LEARNING OBJECTIVES:
At the completion of this session the participant will be able to:

1. Describe the history of pediatric rehabilitation in the United States.

2. Discuss ten concepts in pediatric rehabilitation nursing.

3. Identify the types of children who need rehabilitation services.

4. Describe common etiologic/contributing factors and identify principles of nursing care relevant to the pediatric client with the following diagnosis:
   - seizure disorder
   - cerebral palsy
   - traumatic brain injury
   - burns
   - spina bifida
   - neuromuscular disorder
I. HISTORY OF PEDIATRIC REHABILITATION
Pediatric rehabilitation is a specialty dedicated to the care of children with special health care needs and their families. The commitment to these children has existed for over 100 years.

II. TEN CONCEPTS IN PEDIATRIC REHABILITATION

Concept 1: Each child has an intrinsic worth and value to himself, his family and society, regardless of the level of disability.

1. Patient care approaches must focus on normalization.
2. Encourage children, family members and peers to participate in care.
3. Accept and celebrate accomplishments no matter how small.
4. Help families apply the same rules and limits (discipline) to children with special health care needs that are applied to well siblings and peers.
5. Use “People-First” Terminology.
6. Involve children in activities similar to well children of same chronologic or developmental age.
   - recreational activities
   - organized sport
   - camp programs

<table>
<thead>
<tr>
<th>Use These Words</th>
<th>Avoid These Words</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with a disability</td>
<td>The disabled, the handicapped, invalid, cripple, deformed, victim, defective</td>
</tr>
<tr>
<td>People without disabilities, typical person</td>
<td>Normal, healthy bodied</td>
</tr>
<tr>
<td>Wheelchair user, uses a wheelchair</td>
<td>Wheelchair-bound, confined to a wheelchair</td>
</tr>
<tr>
<td>Congenital disability, birth anomaly</td>
<td>Birth defect, affliction, deformity</td>
</tr>
<tr>
<td>Has cerebral palsy, has spina bifida, person</td>
<td>Victim of cerebral palsy, stroke victim, cerebral palsied, spastic, para, quad</td>
</tr>
<tr>
<td>with a developmental disability, person with</td>
<td></td>
</tr>
<tr>
<td>quadriplegia</td>
<td></td>
</tr>
<tr>
<td>People who have mental retardation, person</td>
<td>The mentally retarded, mentally deficient, retardate, retard, feeble-minded person,</td>
</tr>
<tr>
<td>with mental retardation</td>
<td>idiot, gork</td>
</tr>
<tr>
<td>Seizure, epileptic episode or event</td>
<td>Fits, epileptic fits</td>
</tr>
<tr>
<td>Person with a speech or communication disability</td>
<td>Tongue-tied, dumb</td>
</tr>
<tr>
<td>People who are blind or visually impaired, person</td>
<td>The blind, deaf, the hard of hearing, deaf-mute, deaf and dumb</td>
</tr>
<tr>
<td>who is deaf or hearing impaired</td>
<td></td>
</tr>
</tbody>
</table>

Concept 2: Children continue to grow and mature during the rehab process.

1. The functional level of children with acquired disability is expected to be at the level of their current age rather than the age at which the accident occurred.

2. Children grow and develop in:
   - predictable patterns
   - with individual variation
   - in multiple areas
     - height, weight, head circumference
     - physiologically
     - reflexes and postural reactions

3. Refer to:
   - Figure 1: Factors that Influence Development
   - Table 2: Summary of Developmental Theorists
   - Tables 3: Developmental Milestones
     - Gross Motor - preambulatory skills, walking, and other advanced physical activities.
     - Personal/Social - acquisition of the standards of society and culture in which the child lives.
     - Speech and Language - vocalization, comprehension, and expression in oral or other modes of communication.
     - Play - the work of childhood
Figure 1: FACTORS THAT INFLUENCE DEVELOPMENT

PHYSIOLOGIC
- Heredity
- Neuroendocrine
- Upright posture
- Sex
- Disease

PHYSICAL ENVIRONMENT
- Season, climate, oxygen concentration
- Environmental hazards
- Socioeconomic level

NUTRITION

RESILIENCY

STRESS IN CHILDHOOD
- Coping
- Fears

INTERPERSONAL RELATIONSHIPS
- Significant others
- Love and affection
- Security
- Discipline and authority
- Dependence and independence
- Emotional deprivation

INFLUENCE OF MASS MEDIA
- Reading
- Movies
- TV
- Internet
<table>
<thead>
<tr>
<th>Stage/Age</th>
<th>Psychosexual Stages</th>
<th>Psychosocial Stages</th>
<th>Cognitive Stages</th>
<th>Moral Judgment Stages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freud</td>
<td>Erikson</td>
<td>Piaget</td>
<td>Kohlberg</td>
</tr>
<tr>
<td>Infancy</td>
<td>Oral sensory</td>
<td>Trust vs. mistrust</td>
<td>Sensorimotor</td>
<td>Preconventional</td>
</tr>
<tr>
<td>Birth to 1 year</td>
<td></td>
<td>Does not differentiate between self and mother until 5-7 mo.</td>
<td>(birth to 18 months)</td>
<td>(premoral) Punishment and obedience orientation</td>
</tr>
<tr>
<td>Toddlerhood 1-3 yrs</td>
<td>Anal-urethral</td>
<td>Autonomy vs. Shame and doubt Issue of holding on and letting go</td>
<td>Preoperational thought, preconceptual phase</td>
<td>Preconventional (premoral)</td>
</tr>
<tr>
<td>Early Childhood 3-6 yrs</td>
<td>Phallic-locomotion</td>
<td>Initiative vs. guilt More self-control, makes plans, sets goals</td>
<td>Preoperational thought, intuitive phase (4-7 yrs)</td>
<td>Preconventional (premoral) Naive instrumental orientation</td>
</tr>
<tr>
<td>Middle Childhood 6-12 yrs</td>
<td>Latency</td>
<td>Industry vs. inferiority Begins school, the &quot;hurts&quot; of failure</td>
<td>Concrete operations (7-11 yrs) Inductive reasoning and beginning logic Fact vs. fiction, systematic thought with concrete objects</td>
<td>Conventional Good-boy, nice-girl orientation Law-and-order orientation</td>
</tr>
<tr>
<td>Adolescence 13-19 yrs</td>
<td>Genitality</td>
<td>Identity vs. role confusion Self-absorbed, countless choices/options, &quot;group&quot; identity</td>
<td>Formal operations (11 yr-adult) Deductive reasoning and abstract reasoning Abstract thought, hypotheses</td>
<td>Postconventional or principled Social-contract orientation</td>
</tr>
</tbody>
</table>

