Developmental Disabilities
Web-Based Training for Foster/Adoptive Parents

Introduction to Developmental Disabilities

sponsored by the
New York State Office of Children and Family Services
Bureau of Training

through a training and administrative services agreement with the
Research Foundation of SUNY Buffalo State College
Center for Development of Human Services
New York State Child Welfare Training Institute
Foster/Adoptive Parent Training Project
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In 2005, this updated version was adapted from the original curriculum, to meet the evolving needs of online learners.

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Definitions of Developmental Disability
Federal Definition of Developmental Disability

The federal definition of developmental disability is found in the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (Public Law 95-302).

Definition

To be considered developmentally disabled, individuals must meet all five (5) components of the following definition of developmental disability:

“A developmental disability is considered to be a severe chronic disability of a person…

1. which is attributable to a mental or physical impairment or a combination of both;
2. which is manifested before the age of 22;
3. which is likely to continue indefinitely;
4. which reflects a person’s need for individually planned and coordinated special care, treatment, or other support services for an extended duration or on a life-long basis;
5. which results in substantial functional limitations in three (3) or more areas of major life activities:
   • self-care;
   • receptive and expressive language;
   • mobility;
   • learning;
   • self-direction;
   • capacity for independent living;
   • economic self-sufficiency.
Social Security—Supplemental Security Income (SSI)

The Definition of Disability for Children


- requires a child to have a physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations;

- requires that the medically proven physical or mental condition or conditions must last or be expected to last at least 12 months or be expected to result in death;

- provides that a child may not be considered disabled if he/she is working at a job that SSI considers to be substantial work. (However, the law did not change the rules which allow certain children already on the rolls to continue to receive SSI even though they are working.)

The law requires a continuing disability review (CDR) to determine whether or not the child is still disabled. The CDR must be done:

- at least every three years for recipients under the age of 18 whose conditions are likely to improve; and

- not later than twelve months after birth for babies whose disability is based on their low birth weight.

SSI may do CDRs for recipients under age 18 whose conditions are not likely to improve.

Any person who was eligible as a child in the month before he/she attained age 18 must have an eligibility redetermination during the one-year period beginning on the person’s 18th birthday, under the rules for adults filing new claims.

Social Security, 24-hour number: 1-800-772-1213; TTY 1-800-325-0778, 7 a.m. - 7 p.m. business days.

Source: http://www.ssa.gov
Individuals with Disabilities Education Act (IDEA)

There are thirteen broad categories of child disabilities that by federal mandates require special educational assistance and other related services. The categories include:

1. **AUTISM.** Autism “means a developmental disability significantly affecting verbal and nonverbal communication and social interactions, generally evident before age 3, that adversely affects the child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental changes or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s educational performance is adversely affected primarily because the child has a serious emotional disturbance...” 34. C.F.R. Section 330.7(b)(1).

2. **DEAF-BLINDNESS.** Deaf-blindness “means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that they cannot be accommodated in special education program solely for children with deafness or children with blindness”. 34. C.F.R. Section 300.7(b) (2).

3. **DEAFNESS AND HEARING IMPAIRMENT.** Deafness “means a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, that adversely affects a child’s educational performance”. Hearing impairment “means an impairment in hearing whether permanent or fluctuating, that adversely affects a child’s educational performance but that is not included under the definition of deafness in this section”. 34 C.F.R. Section 300.7(b)(3) and (4).

4. **MENTAL RETARDATION.** (Developmental Handicap.) Mental retardation “means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child’s educational performance”. 34 C.F.R. Section 300.7(b)(5).
**Individuals with Disabilities Education Act (IDEA) (continued)**

5. **MULTIPLE DISABILITIES.** Multiple disabilities “means concomitant impairment (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.) the combination of which causes severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments. This term does not include deaf-blindness.” 34 C.F.R. Section 300.7(b)(6).

6. **ORTHOPEDIC IMPAIRMENT.** Orthopedic impairment “means a severe orthopedic impairment that adversely affects a child’s educational performance. The term includes impairments caused by congenital anomaly (e.g. clubfoot, spina bifida, absence of some member, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g. cerebral palsy, amputations, and fractures or burns that cause contractures).” 34 C.F.R. Section 300.7(b)(7).

