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A

ABLE Accounts: ABLE accounts are tax-free accounts similar to 529 Plans, but they are instead designed to help with putting aside money for disability-related medical costs of up to \$14,000/year without jeopardizing eligibility for other benefits programs.

Accessibility: Accessibility is a concept related to the design and utilization of systems, spaces, objects and programs. If something is accessible, that means that anyone – regardless of disability or special needs – can access, use and benefit from that item, space, service or structure. Accessibility is the degree to which something is available to as many people as possible.

Acute Profound Asphyxia (Acute Near Total Asphyxia): In babies diagnosed with HIE, *acute profound asphyxia* is a term describing the degree to which the baby is deprived of oxygen. When a baby is deprived of oxygen for 10 to 25 minutes, acute profound asphyxia can occur. Complications or injuries that may cause acute profound asphyxia include umbilical cord complications, uterine rupture, placental abruption and more.

Adaptive Equipment: Adaptive equipment includes tools and other items adapted to be more usable for individuals with disabilities, such as mobility limitations or cognitive processing deficits.

Adaptive Recreation: Adaptive recreation involves making sports and other activities accessible to individuals with disabilities by modifying rules, equipment or terrain.

Alternative Therapy: Alternative therapies are therapies outside the conventional medical canon which may be unavailable from typical medical practitioners. In many cases,



alternative therapies are not yet rigorously tested or have not been found to induce clinically significant improvements in health. Such therapies are undergone at a patient's own risk.

Americans with Disabilities Act (ADA): The ADA is a civil rights law that prohibits discrimination against people with disabilities in public life. This law is divided into five sections: employment, state and local government, public accommodations, telecommunications, and other provisions.

Anoxia: *Anoxia* is a severe form of hypoxia (oxygen shortage in the blood). Anoxia is characterized by a complete lack of oxygen reaching the body's tissues.

Anoxic Brain Injury: A brain injury caused by anoxia, a severe form of hypoxia in which a complete absence of oxygen reaches the body's tissues. Cerebral anoxia is a type of anoxic brain injury.

Apgar Score: A quick neonatal diagnostic test used to evaluate and summarize a newborn baby's health during the first few minutes of life. The Apgar score takes into account the baby's heart rate, respiratory function, responsiveness, muscle tone and skin color. Apgar scores are often used to diagnose HIE, as low Apgar scores may indicate that a baby experienced oxygen deprivation during delivery.

Asphyxia: *Asphyxia* is an emergency condition that occurs when the body is severely deprived of oxygen. When asphyxia occurs in the womb shortly before delivery, during delivery, or in the period immediately after delivery, it is known as *birth asphyxia*. Birth asphyxia can cause hypoxic-ischemic encephalopathy (HIE), disability, permanent injury or death.

Assistive and Adaptive Technologies: Assistive and adaptive technologies are a broad classification of items and tools that have either been modified or developed specifically for individuals with disabilities. These tools are designed to help maintain or enhance the



abilities of individuals with disabilities.

Augmentative and Alternative Communication Systems (AACs): AACs helps individuals with limitations in producing or understanding speech or written language by providing an alternate or supplementary means of communication.

Autism: Autism is a developmental disorder that impairs an individual's ability to communicate and interact in a social environment. With early intervention and behavioral therapy, individuals with autism may reduce symptoms and support development and learning.

B

Basal Ganglia (Basal Nuclei): Acute profound HIE typically involves damage to the basal ganglia, which comprise the forebrain's subcortical nuclei. Damage to the basal ganglia of the brain typically cause neurological and behavioral disorders, including cerebral palsy and movement disorders.

Behavioral Therapy: Behavioral therapy is a type of therapy that aims to modify an individual's behaviors to make them more adaptive or to achieve specific goals.

Biophysical Profile (BPP): A noninvasive prenatal test used to assess the health of a baby while he or she is still in the mother's womb. BPP assesses fetal movement, breathing, tone, heart rate and amniotic fluid volume. BPP can help detect and evaluate the presence of HIE.

Birth Asphyxia: A condition characterized by the lack of oxygen flow to a baby's brain before, during or directly after delivery. Birth asphyxia is an emergency condition and can lead to hypoxic-ischemic encephalopathy (HIE) and neonatal encephalopathy (NE). Intrapartum asphyxia is another term for birth asphyxia.