Adapted from Wong (1995)
## Table 3: DEVELOPMENTAL MILESTONES

**INFANCY (Birth to 12 or 18 months)**

<table>
<thead>
<tr>
<th>Age</th>
<th>Gross Motor</th>
<th>Fine Motor</th>
<th>Adaptive Visual Motor</th>
<th>Personal/Social Maternal Person</th>
<th>Speech and Language</th>
<th>Play</th>
</tr>
</thead>
</table>
| **NEWBORN** | Flexor tone predominates  
In prone, turns head to side  
Automatic reflex walking  
Rounded spine when held sitting | Hands fisted  
Grasp reflex  
State dependent ability to fix and follow bright object and human face | Habituation and some control of state | Cry  
State dependent quieting and head turning to rattle or voice | Social-affective play - taking pleasure in relationships with people.  
Cuddling | |
| 4 MONTHS | Head midline  
Head held steadily when pulled to sit  
In prone, lifts head to 90° and supporting on forearms lifts chest slightly  
Rolls from back to side | Hands mostly open  
Midline hand play  
Crude palmar grasp  
Reaches for objects  
Follows objects in 180° circular fashion | Recognizes bottle | Turns to voice and bell consistently  
Laughs, squeals  
Responsive vocalization  
Coos (produces long vowel sounds in musical fashion)  
Blows bubbles and "raspberries" | Exploratory Stage -  
Grasping, holding, and examining articles | |
| 7 MONTHS | Sits well unsupported  
May lean on arms (tripod sitting)  
Rolls to prone  
Puts feet in mouth when supine  
Bears all weight  
Bounces when held erect  
Cervical lordosis | Reaches with either hand  
Raking grasp  
Transfers cube from hand to hand  
Bangs objects  
Inspects hands  
Has permanent eye color | Differentiates between familiar person and stranger  
Holos bottle  "Talks" to his mirror image | Babbles  
Uses single and double consonant-vowel combinations | Resists toy pull  
Picks up object  
Enjoys squeak toys and crumpled paper | |
| 10 MONTHS | Creeps on all fours  
Pivots in sitting  
Stands alone momentarily  
Cruises  
Slight bow leg  
Increased lumbar lordosis | Mature pincer grasp  
Bangs 2 cubes held in hands  
Tilts head backward to see up | Looks for dropped object (object permanence)  
Finger feeds  
Chews with rotary movement | Shouts for attention  
Imitates speech sounds  
Waves "bye-bye"  
Uses "mama" and "dada" with meaning  
Inhibits behavior to "no" | Plays peek-a-boo & pat-a-cake  
Exploration via creeping or crawling | |
<table>
<thead>
<tr>
<th>Age</th>
<th>Gross Motor</th>
<th>Fine Motor</th>
<th>Adaptive Visual Motor</th>
<th>Personal/Social Parental persons</th>
<th>Speech and Language</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 MONTHS</td>
<td>Walks alone, arms in high guard or midguard Wide base, excessive knee and hip flexion Foot contact on entire sole Slight valgus knees and feet Pelvic tilt and rotation</td>
<td>Piles two cubes Scribbles spontaneously Holds crayon full length in palm Throws objects Shows smooth visual pursuit of objects Vision 20/100</td>
<td>Uses spoon with overpronation and spilling Removes a garment Cooperates with dressing</td>
<td>One word expressive vocabulary at 12 months Uses single words Understands simple commands Comes when called Deaf infant loses ability to vocalize</td>
<td>Parallel play - independently but among other children Toy Stage Imitating adult behavior with replicas of adult tools</td>
<td></td>
</tr>
<tr>
<td>18 MONTHS</td>
<td>Walks alone, arms at low guard Mature supporting base and heel strike Seats self in chair Walks backward Kicks ball forward</td>
<td>Emerging hand dominance Crude release Holds crayon butt end in palm Dumps raisin from bottle spontaneously</td>
<td>Drinks from cup neatly</td>
<td>Points to named body part Identifies one picture Says &quot;no&quot; Jargons</td>
<td>Imitates housework Carries, hugs doll</td>
<td></td>
</tr>
<tr>
<td>2 YEARS</td>
<td>Begins running Walks up and down stairs alone Jumps on both feet in place</td>
<td>Hand dominance is usual Builds eight-cube tower Aligns cubes horizontally Imitates vertical line Places pencil shaft between thumb and fingers Draws with arm and wrist action Turns pages one at a time 20/40 vision</td>
<td>Pulls on garment Uses spoon well Opens door turning knob Removes shoes, piece of clothing, etc. Toilet training usually begun</td>
<td>Uses 50 words Two-word phrases are common Uses verbs Refers to self by name Uses &quot;me&quot;, &quot;mine&quot; Names objects in pictures Follows simple directions</td>
<td>Feeds doll with bottle or spoon</td>
<td></td>
</tr>
</tbody>
</table>
### Table 3: DEVELOPMENTAL MILESTONES