7. **OTHER HEALTH IMPAIRMENT.** Other health impairment “means having limited strength, vitality, or alertness, due to chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes that adversely affects a child’s educational performance.” 34 C.F.R. Section 300.7(b) (8).

8. **SERIOUS EMOTIONAL DISTURBANCE.** Serious emotional disturbance is defined as follows:

1. The term means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s education performance.
   
   A. An inability to learn that cannot be explained by intellectual, sensory, or health factors;
   
   B. An inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
   
   C. Inappropriate types of behavior or feelings under normal circumstance;
   
   D. A general pervasive mood of unhappiness or depression; or
   
   E. A tendency to develop physical symptoms or fears associated with personal or school problems.
Individuals with Disabilities Education Act (IDEA) (continued)

2. The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have “serious emotional disturbance.” 34 C.F.R. Section 300.7(b)(9).

9. **SPECIFIC LEARNING DISABILITY.** Specific learning disability “means a disorder in one or more of the basic psychological processes involving understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia. The term does not apply to children who have learning problems that are primarily the result of visual, hearing, or motor disabilities, or mental retardation, or emotional disturbance, or of environment, cultural or economic disadvantage.” 34 C.F.R. Section 300.7(b)(10).

10. **SPEECH OR LANGUAGE IMPAIRMENT.** Speech or language impairment “means a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child’s educational performance.” 34 C.F.R. Section 300.7(b)(11).

11. **TRAUMATIC BRAIN INJURY.** Traumatic brain injury “means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child’s educational performance. The term applies to open or closed head injuries resulting in impairment in one or more areas, such as cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem solving, sensory, perceptual, and motor abilities, psychosocial behavior, physical functions, information processing, and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.” 34 C.F.R. Section 300.79(b) (12).
12. VISUAL IMPAIRMENT INCLUDING BLINDNESS. Visual impairment including blindness “means an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness.” 34 C.F.R. 300.7(b)(13).

13. CHILD WITH DISABILITIES. The term child with disabilities are children aged 3 to 5, and “include children:

1. who are experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and

2. who, for that reason, need special education and related services.” 34 C.F.R. Section 300.7(1)(2).
**State Education Department (SED)**

**Definitions of Educationally Handicapping Conditions**

**Autistic:** A child who manifests a behaviorally defined syndrome which occurs in children of all levels of intelligence. The essential features are typically manifested prior to 30 months of age and include severe disturbances of developmental rates and/or sequences of responses to sensory stimuli, of speech, of language, of cognitive capacities, and of the ability to relate to people, events, and objects.

**Emotionally disturbed:** A child with an inability to learn which cannot be explained by intellectual, sensory, or health factors and who exhibits one or more of the following characteristics over a period of time and to a marked degree:

- an inability to build or maintain satisfactory interpersonal relationships with peers, teachers, and significant others;
- inappropriate types of behavior or feelings under normal circumstances;
- a generally pervasive mood of unhappiness or depression; or
- a tendency to develop physical symptoms or fears associated with personal or school problems.
- The term does not include socially maladjusted children unless it is determined that they are emotionally disturbed.

**Learning disabled:** A child with a disorder in one or more of the basic psychological processes involved in understanding or in using language, which manifests itself in an imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations. The term includes such conditions as brain injury, neurological impairment, minimal brain dysfunction, dyslexia, and developmental aphasia. It does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

**Mentally retarded:** A child who, concurrent with deficits in adaptive behavior, consistently demonstrates general intellectual functioning that is determined to be 1.5 standard deviations or more below the mean of the general population, on the basis of a comprehensive developmental evaluation which includes psychological, physical, and social evaluations.

**Source:** The State Education Department. Part 200, Children with Handicapping Conditions. 1987—Sections 207 and 4403 of the Education Law
State Education Department (SED) Definitions of Educationally Handicapping Conditions (continued)

**Deaf:** A child with a hearing impairment which is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects educational performance.

