

Columbia University Weinberg Family Cerebral Palsy Center

## Weinberg Family Cerebral Palsy Center

## Glossary of Terms to Know

In an effort to help our patients, parents and caregivers better understand the care and treatment options associated with neuromuscular disease, we have put together a comprehensive list of the commonly used terms and their definitions.



**Abduction** — the outward movement of a limb away from the body

Abnormal gait – deviation from normal walking

Absence Seizures — sudden brief loss of consciousness with rapid recovery. They are usually associated with staring and repetitive eye blinking. Also known as petit mal seizures.

Accessibility — the degree to which a product, device, service, or environment is available to as many people as possible.

Accommodations — removing obstacles that impede accessibility, thereby helping a person with disabilities function and participate in a typical environment.

Agenisis of the Corpus Collosum – a birth defect with partial/complete absence of the corpus collosum Alternative and Augmentative Communication (AAC) — the use of non-verbal techniques to communicate. Can include sign language, gestures, pictures, or a computerized device.

Americans with Disabilities Act (ADA) — a federal law that prohibits discrimination of the disabled by employers, public accommodations, public and private services, and in telecommunications. Failure to make reasonable accommodations is considered discrimination.

Adaptive behavior — the ability to adjust to new situations, tasks, environments, people, and objects. Also to learn new adaptive skills and apply them to other situations.

Adaptive equipment — physical props or supports to aid those with special needs. (i.e. corner chair, prone board. etc)

Adduction — the inward movement of a limb towards the body.

**Advocacy** — speaking on behalf of a person, cause, or group to support or promote their actions.

AFO (Ankle Foot Orthoses) — A partial leg brace made of lightweight plastic that controls the foot and ankle and ends at the calf

**Ambulatory** — the ability to walk

Anomaly — departure from what is considered typical

Anticonvulsant (or Antieplieptic drug AED) — A drug used to control seizures

Aqua Therapy – a therapeutic procedure which attempts to improve function through the application of aquatic therapeutic exercises

**Articulation** — the ability to move and control all parts of the mouth to make the sounds of a language. Aspirate — to suck or draw in food or liquids into the lungs by inhaling. Children with CP often swallow improperly while drinking and getting a small portion in the lungs. Drinking through a straw helps prevent

aspiration, as does thickening the liquid, or limiting the amount of each sip or bite.

**Assessment** — or evaluation – the process of determining a person's developmental strengths and weaknesses by observation and testing by a team of professionals and parents.

Astigmatism — blurry vision due to either the irregular shape of the cornea, the clear front cover of the eye, or sometimes the curvature of the lens inside the eye.

**Asymmetrical** — lacking symmetry- i.e. when one side of the body is different from the other.

ATA-Assistive Technology Act — An act which seeks to provide assistive technology to persons with

disabilities so they can more fully participate in education, employment, and daily activities on a level playing field with other members of their communities.

Ataxic — unbalanced gait due to damage in the cerebellum

Athetoid — uncontrolled writhing, Parkinsonian movements

Atonic — lack of normal muscle tissue

Atrophy — to deteriorate or progressively weaken, refers to muscle tissue in children with CP

Auditory processing — being able to understand individual speech sounds quickly enough to comprehend the meaning of what is being spoken.

Augmentative communication — see AAC

**Aura** — a feeling or behavior that often precedes a seizure

Baclofen Pills - a drug used to treat spasticity





Bilateral — relating to both sides

Bone Scan – a nuclear scanning test to find certain abnormalities in bone

Botox – a medication made from the botulism toxin that is injected into stiff muscle groups to reduce stiffness Brain plasticity — see Neuroplasticity

Brain stem — small portion of the brain located between the cerebellum and the spinal cord

**Case manager** — person responsible for coordinating services and information from a multidisciplinary team **Central nervous system** — the brain and spinal cord. It mainly controls voluntary movement and thought processes.