Birth Injury: When a baby's bodily function and/or structure are impaired due to an injury occurring during the process of childbirth, it is known as *birth injury*. Birth injuries most commonly refer to those injuries caused by oxygen deprivation to the baby's brain (such as HIE) or traumatic birth.

Birth Injury Attorney: A birth injury attorney is a lawyer that focuses on helping babies injured at or around the time of birth due to a medical professional's negligence. These lawyers litigate to help secure funding for the child's care, medical expenses, and other needs throughout their lifetime.

Birth Trauma: A general term for when a baby is physically injured during a prolonged or traumatic delivery. Most people think of birth trauma as dealing with strictly mechanical damage (like excessive pulling or the use of a vacuum extractor or forceps). There's a lot of overlap between birth injury and birth trauma. Many people use these interchangeably, though birth injury also includes injuries caused by lack of oxygen to the brain and infections as well.

Bradycardia: Bradycardia occurs when there is an abnormally slow heart rate. Abnormally slow heart rates are sometimes associated with hypoxia (low oxygen levels). In infants, bradycardia and hypoxia can cause HIE, a form of brain damage.

Brain Damage: Brain injury that impacts function. One example is hypoxic-ischemic encephalopathy (HIE), which occurs when brain cells die due to lack of oxygen to the brain.

Brain Imaging (Neuroimaging): When doctors or researchers use techniques like MRI or CT scan to see the structure and function of the brain and determine areas of brain damage.

Brain Injury: Brain dysfunction, often caused by mechanical trauma or compromised blood flow. HIE (hypoxic-ischemic encephalopathy) is an example of brain injury.



C

C-Section Delivery (Cesarean Section): When a baby is delivered surgically through a mother's abdomen and uterus. Often planned when vaginal delivery is unsafe for mother or child, but also done in emergencies when complications like fetal distress occur.

Cerebral Anoxia: Cerebral anoxia occurs when oxygen flow to the brain's tissues is completely cut off. This can cause permanent impairments like HIE.

Cerebral Edema: Cerebral edema is brain swelling caused by head trauma, oxygen deprivation, and other conditions. In babies, cerebral edema is associated with hydrocephalus, HIE and intraventricular hemorrhage (IVH).

Cerebral Hypoxia: Cerebral hypoxia occurs when oxygen supply to the brain's tissues becomes limited, causing brain damage. Cerebral hypoxia is decreased oxygen supply to the brain, unlike cerebral anoxia, which is a *complete* stoppage of oxygen to the brain.

Cerebral Infarction: A type of stroke or ischemic injury caused by compromised blood flow or trauma to parts of the brain. In infants, cerebral infarction is closely related to oxygen deprivation and hypoxic-ischemic encephalopathy (HIE).

Child Care Subsidy Program: Child Care Subsidy Programs help low-income individuals pay for childcare costs.

Cognitive-Behavioral Therapy (CBT): Cognitive-Behavioral Therapy (CBT) is a therapy designed to make people aware of their thoughts and how they impact their actions, emotions and outlook. This therapy seeks to improve a person's outlook on life and improve their behavior by focusing on underlying cognitive processes.



Community Integrated Living Arrangements (CILA): Community-Integrated Living Arrangements are settings where individuals with disabilities can live within the context of a larger community of individuals of varying abilities. These living arrangements can be an apartment complex, group home in a neighborhood, or family home under the supervision of a community developmental services agency.

Community Living Facilities: Residential facilities for individuals who require support in areas of daily living but may not require constant supervision. Community living facilities, which typically resemble apartment-style complexes and employ on-site staff, help residents prepare to live more independently.

CT scan: A CT (or CAT) scan combines X-rays taken from different angles and compiles them to create a cross-sectional image of bones, blood vessels or soft tissues in the body.

D

Decelerations: In the context of labor and delivery, a deceleration is when a baby's heart rate drops. Sometimes decelerations aren't harmful, but some types (especially late decelerations) are related to fetal distress and injury.

Direct Support Professional (DSP): A direct support professional (DSP) is a non-medical support team member that helps individuals with disabilities or limitations live as independently as possible, providing assistance with tasks like driving, homework help, cooking, and medication reminders.