**Hard of hearing:** A child with a hearing impairment, whether permanent or fluctuating, which adversely affects the child’s educational performance but which is not included under the definition of deaf in this section.

**Speech impaired:** A child with a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice or oro-motor impairment, which adversely affects a child’s educational performance.

**Visually impaired:** A child with a visual handicap which, even with correction, adversely affects a child’s educational performance. The term includes both partially seeing and blind children.

**Orthopedically impaired:** A child who is physically handicapped and who has a severe orthopedic impairment which adversely affects his or her educational performance. The term includes impairments caused by congenital anomaly (e.g., club foot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputation, fractures or burns that cause contractures).

**Other health impaired:** A child who is physically handicapped and who has limited strength, vitality, or alertness due to chronic or acute health problems, including but not limited to a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, diabetes, or Tourette Syndrome, which adversely affects a child's educational performance.

**Multiply handicapped:** A child with two or more handicapping conditions that result in multisensory or motor deficiencies and developmental lags in the cognitive, affective, or psychomotor areas, the combination of which cause educational problems that cannot be accommodated in a special education program solely for one of the impairments.
Early Intervention Regulations

New York State Public Health Law §§2500-a,2500-e. Article 25 Title II-A. Subpart 69-4, Early Intervention Program, Sec 69-4.1, Definitions.

Developmental delay means that a child has not attained developmental milestones expected for the child’s chronological age, as measured by qualified professionals using appropriate diagnostic instruments and/or procedures and informed clinical opinion, in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional, or adaptive development.

1. A developmental delay for purposes of the Early Intervention Program, is a developmental delay that has been documented as:
   - twelve-month delay in one functional area, or
   - a 33% delay in one functional area or a 25% delay in each of two areas, or
   - if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or a score of at least 1.5 standard deviation below the mean in each of two functional areas, or
   - if because of a child’s age, condition, or the type of diagnostic instruments available in specific domains, a standardized score is either inappropriate or cannot be determined, a child may be deemed eligible by the informed clinical opinion of the multidisciplinary team.

2. Criteria such as functional status, recent rate of change, and estimated rate of change in the near future based on anticipated medical/health factors and other factors relevant to the needs of that child and family shall be considered.
OMRDD Definition of Developmental Disability

In order to be eligible for Office of Mental Retardation and Developmental Disabilities (OMRDD) services according to Chapter 978S1.0# (22). A person must have a disability which:

1. is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, or autism;

2. is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons;

3. is attributed to dyslexia resulting from a disability described in #1 or #2;

4. originated before the person attains age 22;

5. has continued or can be expected to continue indefinitely;

6. constitutes a substantial handicap to such person’s ability to function normally in society.

Neurological impairments include such specific conditions as neurologically based severe learning disabilities, spina bifida, Tourette syndrome, neurofibromatosis, narcolepsy, traumatic brain injury (originating before age 22), Prader-Willi syndrome, and sensory impairments (that are caused by central nervous system disorders).
### Comparison of Definitions: Similarities and Difference in Criteria