#### EARLY CHILDHOOD - PRESCHOOL (3-6 years)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gross Motor</th>
<th>Fine Motor Adaptive Visual Motor</th>
<th>Personal/Social Basic family</th>
<th>Speech and Language</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 YEARS</td>
<td>Runs well Pedals tricycle Broad jumps Walks up stairs alternating feet</td>
<td>Imitates three-cube bridge Copies circle Can use paint brush Overhand throw with anteroposterior arm and trunk motion Catches with extended arms hugging against body 20/30 - 20/20 vision Clues to visual deficits: squints or favors one eye</td>
<td>Most children toilet trained day and night Pours from pitcher Unbuttons Washes and dries hands and face Can be reasoned with</td>
<td>250 word vocabulary Three-word sentences are usual Uses future tense Knows all pronouns Asks &quot;what&quot;, &quot;who&quot;, &quot;where&quot; Follows prepositional commands, i.e. put it under Gives full name May stutter in eagerness Identifies self as boy or girl Can name body parts Recognizes three colors Comprehends cold, tired, hungry</td>
<td>Parallel/Associative play - playing together and being engaged in a similar or even identical activity but there is no organization, division of labor, leadership assignment, or mutual goal. Each child defines own rules Can take turns</td>
</tr>
<tr>
<td>4 YEARS</td>
<td>Walks down stairs alternating feet Hops on one foot Plantar arches developing Sits up from supine position without rotating</td>
<td>Handles a pencil by finger and wrist action, like adults Copies a cross Draws a frog-like person with head and extremities Throws underhand Cuts with scissors</td>
<td>Dresses and undresses with supervision distinguishing front and back of clothing and buttoning Does simple errands outside of home</td>
<td>Gives connected account of recent experiences Questions &quot;why&quot;, &quot;when&quot;, and &quot;how&quot; Uses past tense, adjectives, adverbs Knows opposites Repeats four digits Knows colors Says song or poem from memory</td>
<td>Begins cooperative play, sharing and interacting Imaginative make-believe play</td>
</tr>
<tr>
<td>Age</td>
<td>Gross Motor</td>
<td>Fine Motor Adaptive Visual Motor</td>
<td>Personal/Social</td>
<td>Speech and Language</td>
<td>Play</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
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<td>-----------------</td>
<td>---------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>5 YEARS</td>
<td>Skips; tiptoes Balances 10 sec on each foot</td>
<td>Hand dominance is expected Draws man with head, body, and extremities Throws with diagonal arms and body rotation Catches with hands</td>
<td>Uses fork for stabbing food Brushes teeth Is self-sufficient in toileting Dresses without supervision except tying shoelaces</td>
<td>Fluent speech Misarticulation of some sounds may persist Gives name, address, age Defines concrete nouns by composition, classification, or use Follows three-part commands Has number concepts to 10</td>
<td>Creative play Competitive team play</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**EARLY CHILDHOOD - PRESCHOOL (3-6 years)**

**MIDDLE CHILDHOOD - SCHOOL AGE (6-11 or 12 years)**

<table>
<thead>
<tr>
<th>6 YEARS</th>
<th>Rides bicycle Roller skates Walks a straight line</th>
<th>Prints alphabet; letter reversals acceptable Mature catch and throw of ball</th>
<th>Teacher is an important authority to child Uses fork appropriately Uses knife for spreading Ties shoelaces</th>
<th>Shows mastery of grammar Uses proper articulation</th>
<th>Cooperative play - organized play which occurs in a group with other children Play Stage Interest in toys diminishes. Interest in games, sports, and hobbies increases</th>
</tr>
</thead>
</table>

8/09 Pediatric Rehabilitation
<table>
<thead>
<tr>
<th>Table 3: DEVELOPMENTAL MILESTONES</th>
</tr>
</thead>
</table>

**MIDDLE CHILDHOOD - SCHOOL AGE** (6-11 or 12 years)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gross Motor</th>
<th>Fine Motor Adaptive Visual Motor</th>
<th>Personal/Social Peer groups</th>
<th>Speech and Language</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>7-11 YEARS</td>
<td>Continuing refinement of skills</td>
<td>20/20 vision</td>
<td>Eats with fork and knife Combs hair Is responsible for grooming</td>
<td>Continues to develop vocabulary and cognitive skills</td>
<td>Reads for pleasure Plays table games</td>
</tr>
</tbody>
</table>

**LATER CHILDHOOD-ADOLESCENCE** (11-19 years)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gross Motor</th>
<th>Fine Motor Adaptive Visual Motor</th>
<th>Personal/Social Peer groups</th>
<th>Speech and Language</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>11-19 YEARS</td>
<td>Good posture impeded by rapid growth spurt</td>
<td>Vision testing is important</td>
<td>Develops relationships with models of leadership partners in friendship, sex, competition</td>
<td>Has adult verbal skills with increasing vocabulary</td>
<td>Daydreaming Stage Plays the martyr misunderstood and mistreated by everyone or the hero or beauty admired by everyone Group/peer activities &quot;Limit-setting&quot; continues to be sought and desired Thrill seeking behaviors develop</td>
</tr>
</tbody>
</table>

Adapted from Burkett (1989); Molnar (1992) and Wong (1995)
Concept 3: Children in pediatric rehab need pediatric care too.
1. Immunizations
2. Specialized dental care
3. Safe car seat and wheelchair transport

Concept 4: The pediatric rehab client is first and foremost a child.
1. Play is the way in which children learn about their world. It is a vehicle for exploration and learning.
2. Play helps children master anxiety-provoking situations.
3. Therapeutic interventions include:
   - adapted toys and games
   - educational devices
   - FUN

Concept 5: Patient-and-family-centered care is a way to make sure we partner with the child and family in everything we do.
1. Principles of patient-and-family-centered care:
   - We should partner with families in all that we do at all levels of healthcare.
   - The family is the child’s primary source of strength and support.
   - We should build on the strengths of every child and family and support their choices and decisions about healthcare for their child.
   - We are here to help families care for their children and make decisions about healthcare for their child.
   - Every child and family should be made aware of options for support services.
   - Families should be a partner in hospital decisions that may affect them.
   - Every child and family has the right to honest and unbiased information.
   - Every child and family should be respected and their cultural diversity honored.

Concept 6: Disability and chronic illness have a profound physical, emotional, and financial impact on the entire family system.
1. Potential family challenges:
   - Extra travel
   - High care needs
   - Financial concerns
   - Lost time from work
   - Problems with school systems
   - Fatigue
   - Trouble finding baby sitters
   - Lost leisure time
   - Typical major and daily life stresses
2. Mothers and fathers experience chronic sorrow and cope with child’s disability or chronic illness differently. Mothers exhibit periodic crisis patterns, often delay or forfeit personal goals, and usually assume caretaking role (Clubb, 1991; Fisman & Wolf, 1991).

3. Fathers show a steady, gradual recovery. They worry about their child’s future and the financial burden, and are often afraid of losing control and displaying lack of confidence (May, 1990).

4. Siblings may have mixed feelings.
   - guilt
   - sadness
   - embarrassment
   - pride in the child’s accomplishments.