**Cerebellum** — lower smaller portion of the brain that coordinates balance and muscle activity

**Chroreoathetosis** — a type of Cerebral Palsy that results in a variety of muscle tone and involuntary movements of the limbs.

**Clonus** — fast alternating relaxation and contraction of the muscles caused by spastic muscles.

**Cognition** — the ability to process and understand the surrounding environment (thinking)

Combat crawling — crawling while on stomach and using mostly your arms to pull the rest of the body forward Contracture — decreased joint mobility due to a shortening of muscle fibers

**Convulsion** — involuntary contractions of the muscles due to abnormal electrical activity of the brain **Corpus Callosum** – a thick band of nerve fibers that connect the left brain with the right

**Cortical blindness** — total or partial blindness resulting from an injury to visual centers in the cerebral cortex. In this condition, the eyes function normally but the brain can not interpret or process the visual information.

**Cortical visual impairment** (CVI)—is a form of visual impairment that is caused by a brain problem rather than an eye problem. (The latter is sometimes termed "ocular visual impairment" when discussed in contrast to cortical visual impairment.) Some people have both CVI and a form of ocular visual impairment

CT scan — an imaging test using radiation to see structures within the body. It involves being placed in a small tube. Time of the test is usually less than 10 minutes.

Cue — also known as a prompt. It is a visual, auditory or physical action that reminds a person to perform a behavior or activity.

**DAFO** – dynamic AFO. A brand name for a flexible AFO.

**Developmental delay** — any delay in physical, cognitive (processing info/thinking), social, emotional, communication, or adaptive (self-help skills) development. It is typically used as a label under IDEA to qualify children between 3-9 for special education service. The percentage of delay to qualify for these services varies from state to state.

**Developmental disability** — an impairment of any developmental area, before age eighteen, that is expected to be substantial and continue indefinitely. Ex: autism, cerebral palsy, and mental retardation.

**Developmental milestone** — age categorized developmental goals based on typical growth and development. Ex: talking in simple sentences by age two, walking while holding onto a prop by 7 to 8 months, etc.

**Developmental Pediatrician** — a pediatrician that specializes in developmental milestones and assessing normal or abnormal child development

Diazepam (Diastat) — a medicine inserted rectally to stop prolonged seizures. It is often given by parents at home when a seizure does not stop in a specific amount of time established between the physician and the parent. The medicine is otherwise known as valium

**Differentiation** — a discrimination between things as different and distinct

**Diplegia** — a type of Cerebral Palsy that primarily produces spasticity of the legs

**Discretionary trust** — a trust in which the trustee (the person responsible for governing the trust) has the authority to use or not use the funds for any purpose as long as it is used only for the beneficiary.

DME-stands for "durable medical equipment" which is supportive medical equipment used to improve the quality of life and independence of the user. Examples include wheelchairs, bathing chairs, standers etc.

Dynamic Stander —a type of durable medical equipment that supports the user in a standing position but it also has wheels that enable the user to move himself through space.

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**Dyskinesia** — difficulty with sequencing and planning movements

**Dystonia** — slow, twisting, rhythmic movements

Early intervention — therapy and family instruction provided for children ages birth to three years old that is intended to minimize presentation of developmental delay.

**Early interventionist** — A person who arranges for a therapist to come to the house or meet at the family at a facility for treatment, provides family training to have the family incorporate practical ideas to improve child's development in-between therapy sessions, and arranges for bi-yearly and yearly assessments and IEP updates. EEG-Electroencephalograpm — a test that charts the level of electrical discharge from nerve cells in the brain. It is used to test for abnormal brain/seizure activity.

**Epilepsy** — a recurring condition where the brain produces abnormal electrical discharges that causes seizures Equilibrium — a child's sense or actual physical balance

**Expressive language** — verbal, written, or use of gestures to communicate

**Extension** — straightening the limbs or trunk.

Febrile Seizures — a generalized tonic-clonic (or grand mal) seizure brought on by sudden rise of body temperatures to 102 or higher. It is most common in children under age six. Duration is often less than five minutes.