<table>
<thead>
<tr>
<th>Developmental Delay</th>
<th>Child Disability</th>
<th>Developmental Disability</th>
<th>SSI</th>
<th>Medically Fragile</th>
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<tbody>
<tr>
<td><strong>Education/Early Intervention:</strong></td>
<td>Individuals with Disabilities Education Act (IDEA) PL 102-119 [Federal]:</td>
<td>Federal:</td>
<td>Federal:</td>
<td>Children at risk for abnormal growth and development and other serious problems. Including life-threatening illness. A condition documented by a physician, which can become unstable and change abruptly, resulting in a life-threatening situation. The child could eventually be diagnosed as developmentally disabled.</td>
</tr>
<tr>
<td>Child has not attained developmental milestones expected for the child’s chronological age, as measured by qualified professionals in one of the following areas: Cognitive, Physical, Communication, Social/Emotional, and Adoptive Development. Standardized score utilizing diagnostic tools or clinical opinion of a multidisciplinary team.</td>
<td>Autism, Deafblindness, Deafness, Hearing Impairment, Mental Retardation, Multiple Disabilities, Orthopedic Impairments, Other Health Impairments, Serious Emotional Disturbance, Specific Learning Disability, Speech or Language Impairment, Traumatic Brain Injury, Visual Impairment including Blindness.</td>
<td>Severe, chronic; disability that is attributable to a mental or physical impairment or both, occurs before 22 years of age, is likely to be on going, reflects the need for specialized care/treatment/service, results in substantial functional limitations.</td>
<td>Children who have a physical or mental condition/conditions that are medically proven and which result in a marked and severe functional limitation. Condition(s) must last or be expected to last at least 12 months or to result in death.</td>
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<tr>
<td>Child may be able to “catch up” to other children.</td>
<td>Child needs special education and related services.</td>
<td>Child needs specialized care/treatment/service. Child cannot “catch up” to other children.</td>
<td>Continuing Disability Review: For children under 18 years of age whose conditions are likely to improve, every 3 years. For babies whose disability is based on low birth weight, no later than 12 months after birth.</td>
<td>Child needs medical and supportive treatment, continuous monitoring; does not necessarily require medical services daily to ensure safety. Can possibly grow and thrive in a supportive loving environment.</td>
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For Further Information, Contact: [DD Web-Based Training for Foster/Adoptive Parents](#)
Developmental Disabilities Categories According to New York State
Developmental Disabilities

Autism

Cerebral Palsy

Epilepsy
- Generalized Tonic-Clonic Seizures
- Absence Seizures
- Myoclonic Seizures
- Simple Febrile Convulsions
- Complex and Partial Seizures

Mental Retardation
- Down Syndrome
- Fragile X Syndrome

Neurological Impairments
- ADD/ADHD
- Speech and Language Disorders (Aphasia, Echolalia...)
- Learning Disabilities (Dyslexia...)
- Other (Tourette’s Syndrome, Prader-Willi Syndrome, Neurofibromatosis, Spina Bifida)
Mental Retardation

According to New York State mental Hygiene Law, mental retardation:

1. is indicated by subaverage intellectual functioning (e.g., IQ score of under 70);
2. originated during the development period (e.g., occurs before age of 22);
3. is attributed associated with impairment in adaptive behavior (e.g., delays across all areas of development, including motor, cognitive, language and social skills; deficits in personal independence and social responsibility).

About 0.5% of the preschool population is identified as mentally retarded. About 10% of the school-age (6-18 years) population is identified as mentally retarded.

Types of Mental Retardation

1. Mild  (IQ range 50-69)
2. Moderate  (IQ range 35-49)
3. Severe  (IQ range 20-34)
4. Profound  (IQ range below 20)

(IQ range 70-84 is “Borderline” and no longer considered mental retardation.)

Some Casual Conditions Associated with Mental Retardation

1. Familial retardation
2. Maternal use of drugs, e.g., certain medications, chemicals, alcohol during pregnancy
3. Lead
4. Child abuse/head trauma
5. Environmental or psychosocial deprivation
6. Parental psychiatric disorders
7. RH factor
Mental Retardation (continued)

Child Abuse and Mental Retardation

Individuals who are retarded are ten times more likely to be abused than are members of the general population.

The American Association of Mental Retardation advocates the following four assumptions:

1. Valid assessment considers cultural and linguistic diversity, and differences in communication and behavioral factors.

2. The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual’s peers and is indexed to the person’s individual needs for supports.

3. Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities.

4. With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve.

This presents a view which focuses on supports, abilities, natural environments and empowerment, rather than on the level of disability. Classification is based on the level of supports needed, rather than an IQ-derived level of retardation. In short, it emphasizes the person, rather than the label.
Down Syndrome

Down Syndrome is one of the most common genetic birth defects associated with mental retardation.

Causes

The causes are unknown. However, a chromosomal abnormality in children with Down Syndrome affects cell development, resulting in 47 instead of 46 chromosomes; the extra chromosome affects the fetus’ normal body and brain development.

Occurrence

- The risk or producing a child with Down Syndrome increases with the age of the mother. For women under age 25, the odds are about 1 in 1400; at age 40 the odds are about 1 in 100. However, the majority of infants with Down Syndrome are born to younger women, since the overall birthrate among them is higher.