5. Other extended family members

Concept 7: Families may exhibit different patterns in parent-healthcare team relationships.
1. Limited contact: Parents choose to have limited involvement and are difficult to engage in decision making.

2. Recipients of care: Parents believe health care team knows what is best for their child. There is a high level of trust in professionals.

3. Monitors of care: Seek information from nurses and other professionals as they monitor performance of health care staff.

4. Managers of care: In control of health related decisions and use health care professionals for direct care and consultation. Many parents of children with special health care needs display this interaction style.

Concept 8: Each child has the right to inclusion in health care services, school, work, and community.
1. Special education is instruction to meet the unique needs of children and young adults (0 to 21 years of age) that is provided at no cost to the family. It is provided in early intervention programs, preschools, elementary and secondary schools, home, hospitals, training centers, work places, etc. By law special education includes:
   - Nonacademic services such as counseling, employment assistance and physical education.
   - Related services that are necessary for the child to benefit such as transportation, therapy, medical services, school health services, and rehabilitation counseling.
   - Transition services to promote movement from school to postsecondary, vocational training, employment, adult services, or independent living.
   - Development of an Individualized Educational Plan (IEP).
   - Education in the least restrictive appropriate placement. Also referred to as mainstreaming or inclusion or inclusive education.
2. Special education legislation
   - Individuals with Disabilities Education Act (IDEA), Public Law 101-476
   - No Child Left Behind (NCLB) Act, Public Law (PL) 107-110
   - Americans with Disabilities Act (ADA)
   - Section 504 of the Rehabilitation Act
   - Assistive Technology Act of 1998

Concept 9: Children and adolescents with disabilities and their families are entitled to the same legal and ethical rights as any other child and family.

1. Common legal issues
   - Guardianship
   - Incompetence
   - Informed consent
   - Estate planning
   - Legal death or brain death
   - Withholding or withdrawing treatment
   - Do Not Resuscitate Orders
   - Disability laws
   - Special education

2. Technologic and medical advances have created a variety of moral and ethical dilemmas. These are just a few examples.
   - Patient rights, including rights of minors
   - Severely ill newborns
   - Diagnosis and prognosis
   - Restraint use
   - Do not resuscitate orders
   - Advance directives
   - Noncompliance
   - Confidentiality, security and privacy of patient information
   - Child abuse
   - Alternative and complementary therapies
   - Health care allocation
     - Privilege vs. right
     - Access
     - Cost containment
     - Length of stay/service
     - Discharge teaching
     - Discharge disposition
Concept 10: Care needs range from the time of diagnosis or injury into the adult years.

1. Families need help transitioning to:
   - Home
   - School
   - Community
   - Adult health care services

2. Pediatric clients need frequent evaluation and adjustments to equipment and educational services.

3. Adolescents with disabilities are often not well prepared for independent decision making.

III. TYPES OF CHILDREN WHO NEED REHAB SERVICES

1. 14% of children in the United States have a special health care need (Child & Adolescent Health Measurement Initiative, 2005).

2. Advances in medical care, trauma services, and pediatric and neonatal intensive care have improved the chances that children with special health care needs will reach adulthood.

3. The variety of disorders seen is a special characteristic of pediatric rehab.
   - Accidents and trauma
   - Problems associated with premature infants
   - Developmental disabilities
   - Chronic illnesses
   - Technology dependence
   - Miscellaneous disorders

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percentage of Facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traumatic Brain Injury</td>
<td>73%</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>55%</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>45%</td>
</tr>
<tr>
<td>Orthopedic problems</td>
<td>30%</td>
</tr>
<tr>
<td>Neurologic problems</td>
<td>28%</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>24%</td>
</tr>
<tr>
<td>Bronchopulmonary dysplasia</td>
<td>17%</td>
</tr>
<tr>
<td>Cerebrovascular accidents</td>
<td>16%</td>
</tr>
<tr>
<td>Burns</td>
<td>12%</td>
</tr>
</tbody>
</table>

IV. SEIZURE DISORDERS IN CHILDREN

1. Definitions:
   - Seizure - discrete event characterized by a sudden, excessive, and disorderly (abnormal) discharge of electrons in the brain that is accompanied by an abrupt alteration in motor and/or sensory function and/or consciousness.
   - Epilepsy - repeated episodes of seizures.

2. Incidence: 200,000 new cases of epilepsy are reported annually.

3. Etiology:
   - Genetic
   - Acquired
   - Idiopathic

4. Refer to Table 5: International Classification of Epileptic Seizures

5. Seizure Workup
   - History
   - Examination
   - Diagnostics

6. The following steps should be taken when administering first aid to an individual having a generalized tonic-clonic seizure:
   - Remain with the person.
   - Unless he or she is in danger, do not move person.
   - Protect the person from injury. Clear the area. Place head on pillow or blanket.
   - Loosen tight clothing, restraints, and seat belts
   - Turn the individual on his or her side so that secretions can drain.
   - Do not attempt to place anything in the mouth.
   - Observe the seizure. Note when it started, pre-seizure activity, how it started, how it progresses, the duration of each phase, level of consciousness, motor and ocular activity, and respiratory difficulty.
   - Call for medical/rescue assistance if the seizure is generalized tonic-clonic and lasts longer than 5 minutes.

[Adapted from Roth & Morse (1994)]
Table 5: International Classification of Epileptic Seizures

