

# Children and Dysautonomia

One of the greatest fears parents face is having a child with a debilitating, life-altering, or life-threatening illness. Concern about their child's health becomes paramount.

The family with an ill child has boundaries set by the illness. It is not just the child that must learn to live and cope with the illness. The entire family must learn to adjust their lives to accommodate an ill child.

Will we need to relocate? Can we afford the medical bills? Will one of us need to quit working to be home with the child? Do we dare leave for vacation? Will the school accommodate our child's needs? These are some of the questions many young families face when a child suffers from a *dysautonomia*.

## Dyautonomias are "Invisible."

Unfortunately, *dysautonomias* can be "invisible" to an outsider. This means that in addition to other challenges, there is the sense of need to "prove" the child is not just "faking it." Comments from family, friends, and sometimes even the child's doctor can be unhelpful or hurtful.

Keep in mind that if these comments upset you, they're likely to upset your child! This is when a parent needs to become the child's advocate. Take time to learn about your child's disorder. Educate yourself and your child about their condition. Make it special time! Ask your child questions. Learn your child's fears, goals, concerns, and ambitions. If your child is concerned over things that you as a parent can't help them with, it may be a good time to talk to a counselor.

We don't want our children to become fearful of every symptom that they may be experiencing, but at the same time if a new symptom arises they need to feel comfortable bringing it to your attention. Create a "Comfort Zone."

It's also important to learn about Federal and State programs that help families and individuals who suffer from disabilities.

The NDRF would like to acknowledge the National Information Center for Children and Youth with Disabilities for the following information. Each year, the National Information Center for Children and Youth with Disabilities (NICHCY) receives thousands of requests from families and professionals for information about special education and related services for children and youth with disabilities. This News Digest has been developed to answer many of the questions and concerns that families and professionals have when they contact NICHCY.

## IDEA and Its Regulations

You should know the mandates and requirements of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA), because it may apply to children with disabilities arising from *dysautonomia*.

This document is the federal law that supports special education and related services programming for children and youth with disabilities. Because States base their programs upon the law and its final Federal regulations, it is helpful for you to read and become familiar with the law itself. To obtain a copy of the law (called the statute) or the final Federal regulations, contact: Superintendent of Documents, U.S. Government Printing Office, Attn: New Orders, P.O.B. 371954, Pittsburgh, PA 15250-7954. Charge orders may be telephoned to: (202) 512-1800. For a copy of the statute, state that you are requesting a copy of Public Law 105-17, the Individuals with Disabilities Education Act Amendments of 1997. To obtain a copy of the final Federal regulations, request the latest copy of the IDEA's regulations: Code of Federal Regulations: Title 34; Education; Part 300-399. There will be a minimal charge for both of these documents.

*This chapter discusses parts of the  
Individuals with Disabilities Education Act*

Both of these documents are also available on the Internet at the Web site of the Office of Special Education Programs (OSEP) at the U.S. Department of Education. OSEP's Web address is: [www.ed.gov/offices/OSERS/IDEA/index.html](http://www.ed.gov/offices/OSERS/IDEA/index.html). Another useful Web site for obtaining these materials is the OSEP-funded IDEA Partnership Projects at: [www.ideapractices.org/lawandregs.htm](http://www.ideapractices.org/lawandregs.htm).

The major **purposes of the IDEA** are: (a) to ensure that all children with disabilities have available to them a "free appropriate public education" that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living; (b) to ensure that the rights of children and youth with disabilities and their parents are protected; (c) to assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities; and (d) to assess and ensure the effectiveness of efforts to educate children with disabilities.

Under the law, a **free appropriate public education** (FAPE) means special education and related services that: (a) are provided to children and youth with disabilities at public expense, under public supervision and direction, and without charge; (b) meet the standards of the State Education Agency (SEA), including the requirements of the IDEA; (c) include preschool, elementary school, or secondary school education in the State involved; and (d) are provided in keeping with an

individualized education program (IEP) that meets the requirements of law.