- Women with Down Syndrome have a 50% chance of having a child with Down Syndrome.

- There is one documented case of a Down Syndrome birth to Down Syndrome parents, although this is rare; thus, it is unclear which parent contributed the defective gene.

Diagnosis

- Amniocentesis (done between 14 and 18 weeks of pregnancy)

- Chronionic villus sampling (CVS) done between 9 and 12 weeks of pregnancy

- Chromosome test after birth
Characteristics of Down Syndrome

1. Physical and intellectual development is slower
2. IQ range, behavior, and developmental progress vary widely
3. Physical characteristics include:
   - Poor muscle tone as infants
   - Slanting eyes with folds of skin at the inner corners
   - Short, broad hands with a single crease across the palm on one or both hands
   - Broad feet with short toes
   - Flat nose bridge
   - Short, low ears
   - Short neck
   - Small head
   - Small oral cavity and/or short, high-pitched cries in infancy
4. Other health-related problems include:
   - Lowered resistance to infection
   - Visual problems
   - Mild-to-moderate hearing loss
   - Speech difficulties
   - Heart defects, now correctable, in about one-third of this population

Down Syndrome has no cure, nor can it be outgrown. With early childhood intervention, good parental support, access to medical care, education, and vocational programs, children with Down Syndrome can become productive and at times somewhat independent.

Sources:


Fragile X Syndrome

Fragile X Syndrome is an inherited defect of the “X” chromosome. Most researchers suspect that it is the most common inherited cause of mental retardation. While Down Syndrome usually occurs by chance, Fragile X Syndrome is passed down from generation to generation. Females are the carriers of the defective gene and can pass it to some of their sons (who would be affected) and their daughters (who in turn become carriers).

Characteristics of Fragile X Syndrome

1. Neurological impairment
2. Mild to moderate retardation (IQ scores between 50-75) in about 75% of affected individuals
3. IQ scores of less than 50 in about 25%
4. Males more often and more severely affected than females
5. Features: generally tall and strong; large and floppy ears; broad nose with prominent ridges above the eyes; long narrow face; loose joints; large testicles; repeats words or phrases
6. Prone to epileptic seizure

Chromosomal analysis and DNA studies show the presence of the Fragile X chromosome in individuals, but the condition is often misdiagnosed. There is no cure and no specific treatment.

Sources:
Pervasive Developmental Disorders (PDD)

Pervasive developmental disorders are characterized by impairment in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activities. Frequently, children may engage in only a few activities that are stereotypic and repetitive. Many basic areas of psychological development are affected at the same time and to a severe degree. Autism is the most severe form. Occurrence has been estimated at 10 to 15 children in every 10,000; PDD is more common among males than females. Onset is typically prior to age 3; in almost all cases PDD is a lifelong severe handicap.

Common Characteristics of PDD

1. Impairment in Reciprocal Social Interactions:
   - failure to cuddle
   - lack of eye contact and facial responsiveness
   - indifference or aversion to affection and physical contact
   - possible treatment of adults as interchangeable or possible clinging to a specific person

2. Impairment in Communication and Imaginative Activity:
   - possible total absence of speech
   - possible immature language characterized by echolalia, pronoun reversals (use of “you” when “I” is intended)
   - inability to name objects
   - idiosyncratic utterances whose meaning is clear only to those familiar with the child
   - abnormal speech melody
   - minimal or absent nonverbal communication (facial expression/gesture)
   - for older children, the inability to understand jokes, puns, sarcasm
Pervasive Developmental Disorders (PDD) (continued)

- absence of symbolic or fantasy play with toys/absence of play-acting adult roles
- lining of toys up in the same manner over and over again
- repetitive mimicking of television characters or jingles

3. Limited Repertoire of Activities and Interests:
- resistance to or tantrum over minor changes in the environment
- attachment to unusual objects
- stereotypic motor behaviors including rocking, swinging, handclapping, etc.
- fascination with watching movement (e.g., an electric fan)
- skill at making all kinds of objects spin

4. Types of Pervasive Developmental Disorders:
- Autism (OMRDD-Developmental Disability)
- Early Childhood Disintegration Disorder
- Rett’s Disorder
- Asperger’s Disorder
- Pervasive Developmental Disorder. Not otherwise specified
Pervasive Developmental Disorders (PDD) (continued)

Autism

Autism is the only Pervasive Developmental Disorder classified as a developmental disability according to New York State. Autism is a rare condition characterized by severe disorders of communication and behavior which interfere with the individual’s ability to learn, communicate, and respond to what is going on in the surrounding environment.