Doppler Imaging: Doppler imaging is a technique that helps determine how well blood is flowing through blood vessels. Doppler imaging is sometimes used in prenatal care, as well as in labor and delivery.



E

Early Childhood Intervention: Early Childhood Intervention programs seeks to provide children at risk of developmental delays with therapy and other interventions between the ages of 0 to 3, as well as provide support to children who are at risk for abuse and/or neglect, helping children to maximize their physical, cognitive, social and emotional abilities. Zero to Three programs are an example of early childhood intervention.

Early Education Evaluation: An Early Education Evaluation is a barrage of tests that children with suspected disabilities undergo in order to evaluate what kind of educational supports and services they may need.

Early Head Start: A federally funded program providing free early childhood development, education and family support services to low-income children ages 0-3.

Early Intervention (EI): Early Intervention (EI) is a system for making sure children at risk for developmental delays get intensive therapy when they are still young (and when therapy is most effective). Early Intervention is available in all states through Zero Through Three Programs and similar efforts.

Emergency C-section: Doctors perform emergency C-sections to rapidly deliver a baby that is showing signs of oxygen deprivation and fetal distress. Delayed emergency C-sections are often medical malpractice, especially if the baby has HIE, brain damage, or disabilities.

Encephalopathy: 'Encephalopathy' is a blanket description for any disturbance in brain function, which can include trouble breathing, eating, poor reflexes, stiffness or floppiness, and seizures.

Epilepsy: Epilepsy is a brain disorder that causes abnormal electrical discharges in the brain.



These discharges cause recurring seizures, sensory issues, and loss of consciousness.

F

Fair Housing Act/laws: The federal Fair Housing Act of 1968 (and the following federal Fair Housing Act Amendments Act of 1988) prohibits discrimination in housing based on race, religion, national origin, familial status, age, pregnancy status, disability, or gender.

Fetal Acidosis (Acidemia): Fetal acidosis occurs when a fetus' blood is too acidic due to lactic acid buildup, caused by fetal oxygen deprivation. Fetal acidosis is a sign of hypoxic-ischemic encephalopathy (HIE). It is particularly dangerous because fetuses don't have the same compensatory physiologic responses as newborns do. Fetal acidosis is detected using an umbilical cord blood gas analysis right after birth, or with fetal heart rate monitoring.

Fetal Distress: An emergency complication where a fetus is deprived of oxygen, causing a drop in heart rate, decreased movement, or meconium in the fluid. Fetal distress must be immediately and aggressively addressed to prevent permanent injury like HIE.

Fetal Heart Rate Monitoring: A way to detect whether the baby is tolerating labor well by tracking how a baby's heartbeat changes in response to labor contractions. Fetal heart rate monitoring helps practitioners identify fetal distress and take appropriate action.

Fetal Monitoring Errors: Fetal monitoring errors occur when medical practitioners either don't properly monitor a baby's heart rate or don't properly interpret the readouts from a fetal heart rate monitor.

G

Gray Matter Injury (GMI): Grey matter injury occurs when the brain's gray matter is



compromised, causing programmed cell death (apoptosis) and neuronal damage.

H

High-Risk Pregnancy: A pregnancy that has underlying maternal health issues that need to be closely monitored for potential complications. High-risk pregnancies include those with preeclampsia, high blood pressure, diabetes, infection, STIs, having twins or triplets, very young or advanced age, prior history of complications and obesity, among others.

Hippotherapy: Hippotherapy is a type of horse-assisted therapy/rehabilitative activity that assists children with motor disorders using the horse's gait. Hippotherapy can improve coordination, balance and strength, and can be used in conjunction with multiple other therapy types.

Home Modification: Modifications made to the living environment of a person with a disability so that he or she may move around more naturally based on limitations.

Hypertonicity: Hypertonicity occurs in the presence of uterine hyperstimulation, when the muscles that contract during labor contractions either do not relax at all or don't relax enough. Reduces blood flow to the baby from the umbilical cord.

Hypothermia therapy (head cooling/brain cooling/cooling therapy/cooling blanket treatment): Hypothermia therapy is a treatment for HIE. The baby's body temperature is cooled down for 72 hours using a cooling blanket or cap to help brain cells recover and prevent further damage.