<table>
<thead>
<tr>
<th>Traditional nomenclature</th>
<th>Nomenclature of the International Classification of Epileptic Seizures</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Partial Seizures (begin focally or locally in one hemisphere of the brain. Also known as focal seizures.)</td>
<td></td>
</tr>
<tr>
<td>A. Simple Partial Seizures (without impaired consciousness)</td>
<td></td>
</tr>
<tr>
<td>1. With motor symptoms</td>
<td>Focal motor seizures</td>
</tr>
<tr>
<td>2. With somatosensory or special sensory symptoms</td>
<td>Focal sensory seizures</td>
</tr>
<tr>
<td>3. With autonomic symptoms</td>
<td></td>
</tr>
<tr>
<td>4. With psychic symptoms</td>
<td>Temporal lobe seizures</td>
</tr>
<tr>
<td>B. Complex Partial Seizures (with impaired consciousness)</td>
<td></td>
</tr>
<tr>
<td>1. with impaired consciousness only</td>
<td>(often confused with absence, or petit mal seizures*)</td>
</tr>
<tr>
<td>2. with automatisms</td>
<td>Psychomotor seizures; temporal lobe seizures</td>
</tr>
<tr>
<td>C. Partial Seizures</td>
<td></td>
</tr>
<tr>
<td>1. secondarily generalized</td>
<td>focal seizures progressing to grand mal (major motor) seizures, such as Jacksonian seizures</td>
</tr>
<tr>
<td>II. Generalized seizures: begin in both hemispheres of the brain at the same time without localization</td>
<td></td>
</tr>
<tr>
<td>A. Absence seizures</td>
<td>petit mal seizures</td>
</tr>
<tr>
<td>B. Generalized tonic-clonic seizures</td>
<td>grand mal seizures; major motor seizures</td>
</tr>
<tr>
<td>C. Myoclonic seizures</td>
<td>myoclonic seizures; minor motor seizures</td>
</tr>
<tr>
<td>D. Akinetic seizures</td>
<td>akinetic seizures; minor motor seizures</td>
</tr>
<tr>
<td>E. Atonic seizures</td>
<td>atonic seizures; minor motor seizures</td>
</tr>
<tr>
<td>F. Tonic Seizures</td>
<td>tonic seizures</td>
</tr>
<tr>
<td>G. Clonic seizures</td>
<td>clonic seizures</td>
</tr>
<tr>
<td>III. Unclassified seizures</td>
<td></td>
</tr>
</tbody>
</table>

Retrieved on 7/31/2009 from http://uwmedicine.washington.edu/PatientCare/LOC/RegionalEpilepsyCenter/conditions/Epilepsy/Classification+of+Seizures.htm
7. Common Seizure Medications
   • Acetazolamide (Diamox)
   • ACTH
   • Carbamazepine (Tegretol, Carbatrol)
   • Clonazepam (Klonopin)
   • Clorazepate (Tranxene)
   • Diazepam (Valium)
   • Diazepam Rectal Gel (Diastat)
   • Divalproex sodium (Depakote)
   • Ethosuximide (Zarontin)
   • Felbamate (Felbatol)
   • Gabapentin (Neurontin)
   • Lacosamide (Vimpat)

   • Lamotrigine (Lamictal)
   • Levetiracetam (Keppra)
   • Lorazepam (Ativan)
   • Oxcarbazepine (Trilpetal)
   • Phenobarbital
   • Phenytoin (Dilantin, Phenytek)
   • Pregabalin (Lyrica)
   • Primidone (Mysoline)
   • Rufinamide (Banzel)
   • Tiagabine (Gabitril)
   • Topiramate (Topamax)
   • Valproate (Depakene)
   • Zonisamide (Zonegran)

8. Other Treatments
   • Vagus Nerve Stimulator

   • Surgeries

   • Ketogenic Diet

9. Life Style Issues
V. CEREBRAL PALSY

1. Disorder of movement and posture caused by nonprogressive lesion to an immature brain, occurring in utero, near the time of delivery or within the first 3 years of life. Incidence is increasing slightly with improved survival especially of extremely premature infants.

2. Risk Factors
   - congenital infections
   - gestational toxins
   - prematurity
   - grade 3 or 4 intraventricular hemorrhage leading to periventricular leukomalacia
   - prolonged seizures
   - Apgar less than 3 at 20 minutes
   - birth asphyxia
   - hyperbilirubinemia
   - postnatal infections
   - brain injury
   - heavy metal and organophosphate ingestion

   *In 30-40% of cases the cause is unknown.*

3. Making the Diagnosis
   - History of risk factors and diagnostic test results
     - Gross motor delays
     - Abnormal motor patterns
     - Abnormal tone
     - Abnormal primitive reflexes
4. Classification & Clinical Features

- **Spastic**: Most common type (70-85%)
  - Hemiplegia – affects one side of body more than other and upper extremities more than lower.
  - Diplegia - spastic paresis affecting lower extremities more than arms.
  - Quadriplegia – total body affected with greater impairment of lower limbs.
  - Triplegia – affects lower extremities and one arm.

  **Clinical Features:**
  - hypotonic becoming spastic by 6 months
  - absent, poorly developed, or delayed control of postural mechanisms
  - spastic paresis with inability to perform coordinated volitional movements
  - unbalanced muscle action leads to soft tissue contractures
  - hip dislocation and scoliosis

- **Dyskinetic: (8-10%)**

  **Clinical Features:**
  - hypotonic first few days
  - hypertonicity & opisthotonos thereafter
  - obligatory tonic neck & neck righting reflexes
  - extrapyramidal movement disorder evident at 12 months to 3 years
  - altered swallowing, mastication, phonation, articulation, increased drooling & dysarthric speech
  - upper extremities more involved
  - paralysis of conjugate upward gaze
  - athetosis in fingers, toes, & facial musculature
  - equinovarus foot deformities and scoliosis

- **Mixed (5-15%)**

5. Associated Disabilities

- Speech & language: sensorineural hearing loss, language disorder, speech impairment
- Feeding disorders, drooling, and abnormal dentition
- Seizure disorders
- Vision: extraocular movement deficits, vision deficits
- “Neurogenic” bowel and bladder
- Cognitive: mental retardation, perceptual dysfunction, behavior disorders
- Respiratory infections
6. Therapeutic Management
   • Postural and movement control
   • Adaptive equipment
   • Functional mobility
   • Promoting function in Daily Living Skills
   • Spasticity management
   • Socialization
   • Communication

7. Outcomes
   • Will they walk?
     ◦ independent sitting by 2 years
     ◦ quadruped crawling by 15 months
     ◦ turn supine to prone by 18 months
   • Long term
     ◦ lower extremity contractures
     ◦ progressive scoliosis
     ◦ decreased ambulation
     ◦ osteoporosis
     ◦ periodontal disease
     ◦ pain

VI. PEDIATRIC TRAUMATIC BRAIN INJURY (TBI)

1. Epidemiology
   • Age specific rates peak in adolescence and are higher for boys at all ages.
   • Major cause of mortality among all childhood injuries. 1.4 million people sustain a
     brain injury each year.
   • Major causes of pediatric TBI: falls (42%); MVA (34%); other (24%); ¼ of TBI in
     children less than 2 years of age is related to child abuse