This disorder, also called infantile autism, is typically noted in the first few months of life and is always present by the time the child who has this disorder reaches the age of three.

The cause of autism is unknown and occurs in about one person in two thousand.

Current research is focusing on possibilities of brain damage and biochemical imbalances in the brain.

Characteristics of Autism

1. Absence or delay of speech or other communication skills
2. Lack of responsiveness to other people
3. Self-injurious behavior
4. Ritualistic or repetitive behaviors
5. Mental retardation frequently present
6. Acting-out behaviors
7. A need for sameness and a resistance to change
8. Seizures are not uncommon, especially during adolescence
Pervasive Developmental Disorders (PDD)  
(continued)

FAQ about Autism

- Autism is a multispectrum disorder. It interferes with the ability to navigate the environment.

- Some autistic children are not diagnosed until school age; and some may have spurts and plateaus in development, but the rates of physical, cognitive, social, and emotional growth may be very inconsistent.

- Those whose language develops before age 5, even if very concrete (not figurative), are able to develop minimal social skills. With some supervision they can live independently and hold jobs. However, they will be unable to form intimate relationships.

- If language does not emerge by age 5, it is possible that it may not occur, and the prognosis for these children is believed to be very poor. However, this concept is being challenged. Parents need to be encouraged to keep learning about current research findings and advances.

- A small number have normal motor development and use language enough to allow them to attend school and get vocational skills, but they may be socially immature and rather introverted.

- Approximately 2/3 have mental retardation, or are mentally ill (psychotic) as adults.

- Autism cannot be cured, and there is no medication or drug treatment. Behavior modification can, to some degree, help some children develop language and basic adaptive skills.

- Parents also need to be reminded that IQ scores are not necessarily static; they are a picture of a moment in time in the life of a child – especially for those who may test quite low because of their communication problems and whose IQ scores may dramatically change as their communication improves.
Pervasive Developmental Disorders (PDD)
(continued)

- For reasons unknown, there has been noticeable increase in the number of children diagnosed with autistic-like features (source: DSM IV).

- Home therapy twice a week for autism is not enough, but that is all that is currently allowed. Children need daily intervention at home and out of the home to maintain gains. Parents need special training on how to maintain learning achieved at the treatment center.

- Because OMRDD does not provide services to children 0-3, it is imperative that children suspected of having autism be diagnosed as soon as possible.

- For autism to be classified as a DD, it has to meet the requirements stated in the DD federal definition (that is, fall under any of the five categories, and the condition has to be “severe” and chronic”).

- The undiagnosed autistic child may be diagnosed as MR and could qualify for services under the MR category.

- The child may also have an learning disability (LD) and qualify under neurological impairment (NI). They would receive services, but the focus and approaches would be different.

- Families need lots of help and support such as respite, and for some children, eventually require placement in group homes.

In addition to autism, there are several other types of PDD, all of which are less frequently found in the general population.

Early Childhood Disintegration Disorder

- Marked regression occurs in multiple areas of functioning following a period of at least two years of apparently normal development, but before the age of 10.

- Areas of skill loss include: expressive or receptive language, social skills, adaptive behavior, bowel or bladder control, play, and motor skills.

- Onset may be slow or abrupt, usually occurring between 3 and 4 years of age.

- Social, communicative, and behavioral features are those generally found in autism.
Pervasive Developmental Disorders (PDD) (continued)

Rett’s Disorder

- Multiple specific deficits occur following a period of normal functioning at birth.
- Deficits include: head growth deceleration between 5 and 48 months, loss of hand skills between 5 and 30 months, decrease of social interest, problems of trunk movement development, severe language impairment. Child may develop severe or profound mental retardation and seizures.
- Onset occurs prior to age 4, usually between ages 1 and 2, to females only.
- Deterioration continues through adolescence and can be fatal.