Hypoxia: Hypoxia occurs when not enough oxygen reaches the body's tissues.

Hypoxic-Anoxic Injury (HAI): A hypoxic-anoxic brain injury is permanent brain damage



specifically caused by oxygen deprivation.

Hypoxic-Ischemic Encephalopathy (HIE): Hypoxic-Ischemic Encephalopathy (HIE) is the formal name of brain damage in a baby's brain caused by oxygen deprivation. If a baby is diagnosed with HIE, they should receive brain cooling within 6 hours of birth. HIE can cause cerebral palsy, seizures, and learning, intellectual or developmental disabilities.

I

Inclusion: Inclusion is a philosophical and policy goal that seeks to ensure that all individuals are part of the larger social fabric. In the context of education policy, this involves ensuring that children with special needs are included in the general classroom setting as frequently as possible in order to maximize educational benefit.

Individuals with Disabilities Education Act (IDEA): IDEA is a law designed to make sure that children with disabilities receive a free and appropriate public education (FAPE) in the least restrictive environment. This law also gives parents a voice in their child's education.

Individualized Education Plans (IEPs): An IEP is an individualized legally-binding document that outlines what kind of assistance a school will provide to a child to ensure they get educational benefit.

Individual Family Service Plan (IFSP): An IFSP is a plan designed to help support children between the ages of 0-3 who have developmental delays. This family-centered document helps secure Early Intervention services to maximize the child's abilities.

Intrapartum/Intrauterine Asphyxia: Lack of oxygen to a baby's brain before or during labor and delivery or childbirth. Intrapartum asphyxia is the layman's term for HIE.



Ischemia: Ischemia is a medical condition where there is a shortage of blood flow to part of the body. This is especially dangerous in the brain, as it can compromise brain function.

M

Massage Therapy: Massage therapy is an alternative therapy designed to help manipulate tight muscles, tendons, connective tissue and ligaments, relax tight muscles and reduce stress and anxiety. There are many different types of massage therapy.

Medicaid/Medicare: Medicaid and Medicare are the primary programs available to cover the costs of medical care for individuals with disabilities, as well as the elderly. These programs often cover the costs of basic medical care, some equipment, and additional support.

Medicaid Waivers: Medicaid waivers are part of a program that helps defray the costs of home care assistance for individuals with disabilities. Medicaid waivers are designed as a stop-gap measure and do not generally cover the whole cost of care, so families often pay some portion of costs out-of-pocket.

Music Therapy: Music therapy is an alternative therapy that uses music within a therapeutic content to address an individual's physical, emotional, cognitive and social development.

Medical Malpractice: Medical malpractice occurs when a medical professional's care doesn't meet industry 'standards of care' for a particular situation, causing harm or injury to a patient.

Mild Hypoxic-Ischemic Encephalopathy (HIE) / Sarnat Stage I HIE: Mild HIE is the least severe class of HIE as determined by the Sarnat Grading Scale, which has three categories.

Mixed Injury Pattern Asphyxia: Mixed injury pattern asphyxia is a technical term for brain



damage that has characteristics of both ‘acute profound asphyxia’ and ‘partial prolonged asphyxia.’

Moderate Hypoxic-Ischemic Encephalopathy (HIE) / Sarnat Stage II HIE: Moderate HIE (also known as Sarnat Stage II HIE) encompasses more severe characteristics than mild HIE, including lethargy, mild low muscle tone, decreased activity, weak or absent suck reflex, weak startle reflex, pupil constriction, low heart rate and seizures.

MRI (Magnetic Resonance Imaging): MRI is one of the most precise methods of imaging the brain and other organs. MRIs use magnetic fields and radio waves to take highly detailed snapshots of the body.

MRS (Magnetic Resonance Spectroscopy): A non-invasive diagnostic test used to evaluate lactate levels in the brain, seizure disorders, strokes, brain disorders, and more.

N

Neonatal Asphyxia: See *Birth Asphyxia*.

Neonatal Brain Damage/ Neonatal Brain Injury: Injuries to the baby’s brain that occur before or during labor and delivery or after birth. Newborn brain damage can occur due to infection, elevated bilirubin, trauma, low blood sugar, overventilation, and HIE, among other things.