2. Pathophysiology
   • Physical characteristics put them at increased risk
   • Open fontanels and sutures can accommodate expansion
3. Rehabilitation Issues
   - 4% incidence of concomitant SCI. SCI can be present in children without radiological
     signs of vertebral fracture or dislocation.
   - Motor dysfunction
     - Ataxia with or without spasticity is the most frequent neuromuscular
       deficit in children.
     - Scoliosis
   - Neuropsychological deficits
     - Disinhibition
     - Passivity
     - Anterograde amnesia
     - Greater plasticity in terms of cognitive and language development. Can
       proceed despite severe injury.
     - Learning problems

4. Outcomes
   - Ongoing development influences assessment.
   - Most recovery and assessment scales are not adapted to infants, toddlers, and
     preschoolers.
   - Adolescents (15-18 year olds) have better prognosis than younger children do.
   - Coma
     - Children with deeper coma have more profound cognitive deficits
       especially if injured before 9 or 10 years of age.
     - There is high morbidity and mortality when Glasgow Coma score is 3 or
       less.
     - If comatose for less than 3 months there is good chance of recovery to
       moderate disability within 1 year.
   - Overall there is greater recovery from neuromuscular dysfunction and deficits caused
     by focal lesions than from cognitive and behavioral consequences.
   - Children transferred from acute care to rehab setting early have better outcomes.
   - Reinjury
   - Common long-term problems that affect learning are: learning disabilities, selective
     attention deficit, poor impulse control, impaired social judgment.
II. BURNS

1. Tissue injury caused by excessive exposure to thermal, chemical, electrical or radioactive agents.

   - males
   - under 2 years of age
   - disabled
   - no smoke detector in home
   - child abuse

3. Causes: Type of injury closely related to developmental stage and cognitive abilities.

4. Determining Burn Severity
   - Degree of burn - Refer to Table 7: Levels of Burn Severity
   - Extent of burn – Use Rule of Nines
   - Level of skin injury – Refer to Table 6: Level of Skin Injury
   - Location
   - Patient’s age
   - Preexisting conditions

<p>| Table 6: Level of Skin Injury |</p>
<table>
<thead>
<tr>
<th>Classification</th>
<th>Child</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage outpatient</td>
<td>&lt; 10% TBSA</td>
<td>&lt; 15% TBSA</td>
</tr>
<tr>
<td>No preexisting conditions</td>
<td>&lt; 2% TBSA full thickness</td>
<td>&lt; 2% TBSA full thickness</td>
</tr>
<tr>
<td>Moderate</td>
<td>10-20% TBSA partial thickness</td>
<td>15-25% TBSA partial thickness</td>
</tr>
<tr>
<td>No concurrent injury</td>
<td>2-10% TBSA full thickness</td>
<td>2-10% TBSA full thickness</td>
</tr>
<tr>
<td>No preexisting conditions</td>
<td>&gt; 20% TBSA partial thickness</td>
<td>&gt; 20% TBSA partial thickness</td>
</tr>
<tr>
<td>Major</td>
<td>&gt; 10% TBSA full thickness</td>
<td>&gt; 10% TBSA full thickness</td>
</tr>
<tr>
<td>Extend into muscle and bone</td>
<td>&gt; 20% TBSA partial thickness</td>
<td></td>
</tr>
<tr>
<td>Face, eye, ears, hands, feet, or perineum involved</td>
<td>&gt; 10% TBSA full thickness</td>
<td></td>
</tr>
<tr>
<td>Electrical burns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major trauma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preexisting diabetes, congestive heart failure, chronic renal failure</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TBSA = Total body surface area
<table>
<thead>
<tr>
<th>SEVERITY</th>
<th>SURFACE APPEARANCE</th>
<th>COLOR</th>
<th>SENSATION</th>
<th>PART OF SKIN</th>
<th>HEALING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Superficial</strong> (first degree)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Common causes:</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sunburn</td>
<td>Dry, no blisters</td>
<td>Erythematous</td>
<td>Very painful</td>
<td>Does not extend beyond epidermis</td>
<td>3-7 days with peeling No scarring May have discoloration</td>
</tr>
<tr>
<td>Ultraviolet exposure</td>
<td>Edema-amount</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short flash</td>
<td>variable</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Partial Thickness</strong> (second degree)</td>
<td>Weeping</td>
<td>Mottled white to pink to cherry red</td>
<td>Very painful</td>
<td>Involves the epidermis and part of the dermis</td>
<td>Superficial 7-21 days, no grafting No/minimal scarring Pigment changes</td>
</tr>
<tr>
<td><em>Common causes:</em></td>
<td>Moist blebs</td>
<td>Red, will blanch with pressure and refill</td>
<td>Deeper injuries are less painful</td>
<td></td>
<td>Deep</td>
</tr>
<tr>
<td>Scald</td>
<td>Blisters that increase in size</td>
<td></td>
<td></td>
<td></td>
<td>21-35 days if no infection; if infected, may convert to full-thickness May develop severe hypertrophic scarring Dryness and itching with healing</td>
</tr>
<tr>
<td>Short exposure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immersion scald</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flame</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Full-Thickness</strong> (third degree)</td>
<td>Dry, leathery or nonpliable until debridement</td>
<td>Can be any color (white, black, yellow, brown, charred)</td>
<td>Little or no pain</td>
<td>Extends into dermis</td>
<td>Large areas need skin grafting to heal Small areas may heal from edges after weeks.</td>
</tr>
<tr>
<td><em>Common causes:</em></td>
<td>Covered with eschar</td>
<td></td>
<td>Hair pulls out easily</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemical</td>
<td>Usually no blisters, but if present, thin-walled and will not increase in size</td>
<td>Anesthetic to temperature</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electrical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flame</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scald</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Full-Thickness</strong> (fourth degree)</td>
<td>Same as third degree</td>
<td>Same as third degree</td>
<td>Same as third degree</td>
<td>Extends beyond fat and into muscle and bone</td>
<td>Amputation of extremity is often necessary</td>
</tr>
</tbody>
</table>