Asperger’s

- There is severe and sustained impairment in social interaction, with repetitive patterns in behavior, interest, and activities.
- Some motor clumsiness manifests.
- No delays in language or cognitive development are caused, including self-help skills, adaptive skills, or curiosity of environment.
- Onset occurs later than autism, and condition is more common in boys. It may be recognized particularly in school settings.
- Adults may have significant problems exhibiting empathy.

Pervasive Developmental Disorder: Not Otherwise Specified

Source: DSM IV
Cerebral Palsy

Cerebral palsy is a condition characterized by problems in movement, balance, and posture due to damage to the brain. The type and severity of cerebral palsy will depend on the location and extent of brain damage. The damage can occur before birth, during birth, and after birth.

Characteristics of Children with Cerebral Palsy

1. All will have difficulty controlling body movement.

2. Lack of balance, tremors, stiffness, jerky involuntary movements, poor control of facial muscles, difficulty sitting, standing, grasping, walking, etc.

3. Accompanying or associated problems:
   - speech and language difficulties
   - mental retardation (50%)
   - visual impairments (eye muscle imbalance problems)
   - hearing impairment
   - emotional and social adjustment issues
   - seizures
Cerebral Palsy (continued)

Causes of Cerebral Palsy
Environmental causes of cerebral palsy may be: (1) accidental head injury (e.g., injury resulting from a car accident) and (2) child abuse.

Recent studies document that for as many as 25% of abused children with cerebral palsy, the abuse caused the condition.

Sexual abuse and Cerebral Palsy
Among children with disabilities, children with cerebral palsy are at highest risk for sexual abuse. In approximately 99% of the reported cases of sexual abuse of children with cerebral palsy, the abuser is well known to the child.

Implications for Parents Who Have Cerebral Palsy
Depending on the severity of cerebral palsy, parents with cerebral palsy may have their parenting skills affected by the following:

1. difficulty controlling body movement may interfere with physical care of infants and young children (i.e., inability to lift, move about independently, feed infant, purchase food, etc.);

2. mental retardation may interfere with parenting due to the individual’s slow thinking ability, inability to attend to two events simultaneously, inability to understand abstract directions, inability to understand other than simple cause and effect relationships, mental flexibility, and poor judgment about feeding, play, sleeping, safety, and medical issues;

3. vision and hearing difficulties which if unrecognized may interfere with responsiveness to child’s cues and needs;

4. speech and language difficulties may impede communication with child and may interfere with meeting the child’s medical, educational and social needs.

Remember that parents with cerebral palsy may have normal intellectual ability and their physical difficulties may not interfere with their ability to physically care for their child. For some parents with cerebral palsy, their inability to physically care for their child may be the only and primary area of difficulty.
What is Epilepsy?

Epilepsy is a neurological condition that occasionally produces brief disturbances in the normal electrical functions of the brain. With epilepsy, the tendency of the brain is to produce sudden bursts of electrical energy that disrupt other brain functions.

When normal brain function occurs, millions of tiny electrical charges pass between nerve cells in the brain and to all parts of the body. However, when someone has epilepsy, the normal pattern may be interrupted by intermittent bursts of electrical energy that are much more intense than usual. These bursts of energy, also called epileptic seizures, may briefly affect consciousness, body movements, and/or sensations, and normal brain function cannot return until the electrical bursts subside. When seizures continue to occur for some unknown reason (or because of an underlying problem that cannot be corrected) the condition is known as epilepsy.

Epilepsy was long thought to be a progressive, lifelong disorder with high mortality and a generally poor prognosis. However, approximately 70% of all children with epilepsy will eventually become seizure free either with or without medications. Remission rates depend on a series of factors such as the presence of other neurological disabilities (cerebral palsy, autism, or mental retardation associated with an IQ under 50), symptom onset before adolescence, and the specific epileptic syndrome involved. Other milder neurological disabilities (attention deficit disorder or learning disabilities such as dyslexia) do not alter the prognosis for remission.