The regulations for IDEA define a “child with a disability” as including a child (a) who has been evaluated according to IDEA’s evaluation requirements; (b) who has been determined, through this evaluation, to have one or more of the disabilities listed below; and (c) who, because of the disability, needs special education and related services. The disabilities listed by IDEA are: mental retardation; a hearing impairment, including deafness; a speech or language impairment; a visual impairment, including blindness; serious emotional disturbance (hereafter referred to as emotional disturbance); an orthopedic impairment; autism; traumatic brain injury; other health impairment; a specific learning disability; deaf-blindness; or multiple disabilities.

For children ages 3 through 9, a “child with a disability” may include, at the discretion of the State and the local educational agency (LEA), and subject to certain conditions, a child who is experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development; cognitive development; communication development; social or emotional development; or adaptive development; and who needs, for that reason, special education and related services. From birth through age 2, children may be eligible for services through the Infants and Toddlers with Disabilities Program of the IDEA.

**Special education** is defined as instruction that is specially designed, at no cost to you as parents, to meet your child's unique needs. Specially designed instruction means adapting the content, methodology, or delivery of instruction: to address the unique needs of your child that result from his or her disability, and to ensure your child's access to the general curriculum so that he or she can meet the educational standards that applies to all children within the jurisdiction of the public agency. Special education can include instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings. It can include instruction in physical education as well. Speech-language pathology services or any other related service can be considered special education rather than a related service under State standards if the instruction is specially designed, at no cost to the parents, to meet the unique needs of a child with a disability. Travel training and vocational education also can be considered special education if these standards are met.

Special education instruction can be provided in a number of settings, such as: in the classroom, in the home, in hospitals and institutions, and in other settings. Public agencies must ensure that a continuum of alternative placements is available to meet the needs of children with disabilities. This continuum must include the placements just mentioned (instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions) and make provision for supplementary services (such as resource

room or itinerant instruction) to be provided in conjunction with regular class placement.

Unless a child's IEP requires some other arrangement, the child must be educated in the school he or she would attend if he or she did not have a disability. Special education instruction must be provided to students with disabilities in what is known as the least restrictive environment, or LRE. Both the IDEA and its regulations have provisions that ensure that children with disabilities are educated with nondisabled children, to the maximum extent appropriate. The IDEA's LRE requirements apply to students in public or private institutions or other care facilities. Each State must further ensure that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

**Related services** are defined in the regulations as transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education. Related services may include: speech-language pathology and audiology; psychological services; physical therapy and occupational therapy; recreation, including therapeutic recreation; early identification and assessment of disabilities in children; counseling services, including rehabilitation counseling; orientation and mobility services; and medical services for

diagnostic or evaluation purposes only; school health services; social work services in schools; parent counseling and training. The list of related services identified in the IDEA's regulations is not intended to be exhaustive and could include other developmental, corrective, or support services if they are required to assist a child with a disability to benefit from special education.

You can learn more about Federal and State Disability programs by contacting the following:

NICHCY National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013-1492, Phone: 1-800-695-0285 or (202) 884-8200, Fax: (202) 884-8441, e-mail: [nichcy@aed.org](mailto:nichcy@aed.org).

U.S. Department of Education OSERS/NIDRR Room 3431, FB6 Washington, DC 20202, Phone: (202) 205-5633, website: [www.ed.gov](http://www.ed.gov), e-mail: [david\\_keer@ed.gov](mailto:david_keer@ed.gov).

The National Council on Disability, website: [www.ncd.gov](http://www.ncd.gov). A Guide To Disability Rights Laws is available at <http://www.ncd.gov/newsroom/publications/disabilityrights.html>.

It is also important to become familiar with your **State special education law**. The IDEA is a Federal law and, as such, provides minimum requirements that States must meet in order to receive Federal funds to



assist in providing special education and related services. Your State law and regulations may go beyond the Federal requirements, and it is important to know their specifics. You may want to contact your State Department of Education, Office of Special Education, and ask for a parent handbook on special education.