Adapted from Richard & Staley (1994) and Molnar (1992)
5. Results of Burn Injuries
   - Loss of protective covering = increased risk for infection
   - Loss of body fluids
   - Systemic responses
   - Pain related to damaged nerve ending
   - Contractures
   - Altered sensation
   - Lack of temperature control
   - Loss of sweat and sebaceous glands and hair follicles
   - Pruritis or itching as wounds heal
   - Photosensitivity
   - Emotional distress

6. Rehab Management of Burns
   - Prevent skin/wound infection
   - Protect delicate skin
     - moist dressings
     - sun screen
     - frequent skin assessment
   - Control itching
   - Minimize scarring
     - massage and lotion
     - ROM exercises
     - compression therapy
   - Prevent contractures
     - splints
     - positioning
     - ROM exercises
     - activity
   - Manage pain
   - Provide adequate nutrition
   - Psychosocial issues
     - anticipatory guidance
     - school re-entry programs
     - caregiver support and teaching
VIII. SPINA BIFIDA

1. Etiology
   - Failure of neural tube closure or reopening of neural tube
   - Heredity $\Leftrightarrow$ environment $\Leftrightarrow$ vitamin deficiency
   - Elevated alpha-fetoprotein

2. Incidence: 1/2500 babies in United States

3. Risk Factors
   - A previous neural tube defect (NTD)-affected pregnancy increases a woman's chance to have another NTD-affected pregnancy by approximately 20 times
   - Maternal insulin-dependent diabetes
   - Use of certain anti-seizure medication (Valproic acid/Depakene, and Carbamazapine/Tegretol)
   - Medically diagnosed obesity
   - High temperatures in early pregnancy (i.e., prolonged fevers and hot tub use)
   - Race/ethnicity (NTDs are more common among white women than black women and more common among Hispanic women than non-Hispanic women)
   - Lower socio-economic status

   There has been a 24% decline in spina bifida since the United States started fortifying grains with folic acid. (CDC, 2002)

4. Different Types of Spina Bifida
   - Spina bifida cystica - cyst or sac protrudes through opening in the vertebrae.
   - Spina bifida occulta - defect covered by tuft of hair or layer of skin. Vertebrae not properly fused by spinal cord and meninges normal. Lease severe.
   - Meningocele - the sac contains only meninges and CSF. No neurologic impairment of legs, bowel, or bladder.
   - Myelomeningocele - sac contains portions of spinal cord and meninges herniate through opening in the vertebral column. Most common and most severe defect. The degree of neurological dysfunction is directly related to the anatomical level of defect and the nerves involved.

5. Primary Functional Deficits
   - Paraplegia with motor and sensory impairment.
   - Mental retardation especially when hydrocephalus is present.
   - Neurogenic bladder and bowel dysfunction leading to incontinence.

6. Secondary Functional Deficits (See Table 8: Neurological Levels, Complications and Ambulation in Spina Bifida)
   - Musculoskeletal

   - Sensory deficit decubitus ulcers
• Renal damage
• Family dysfunction
• Emotional maladjustment

7. Treatment
• Treatment depends on extent of neurological deficit, level of lesion and complications.
• Early anticipatory intervention to prevent secondary disabilities.
• ROM exercises and stretching
• Positioning and orthoses
• Surgical intervention
• Adaptive functional training
• Ambulation training
• Skin assessment and care
• Bladder program
• Bowel program
<table>
<thead>
<tr>
<th>Groups</th>
<th>Musculoskeletal deformities (most frequent)</th>
<th>Orthosis and Crutches</th>
<th>Range of Locomotion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Preambulation (positioners)</td>
<td>Ambulation Training</td>
</tr>
<tr>
<td>I</td>
<td></td>
<td>Hip extension with 15°-15° hip abduction and Denis Browne bar</td>
<td>Parapodium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Early surgery</td>
<td>Gait swivel and drag</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hip flexion and abduction, external rotation</td>
<td>Crutch: underarm</td>
</tr>
<tr>
<td>II</td>
<td></td>
<td>Hip flexion and adduction with dislocation</td>
<td>Presurgical (to prevent hip flexion contractures)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contralateral hip abduction, flexion</td>
<td>Hip extension with 15°-15° hip abduction and Denis Browne bar</td>
</tr>
<tr>
<td></td>
<td>Scoliosis</td>
<td>Parapodium</td>
<td>Gait: four point</td>
</tr>
<tr>
<td></td>
<td>Calcaneo-valgus</td>
<td>Crutch: Lofstrand</td>
<td>Crutch: Lofstrand</td>
</tr>
</tbody>
</table>

Table XX: NEUROLOGICAL LEVELS, COMPLICATIONS, AND AMBULATION IN SPINA BIFIDA
<table>
<thead>
<tr>
<th>Groups</th>
<th>Musculoskeletal deformities (most frequent)</th>
<th>Orthosis and Crutches</th>
<th>Range of Locomotion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Preambulation (positioners)</td>
<td>Ambulation Training</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>Slow progression of hip flexion and lumbar lordosis; late hip dislocation Calcaneo-valgus, varus</td>
<td>90° AFO or high-top shoes</td>
<td>Presurgical (to prevent calcaneus deformities)</td>
</tr>
<tr>
<td>L4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>L5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>AFO</td>
<td>High-top shoes Plantigrade inserts May need crutches</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gait: four point</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Calcaneo-varus</td>
<td>None</td>
<td>Presurgical (to obtain plantigrade feet)</td>
</tr>
<tr>
<td>S1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S2</td>
<td>Toe clawing</td>
<td>None</td>
<td>High-top shoes</td>
</tr>
<tr>
<td>S3</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Molnar (1992)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
IX. PEDIATRIC NEUROMUSCULAR DISEASES

Principal symptom is weakness presenting as hypotonia.

1. Spinal Muscular Atrophy (SMA)
   - Most common neuromuscular disorder of infants and children.
   - Inheritance - autosomal recessive
   - Pathology - degeneration of anterior horn cells in the spinal cord and neurocytes in the motor nuclei of some cranial nerves. There is active axonal degeneration.
   - Clinical Features
     - Type I SMA or Werdnig-Hoffman disease: Normal at birth then suddenly develop diffuse weakness. Early demise from respiratory failure.
     - Type II SMA or Chronic generalized SMA: more chronic course. Some attain motor milestones.
     - Type III SMA or Kugelberg-Welander syndrome: Slowly progressive.
   - Management of Spinal Muscular Atrophies
     - Supportive feeding techniques
     - Maintain airway patency
     - Developmental positioning
     - ROM exercises
     - Orthotics/adaptive equipment

2. Duchenne Muscular Dystrophy - severe
   - Inheritance is X-linked. Affects males only.
   - Clinical Features:
     - no overt signs until 3-6 years of age except possible late walking.
     - precipitous decline in motor skills
     - wheelchair bound by 9-12 years
     - cardiac abnormalities
     - restrictive pulmonary disease
     - scoliosis
     - low cognitive function
     - death in second decade from respiratory failure.