Feeding tube — a tube of soft plastic used in feeding for those who have difficulty getting enough nutrition through regular eating.

Fine motor —using small muscle groups, such as face, hands, feet, fingers, toes. Fine motor skills include feeding, holding an object between thumb and fore finger (pincher grasp), turning/twisting, etc

Flexion — bending of joints

Floppy — loose movements and weak posture

**Flexor** — a muscle controlling the bending of joints

Gag reflex — a reflex that can often be extra sensitive with those with Cerebral Palsy, to the point where the child may gag or choke when something touches their tongue or palate. Over sensitization of the oral reflexes are often addressed by occupational therapist, speech language pathologist, or physical therapist.

**Gait** — the way (or manner) in which a child walks

Gait Analysis – a study of body movements, body mechanics, and the activity of the muscles.

Gait Trainer — a device that acts like a walker but with supports to stabilize the hips and ankles to encourage good posture and placement of feet and legs while walking.

Genetics – the study of gene and heredity

**GMFCS**- Gross Motor Functional Classification System

Gross motor — using large muscle groups, such as legs, arms, and abdomen. Gross motor skills include transitioning between postures, standing, walking, running, jumping, etc.

**Habilitation** — teaching new skills to those with developmental delays

Handicapped — broad category for having any type of disability, such as, sensory impairments, behavioral disorders, mental disorders, physical impairments, or multiple handicaps.

Head control — the ability to control movement of the head.

**Hemiplegia** — a type of cerebral palsy where only the right or the left side is affected.

**High tone** — tightness, or spasticity, of the muscles.

Hip Dysplasia – a congenital or acquired deformation or misalignment of the hip joint

Hip Dislocation – a common injury in which the ball-shaped head of femur comes out of the cup-shaped acetabulum set in the pelvis.

**Hippotherapy** — also called equine therapy – the use of horseback riding to improve a child's muscle movements and range of motion. Additional resources can be found on the American Hippotherapy Association website, www.americanhippotherapyassociation.org

Hydrocephalus — a blockage of the flow of cerebrospinal fluid that increases pressure in the ventricals of the brain. Can cause brain damage. Often relieved by surgical insertion of a tube called a shunt to drain the fluid.





## Hyperplasia — excessive growth of tissue

**Hypertonia** — increased tension in the muscles, also known as high tone.

**Hypotonia** — decreased tension in the muscles, also known as low tone.

IDEA — Individuals with Disabilities Education Act. A federal law passed in 1975 to ensure that children with disabilities have a free and appropriate education in the least restrictive environment. Free and appropriate education means that every part of the special education program is provided by public funds or, if there is no suitable public program available, the school district will pay the cost for the child to attend a private program that addresses the necessary services. Keep in mind that it does not provide for educational services that are not approved by the school district or governing agency. Least restrictive environment (LRE) involves having the child with special needs be included in an age typical classroom as much as their disability will allow them. This can range from being fully involved in the classroom with extra time allowances or an aide, having a limited amount of time in the classroom with the rest of their education taking place in a special needs class, or a self-contained class with no time in a typical classroom other than school activities (gym, lunch, assemblies, music, recess, etc.). Which LRE is most suitable for your child is often determined at the IEP meeting.

**IEP** — Individualized Education Program. Once the child is determined to be eligible for services by the school district (can be as early as age three), a written plan is developed by involved therapists, school professionals, and the parents to create learning goals and determine how the school district will provide for them. An IEP is reviewed once a year; however, the parent can also initiate an IEP meeting besides the annual required meeting, if they feel that their child's goals should be changed or aren't being addressed properly.

**IFSP**—Individualized Family Service Plan. Pertains to children three and younger. Usually set up by an early interventionist (EI). The family and the EI discuss areas of development that the child needs improvement on, set goals, and lists different methods to work on improving those areas. It is updated at least every six months.

**Inclusion** — being included or involved in a typical classroom as much as the child's disability will allow (see also least restrictive environment under IDEA).