Neonatal Encephalopathy (NE): A general term for disturbed neurological function in newborns; hypoxic-ischemic encephalopathy (HIE) is a subset of NE.

Neonatal Intensive Care Unit (NICU): The NICU is a highly specialized unit in a hospital that cares for fragile and very ill newborns.



Nonreassuring Fetal Heart Tones: Nonreassuring fetal heart tones show that a baby is not getting enough oxygen in the womb. These are visible in the tracings printed out by electronic fetal heart rate monitors.

O

Occupational Therapy: Occupational therapy is a type of therapy that focuses on developing and extending an individual's independence and ability to complete age-appropriate activities of daily living (ADLs). Occupational therapy for children and adults differs – for children, occupational therapy often focuses on play and fine motor coordination. For adults, the focus is often more vocational in nature.

Orthopedic Surgery: Orthopedic surgery seeks to correct skeletal and muscular abnormalities surgically, often in the case of cerebral palsy.

Oxygen Deprivation: Oxygen deprivation occurs when oxygen does not reach the body's tissues, which need oxygen to stay functional. Oxygen deprivation can quickly cause widespread cell damage and death as the cells lose power and begin to die.

P

Partial Prolonged Asphyxia: Partial prolonged asphyxia occurs when a baby has been oxygen-deprived for 30 minutes or more.

Pediatric Neurologist: Pediatric neurologists are doctors who specialize in treating disorders of children's brains and spinal cords.

PEG Tube: A percutaneous endoscopic gastrostomy (PEG) tube is a feeding tube placed through the wall of the abdomen directly into the stomach, bypassing the mouth and



esophagus. PEG tubes are sometimes used in individuals with swallowing problems/dysphagia, among other conditions.

Perinatal Asphyxia: See *Birth Asphyxia*

Placental Insufficiency (uteroplacental insufficiency): Placental insufficiency occurs when not enough blood flow reaches the fetus from the mother. This can be caused by postdate pregnancy and placental abnormalities, and can in turn cause HIE.

Physical Therapy: Physical therapy is a therapy that seeks to correct physical, skeletal or muscular deficits using mechanical techniques rather than medications or surgery. The broad goals of physical therapy are to increase range of motion, reduce pain, restore function and reduce or prevent disability.

R

Recreational Therapy: Recreational therapy seeks to promote the health and address the needs of individuals with illnesses or disabilities using a systematic process of fun activity-based interventions. Types of recreational therapy include music therapy, visual art therapy, sports therapy, play therapy, and more.

Reperfusion Injury: Reperfusion injury occurs when blood rushes into an oxygen-deprived tissue too quickly, causing further damage due to inflammation and the release of free radicals that cause oxidative damage.

Respiratory Therapists: Respiratory therapists are specialized healthcare providers that provide assistance with airway management and breathing in a variety of settings, including in intensive care settings, operating rooms, outpatient clinics, and in the home healthcare environment.



Respite Care: Respite care is a temporary service that allows caregivers to take a short period of time off to rest, recharge and engage in leisure and recreation activities. Respite care can be provided in-home or out-of-home depending on the child's disabilities and parental resources.

S

Sarnat Classification/ Sarnat Grading Scale/ Sarnat Scoring/ Sarnat Scale: The Sarnat scale is a way of figuring out how severe a baby's HIE is, based on a combination of (1) how abnormal the baby's EEG readouts are and (2) the severity of the baby's clinical indications of brain damage.

Seizures: Seizures are involuntary muscle twitching, contractions and movements caused by abnormal electrical activity or chemical imbalances in the brain. If left untreated, seizures can make existing brain damage worse. Seizures in newborns are often more subtle than in adults and must be promptly controlled.

Seizure Dog: A seizure dog is a dog that has been trained (or has spontaneously learned) to warn their owner of impending seizures and/or provide assistance when seizures occur. They are legally recognized as service dogs. Therefore, under the Americans with Disabilities Act, they are allowed in public spaces and buildings.

Sensory Integration Therapy (SIT): Sensory Integration Therapy (SIT) is an alternative therapy that seeks to help children with sensory processing issues to 'integrate' and 'organize' their sensory input via a structured set of activities designed to provide the child with sensory input. Research has found inconclusive evidence regarding the effectiveness of sensory integration therapy.