3. Becker Muscular Dystrophy - benign
   - Inheritance is X-linked
   - Ambulation into 20's; survival to 40's

4. Limb Girdle Dystrophy
   - Inheritance is autosomal recessive
   - Proximal weakness with greater involvement of pelvic girdle than shoulder musculature
   - Hard to differentiate from Duchenne and Becker
5. **Congenital Muscular Dystrophy**
   - Hypotonia at birth
   - Affects muscles of limbs and face
   - Contractures common and progressive
   - Normal intelligence

6. **Myotonic Dystrophy**
   - Mother is affected in 94% of cases.
   - Fetal form presents with polyhydramnios secondary to inability to swallow amniotic fluid
   - Other signs and symptoms of hypotonia: floppy, poor feeding, sleep apnea, slow motor gains etc.
   - Childhood form may be symptom free except for myopathic facies

7. **Management of Muscular and Myotonic Dystrophies**
   - Treatment focuses on preventive care and complication management
   - Encourage self-help skills and ambulation
   - Anticipate and treat complications
   - Recreational and vocational programs
   - Family counseling

X. **OUTCOMES IN PEDIATRIC REHAB**
1. Outcomes Measurement Tools
   - WeeFIM
   - Pediatric Evaluation of Disability Inventory (PEDI)
   - Minimum Data Set (MDS)

2. Factors Affecting Outcomes
   - Child’s age at initiation of services
   - Period of child’s development and tasks to be achieved during that developmental stage
   - Severity and extent and location of injury
   - Overall health status, nutrition and intrinsic biologic factors
   - Psychosocial factors (culture, resilience, locus of control) and Environmental Factors (physical environment, school socioeconomic)
   - Quality and quantity of intervention

3. Medical Home Principles
   - personal physician
   - whole person orientation
   - coordinated care
   - quality and safety
   - enhanced access
   - appropriate payment
   - family-centered
   - community-based
   - transitions
   - values
PEDIATRIC REHABILITATION GLOSSARY

Child with a Special Health Care Need - Those [children] who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998, p. 138)

Chronic sorrow - Chronic grief. Parental response to a child's disability or illness. This sorrow tends to be acutely reactivated with each new developmental stage that the child would normally experience were it not for the disability or illness (Clubb, 1991). Parents need extra support at critical points in the child’s development:
- when the child should start to walk
- when the child should start to talk
- when the child should start to be toilet trained
- when other children of the same age enter regular school
- when younger siblings advance beyond the child with the disability
- at the onset of puberty
- when the child turns 16 – (Will she ever be independent?)
- when the adolescent turns 21 – (Who will care for the child when the parents are deceased?)
- when alternative placement is considered
- when guardianship is required

Developmental delay - A maturational lag. An abnormal, slower rate of development in which a child demonstrates a functioning level below that observed in normal children of the same age (Wong, 1995, p. 934)

Developmental disability - A severe, chronic disability of a person which: is attributable to a mental or physical impairment or combination of mental and physical impairment; is manifested before the person attains age 22; is likely to continue indefinitely; results in substantial limitations in three or more of the following areas of major life activity: 1) self care, 2) receptive and expressive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, 7) economic sufficiency; reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or the services which are of lifelong or extended duration and are individually planned and coordinated. (U.S. House of Representatives [as cited in Morse, 1994, p. 20).

Developmental task - a set of skills and competencies peculiar to each developmental stage that children must accomplish or master in order to deal effectively with their environment.

Early Intervention Program (EIP) - Any sustained and systematic effort to assist children from birth to age 3 years who are young, disabled, and developmentally vulnerable, as well as their families. These programs were originally authorized under Public Law 99-457. They include services to assist the family in promoting their child's development.
Epilepsy - repeated episodes of seizures.

Habilitation - all activities and interactions that enable an individual with a disability to develop new abilities to achieve his or her maximum potential.

Individualized Education Plan (IEP) - A written statement for the education of a child with disabilities that is developed and implemented according to the IDEA. This statement is reviewed at least once a year.

Individualized Family Service Plan (IFSP) - A statement of child and family needs, outcomes to be achieved, and a plan of services necessary to meet these needs, including frequency, intensity, location, method of delivery, and payment arrangements. This plan was mandated under The Education of the Handicapped Act Amendment of 1986.

Mainstreaming - An educational term indicating the placement of children with disabilities in general classrooms and child care centers.

Medical Home – “… is not a building, house, or hospital, but rather an approach to providing health care services in a high quality and cost-effective manner.” (American Academy of Pediatrics, 2007)

Seizures: discrete event characterized by a sudden, excessive, and disorderly (abnormal) discharge of electrons in the brain that is accompanied by an abrupt alteration in motor and/or sensory function and /or consciousness,

Technology-dependent child - A child who needs both a medical device to compensate for the loss of a vital body function and substantial ongoing nursing care to avert death or further disability (OTA, 1988, p. 3); Also known as medically fragile child.
PEDIATRIC REHABILITATION GLOSSARY


Helpful Websites

www.disabilityinfo.gov: DisabilityInfo.gov is a comprehensive online resource designed to provide people with disabilities with quick and easy access to the information they need on numerous subjects, including benefits, civil rights, community life, education, employment, housing, health, technology and transportation.

www.medicalhomeinfo.org: This web site provides information related to all of the activities of the National Center, including the "Every Child Deserves a Medical Home" Training Program, Screening Initiatives and a variety of resources developed by the AAP and/or other collaborating organizations

www.nichcy.org: NICHCY stands for the National Dissemination Center for Children with Disabilities. This is the national central source of information on: disabilities in infants, toddlers, children, and youth; IDEA, which is the law authorizing special education; No Child Left Behind; and research-based information on effective educational practices.