Incontinence — lack of control of bladder or bowel movements.

**Interdisciplinary team** — a team of professionals from varying fields (teacher, therapists, doctors) who evaluate a child and then develop a summary of the child's abilities, progress, and needs in each of their areas of expertise to get a total picture of each area of the child's life.

**Intracerebral** — within the brain

Intracranial — within the skull

Intrathecal Baclofen Therapy — a treatment for muscle spasticity. A small pump is inserted under the skin to release small amounts of the medication, baclofen, into the spinal fluid.

In utero — literally in the uterus, referring to the period during fetal development.

**Involuntary movements** — uncontrolled movements.

KAFO — (Knee Ankle Foot Orthoses) a long plastic leg brace, which supports the whole leg, and hinges at the knee.

Learned Helplessness — a psychological term used to describe people who have been in a situation where they cannot help themselves for a long amount of time or who have been told repeatedly they can't do something. These people develop an attitude of helplessness that extends past the initial situation and instead of trying to do or learn a new skill later on in life, immediately give up because they assume they aren't able to perform the task.

**Learning disability** — a child with normal intelligence who has difficulty processing certain types of information. Least restrictive environment — allowing a special needs child to be made part of a regular school to the fullest extent possible

Low tone — decreased muscle tone.

Lower extremities — legs.

**Mainstreaming** — incorporating a child with special needs into a typical classroom. (see also inclusion)

**Medicaid** — a state and federal program that offers medical assistance for those eligible to receive Supplementary Security Income (SSI).

**Mental retardation** — a child who, before eighteen, has below average intellectual functioning and self-help behavior.

Midline — an imaginary reference line separating the right side of the body from the left. Most often used in doctor's and therapy notes

Monoplegia — a type of cerebral palsy where only one limb is affected.

Motor — ability to move oneself







Motor delay — slower development of movement skills

Motor patterns — the way body and limbs work to make a sequenced movement, such as crawling

Motor planning — The ability to think through and carry out a physical task

MRI — Magnetic Resonance Imaging. Use of electromagnetic forces to make an image of the inside of a body

Muscle tone — the amount of resistance or tension to a movement in a muscle

Multihandicapped — Having more than one disability.

**NAEYC** — The National Association for the Education of Young Children

**Neurologist** — a physician who specializes in disorders of the nervous system

Neuromotor — involving the nerves and muscles.

Neuroplasticity — the brain's ability to reorganize itself by forming new connections

**Neurotransmitter** — chemical substances in the brain that are used between nerve cells to carry, or transmit, signals from one nerve to another.

Neurosurgeon – doctors specialized in the surgical treatment of neurological diseases.

NICHCY — National Dissemination Center for Children with Disabilities. A central source of information on children with disabilities.

NICU — Neonatal Intensive Care Unit. A unit in the hospital designed to care for premature babies or babies born with urgent medical conditions.

**Nutritionist** – a person who advises on matters of food and nutrition impacts on health

Occupational therapist (OT) — therapists that help children and adults participate in the things they want and need through the use of everyday activities.

**Optometrist** — a doctor of optometry who studies and treats disorders of the eyes, vision, and surrounding tissues. Not a medical doctor.

**Orthopaedic** — relating to the joints, ligaments, bones, and muscles.

Orthopaedist vs. Podiatrist — an orthopedist is a doctor who specializes in preventing or correcting problems related to the joints, ligaments, bones and muscles, whereas a podiatrist is a doctor who specializes in preventing or correcting problems related to the feet.

**Orthotics** — lightweight devices that provide stability at the joints or passively stretch the muscles. Can be made of plastic, metal, or leather.

**Orthotist** — a specialized professional who creates, measures, and fits orthotics

**Osteotomy** — an operation to cut and realign the bones. Ex: to change the angles of the femoral bone and the hip joint.

Parent Advocate —a parent with knowledge and/or training about special education law and who provides advocacy support to fellow parents facing obstacles obtaining an education and related accommodations for his/her child.

