifted Education. (Available online at: http://ericec.org/digests/e617.html)

Charkins, H. (1996). *Children with facial differences: A parents' guide.* Bethesda, MD: Woodbine House. (Phone: 800.843.7323. Web: www.woodbinehouse.com)

Cleft Palate Foundation. (1997). *For parents of newborn babies with cleft lip/cleft palate.* Chapel Hill, NC: Author. (Phone: 800.242.5338. Also available online at: www.cleftline.org)

Gruman-Trinker, C. (2001). *Your cleft-affected child: The complete book of information, resources and hope.* Alameda, CA: Hunter House. (Web: www.hunterhouse.com)

Hamaguchi, P.M. (2001). *Childhood speech, language, and listening problems: What every parent should know* (2nd ed.). New York: John Wiley. (Phone: 800.225.5945. Web: www.wiley.com/)

✧ Organizations ✧

Alliance for Technology Access
2175 E. Francisco Blvd., Suite L
San Rafael, CA 94901
415.455.4575; 800.455.7970
atainfo@ataccess.org
www.ataccess.org

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike, Rockville, MD 20852
301.897.5700 (V/TTY); 800.638.8255
actioncenter@asha.org
www.asha.org

Childhood Apraxia of Speech Association of North America (CASANA)
123 Eisele Road, Cheswick, PA 15024
412.767.6589
helpdesk@apraxia.org
www.apraxia-kids.org

Cleft Palate Foundation
104 South Estes Drive, Suite 204
Chapel Hill, NC 27514
919.933.9044; 800.242.5338
info@cleftline.org
www.cleftline.org

Easter Seals—National Office
230 West Monroe Street, Suite 1800
Chicago, IL 60606
312.726.6200; 312.726.4258 (TTY);
800.221.6827
info@easter-seals.org
www.easter-seals.org

Learning Disabilities Association of America (LDA)
4156 Library Road
Pittsburgh, PA 15234-1349
412.341.1515
info@ldaamerica.org
www.ldaamerica.org

Scottish Rite Foundation
Southern Jurisdiction, U.S.A., Inc.
1733 Sixteenth Street, N.W.
Washington, DC 20009
202.232.3579.
www.srmason-sj.org/web/index.htm

Trace Research and Development Center
University of Wisconsin- Madison
1550 Engineering Dr.
2107 Engineering Hall
Madison, WI 53706
608.262.6966; 608.263.5408 (TTY)
info@trace.wisc.edu
www.trace.wisc.edu

FS11, January 2004

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

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NICHCY Disability Fact Sheet—No. 18

Traumatic Brain Injury

✧ 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 right.) 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.

The definition of TBI in the box on page 4 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.

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Disability Fact Sheet, No. 18
May 2006

✧ How Common is TBI? ✧

More than one million children receive brain injuries each year. More than 30,000 of these children have lifelong disabilities as a result of the brain injury.

✧ 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.

✧ 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 mental retardation. 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.

✧ Tips for Parents ✧

☐ Learn about TBI. 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.

☐ 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. Call NICHCY (800-695-0285) or find resources in your state, online at (www.nichcy.org/states.htm) to locate parent groups near you.

☐ 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. See the list of resources and organizations at the end of this publication.

☐ Give the student more time to finish schoolwork and tests.

☐ Give directions one step at a time. For tasks with many steps, it helps to give the student written directions.

☐ Show the student how to perform new tasks. Give examples to go with new ideas and concepts.

☐ 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.

☐ Check to make sure that the student has actually learned the new skill. Give the student lots of opportunities to practice the new skill.

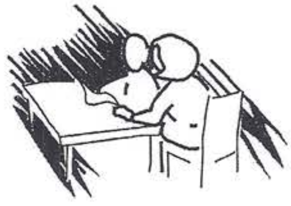
☐ Show the student how to use an assignment book and a daily schedule. This helps the student get organized.

☐ 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.

☐ Be flexible about expectations. Be patient. Maximize the student's chances for success.



✧ Resources ✧

DeBoskey, D.S. (Ed.). (1996). *Coming home: A discharge manual for families of persons with a brain injury.* Houston, TX: HDI. (Phone: 800-321-7037; Web: www.braininjurybooks.com)

DePompei, R., Blosser, J., Savage, R., & Lash, M. (1998). *Special education: IEP checklist for a student with a brain injury.* Wolfeboro, NH: L&A Publishing/Training. (Phone: 919-562-0015. Web: www.lapublishing.com)

DePompei, R., & Cluett, B. (1998). *All about me!* Wolfeboro, NH: L&A Publishing/Training. (For use by elementary school children with TBI. See contact information above.)

DePompei, R., & Tyler, J. (2004). Learning and cognitive communication challenges: Developing educational programs for students with brain injuries. Wolfeboro, NH: L&A Publishing/Training. (See contact information above.)