Selective Dorsal Rhizotomy (SDR): Selective Dorsal Rhizotomy (SDR) is a surgical intervention aimed at reducing cerebral palsy spasticity. The surgery involved carefully severing the nerve



rootlets that contribute the most to a particular limb's spasticity and pain.

Service Animal: A service animal is a working dog trained to complete disability-related tasks to assist an individual with disabilities, allowing the individual with disabilities to function in ways that individuals without disabilities take for granted. Emotional Support Animals (ESAs) do not qualify as service animals.

Severe Hypoxic-Ischemic Encephalopathy (HIE) (Sarnat Stage III): Sarnat Stage III HIE generally has the most severe outcomes of all of the classifications of HIE.

Skilled Nursing Facilities (SNF): Skilled nursing facilities are healthcare facilities designed to support individuals who need skilled nursing support in the short term. These are not intended for long-term care and are often centers for the provision of intensive rehabilitation and therapy services.

Spasticity: Spasticity is a common feature of cerebral palsy that results in high muscle tone, tightness, stiffness and a 'pull' in the muscles. If left untreated, spasticity can eventually cause contractures, permanent joint damage and reduced range of motion. Many kids with HIE have spastic cerebral palsy.

Special Education: Special education is a curriculum designed to teach students with physical, emotional or cognitive disabilities. Special education services are tailored to the student's needs, and can be provided as part of an integrated program or in a separate school, depending on parental preference, available resources, and IEP plan.

Special Needs Trusts: Special needs trusts are set up to make sure a child can have savings without hitting the \$2000 asset limit that makes them ineligible for government assistance. Trusts are often set up to accrue interest over time and are often a vehicle for securing the child's future after a successful medical malpractice lawsuit.



Speech-Language Pathology (AACs): Speech-language pathology is a type of therapy that seeks to help individuals with expressive or verbal disorders find ways to communicate more effectively. For nonverbal individuals, speech-language pathologists may help the individual use AACs to communicate.

Stem Cell Therapy: Stem cell therapy uses cells harvested from a newborn's umbilical cord blood and re-injects them in an effort to reduce disability. Stem cell therapy is still an experimental treatment undergoing clinical trials and has not been approved for commercial use yet.

T

Tachycardia: Tachycardia is an abnormally fast heart rate (160+ BPM). This can occur as an attempt to compensate for poor oxygenation. In some fetuses, tachycardia indicates that a baby is showing signs of fetal distress and needs to be delivered immediately.

TANF: The Temporary Assistance for Needy Families (TANF) program provides short-term assistance to families who are having difficulty paying for basic needs. The program also provides social services and other supports to help individuals find work.

U

Ultrasound (Ultrasonography): Ultrasounds are a diagnostic imaging method often used in prenatal care to check on the baby's health, development, growth and amniotic fluid level, as well as to see if a baby's brain is structurally normal after birth.

Umbilical Cord: The umbilical cord connects the fetus to the mother's placenta during pregnancy. Because the cord is responsible for exchanging nutrients, oxygenated blood, and waste between the mother and fetus, and umbilical cord complications or interruptions can



cause fetal oxygen deprivation and HIE.

Umbilical Cord Blood Gas Test: These types of tests are often used to help diagnose HIE in a newborn baby. When a baby is deprived of oxygen during delivery, something known as *anaerobic metabolism* occurs, and this becomes evident in the umbilical artery blood. Umbilical cord blood gas tests evaluate this by measuring the acidity of the baby's blood and the amount of oxygen and carbon dioxide in the baby's blood.

Uterine Hyperstimulation (Tachysystole): Uterine hyperstimulation occurs when labor contractions are too fast and too strong, limiting how much blood and oxygen are getting to the baby through the umbilical cord, contributing to HIE.

Uterine Rupture: Uterine rupture occurs when a pregnant woman's uterus tears open. Uterine rupture is considered a medical emergency and can cause hemorrhaging, expulsion of the baby into the abdomen, premature rupture of membranes, and more. These resultant complications can interrupt the flow of oxygenated blood to the baby, thereby causing HIE.

Z

Zero to Three Programs: Zero to Three Programs are state-level programs designed to make sure children get physical, occupational and speech therapy support early to maximize their chances of succeeding in school



HIE HELP CENTER
GLOSSARY

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