Parent to parent organization —an organization staffed by parents who provide support and resources to other parents facing similar challenges raising their children.

Petit mal seizures — see absence seizures

Physical therapist (PT) — a therapist who assesses and treats problems relating to gross motor skills, such as sitting up without support, crawling, walking, etc.

**Pommel** — a support between the legs

**Posture** — positioning or alignment of the body

**Pragmatics** — understanding how and why language is used

**Primitive reflexes** — early patterns of movement in a child that usually disappear after about six months of age

Psyiatrist – Rehabilitation Doctor – a nerve, muscle and bone expert who treat injuries or illnesses that affect how you move **Quadriplegia** — A type of cerebral palsy where the whole body is affected

**Rage of motion (ROM)** — the degree of motion present at a joint.

**Reasonable accomodation** — efforts made to remove obstacles that prevent handicapped accessibility but don't result in an unreasonable financial burden, such providing a ramp to the entrance of a building.

**Receptive language** — the ability to understand what is written or being said

**Reflex** — an involuntary movement in response to stimulation such as touch, pressure or joint movement

**Reinforcement** — providing a pleasant consequence (such as getting to do favorite activity or eat favorite food) or removing an unpleasant consequence (such as a chore or a punishment that was in place) after a behavior in order to increase or maintain that behavior

**Respite care** — publicly funded skilled care and supervision of a person with disabilities in the family's or caregiver's home. It is usually available for several hours per week or for overnight stay.





**Rhizotomy, Selective dorsal** — a neurosurgical procedure involving cutting nerves in the spine to reduce tightness in muscle groups.

Rigidity — extremely high muscle tone in any position with very limited movements.

Scissoring — crossing of the legs together when standing, being held upright, or walking.

**Scoliosis** — curvature of the spine

**Seizure** — abnormal bursts of electricity in the brain resulting in changes in behavior, consciousness, and involuntary movement. They can be categorized as partial or generalized. A partial seizure only effects one area or one side of the brain. Several different types of partial seizures include: Focal Motor (simple partial), Sensory, Autonomic, and Psychomotor (temporal lobe) Seizures. Generalized seizures are where both sides of the brain are effected. Several different types of generalized seizures are: Absence (petit mal), Tonic-Clonic (grand mal), Infantile Myoclonic (infantile or jackknife), Febrile, and Atonic (Akinetic) Seizures.

**Sensory Integration**- is the neurological process that organizes sensation from one's own body and the environment, thus making it possible to use the body effectively within the environment. Specifically, it deals with how the brain processes multiple sensory modality inputs into usable functional outputs. (taken in part from Wikipedia)

**Service coordinator** — a professional who arranges services for a person with special needs. These services can be medical, therapeutic, educational, material goods or even social in nature. The service coordinator usually does not provide these resources themselves but connects the client with an organization or person that does. Most typically associated with early intervention but other organizations provide service coordination as well.

Shunt — a device used to drain excess spinal fluid from the brain for those with hydrocephalus

Side sitting — sitting with both knees bent and to one side of the body

SMO – Supra-Malleolar Orthosis – brace above the ankle bone

**Spastic** — having stiff muscles that impede movement.

**Special education** — specialized instruction based on educational disabilities determined by a team evaluation. It must be relevant to their educational needs and adapted to the child's learning style.

Special needs — needs generated by a person's disability

**SSDI** or Social Security Disability Insurance— Money that has been paid into the Social Security system through payroll deduction on earnings. These benefits can be paid to people who have become disabled before the age of twenty two, who can collect under a parents account if the parent is retired, disabled, or deceased, and disabled workers.

**SSI or Supplemental Security Income**- funds available for elderly or those with disabilities with low income. Eligibility is determined by financial need not on past earnings.

Strabismus — a disorder where the eyes do not line up in the same direction

**Subluxation** — partial dislocation of any joint. Ex: when the ball of that connects with the hip socket slowly pulls partially out of position.

Unilateral — one-sided





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