Hibbard, M., Gordon, W., Martin, T., Rashkin, B., & Brown, M. (2001). *Students with traumatic brain injury: Identification, assessment, and classroom accommodations.* New York: Research and Training Center on Community Integration of Individuals with Traumatic Brain Injury. (Phone: 888-241-5152; Web: www.mssm.edu/tbinet/alt/pubs/tbikids.pdf

Lash, M., Wolcott, G., & Pearson, S. (2000). *Signs and strategies for educating students with brain injuries: A practical guide for teachers and schools.* (2nd ed.). Houston, TX: HDI. (See contact information above.)

Schoenbrodt, L. (Ed.). (2001). *Children with traumatic brain injury: A parents' guide.* Bethesda, MD: Woodbine House. (Phone: 800-843-7323; Web: www.woodbinehouse.com)

Senelick, R.C., & Dougherty, K. (2001). *Living with brain injury: A guide for families* (2nd ed.). San Diego, CA: Singular. (Phone: 800-347-7707; Web: www.delmarhealthcare.com)

Snyder, H. (1998). *Elvin the elephant who forgets.* Wolfeboro, NH: L&A Publishing/Training. (A 16-page picture book for children. See contact information above.)

Our nation's special education law, the Individuals with Disabilities Education Act (IDEA) defines traumatic brain injury as. . .

> ". . . 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. The term 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; psycho-social behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma." 34 *Code of Federal Regulations* §300.7(c)(12)

✧ Organizations ✧

Brain Injury Association (formerly the National Head Injury Foundation), 8201 Greensboro Drive, Suite 611
Mclean, VA 22102. Phone: 703.761.0750;
800.444.6443 (Family Helpline)
Email: FamilyHelpline@biausa.org
Web site: www.biausa.org

Emergency Medical Services for Children—
National Resource Center, 111 Michigan Avenue N.W.,
Washington, DC 20010. Phone: 202.884.4927
Email: information@emscnrc.com
Web site: www.ems-c.org/

Epilepsy Foundation-National Office, 4351 Garden City Drive, Suite 500, Landover, MD 20785-7223.
Phone: 301.459.3700; 800.332.1000; 800.332.2070 (TTY)
Web site: www.epilepsyfoundation.org

Family Caregiver Alliance, 180 Montgomery St., Suite 1100
San Francisco, CA 94104. Phone: 415.434.3388;
800.445.8106 Email: info@caregiver.org
Web site: www.caregiver.org

Family Voices, 2340 Alamo SE, Suite 102
Albuquerque, NM 87106. Phone: 505.872.4774; 888.835.5669
Email: kidshealth@familyvoices.org
Web site: www.familyvoices.org

Head Injury Hotline, 212 Pioneer Building,
Seattle, WA 98104-2221. Phone: 206.621.8558
Email: brain@headinjury.com
Web site: www.headinjury.com

National Resource Center for Traumatic Brain Injury
Department of Physical Medicine and Rehabilitation
P.O. Box 980542 Richmond, VA 23298-0542 .
Phone: 804.828.9055 E-mail: mbking@hsc.vcu.edu
Web site: www.neuro.pmr.vcu.edu

FS18, May 2006

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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.

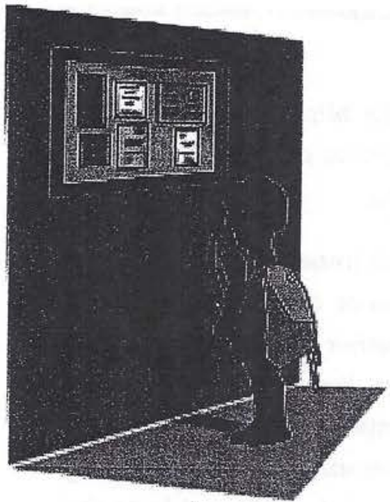
NICHCY *is the*
National Dissemination Center
for Children with Disabilities.

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

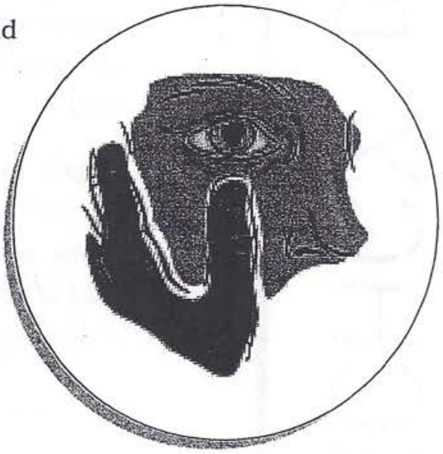
If you'd like personalized assistance, email or call us:

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)

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.

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

✧ 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

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