For some people, seizures may become less severe, infrequent, or even disappear altogether. However, recent research suggests they may still experience the devastating effects associated with epilepsy and impact their psychosocial, academic, and behavioral adjustment.

What is a Seizure?

Epilepsy is an underlying condition (or the result of a permanent brain injury) that affects the systems governing how electrical energy behaves in the brain, and making the brain susceptible to recurring seizures. Seizures are a symptom of epilepsy, and they are characterized by changes in sensation, awareness, and/or behavior brought about by brief electrical disturbances in the brain. Seizures may include convulsions, short periods of unconsciousness, distortion of the senses, and/or loss of control over movements, depending on which part of the body is affected by the electrical disturbance.
Epilepsy (continued)

Experiencing a single seizure does not mean that a person has epilepsy. Epilepsy is a condition involving recurring seizures, sometimes over a lifetime. High fever, severe head injury, lack of oxygen, and/or reaction to anesthesia or strong drugs may all affect the brain and cause a single seizure episode.

Causes of Epilepsy

Both prenatal and/or postnatal factors and/or injuries may affect the very susceptible developing brain and thereby cause epilepsy in a child:

Prenatal Factors
- abnormality in the genes that control development
- maternal infections during pregnancy
- drug and/or alcohol use during pregnancy
- poor maternal nutrition during pregnancy
- environmental contaminants (toxic substances such as lead, etc.)
- anoxia (oxygen deficiency) during the birthing process

Postnatal Factors
- brain infections (meningitis, encephalitis)
- brain tumors
- brain injuries (including those from child abuse)
- stroke
- metabolic imbalances
- anoxia (oxygen deficiency)
- environmental contaminants (toxic substances such as lead, etc.)
- any disturbances of the normal pattern of neuron activity

Note: Some prenatal and postnatal conditions may also produce cerebral palsy, which often is associated with epilepsy, or they may cause epilepsy that is unrelated to any other disorders. About 20 percent of seizures in children are due to cerebral palsy.
Epilepsy  (continued)

Types of Seizures
The Epilepsy Foundation of America has identified more than 30 different seizure disorders. It is possible for an individual to experience just one type of seizure or more than one, depending on which part of and how much of the brain is affected by the electrical disturbance that produces seizures. The most common types of seizures are described below.

First Seizure
When someone has experienced a seizure for the first time, the attending physician will usually order an electroencephalogram test (EEG) to identify the type of seizure that occurred and to determine if there are any detectable abnormalities visible in the brain. Test results help determine whether or not anti-epileptic drugs should be prescribed. In some cases, administration of medication after the first seizure may help prevent future seizures and epilepsy. However, since medications may also cause detrimental side effects, they are usually prescribed only when it has been determined that the benefits outweigh the risk involved. Evidence suggests that it may be beneficial to begin anticonvulsant medication after a second seizure, as the chance of future seizures increases significantly when a second seizure occurs.

Febrile Seizure
Sometimes a child will have a seizure during the course of an illness with a high fever. Such seizures are called febrile seizures (derived from febrile, the Latin word for “fever”). While this type of seizures can be very alarming to parents and other caregivers, most children who have a febrile seizure do not develop epilepsy. Researchers have now identified several different genes that influence the risk of febrile seizures in certain families.

Generalized Seizure
Such seizures are characterized by massive bursts of electrical energy sweeping through the whole brain at once, causing loss of consciousness, falls, convulsions (also called tonic-clonic seizures), and/or massive muscle spasms. There are three types of generalized seizures:
Epilepsy (continued)

**Tonic-Clonic Seizure**  Formerly known as Grand Mal seizures, these are the most frequently observed type and may develop at any time between infancy and adulthood. Such seizures are associated with the following symptoms:

- loss of consciousness
- temporary loss of bladder control
- stiffening of the body
- repeated jerks of the arms and/or legs
- confusion and/or fatigue follow by return to full consciousness

**Absence Seizure**  Previously known as Petit Mal seizures, this type may occur only once or twice a day or up to a hundred times. Generally lasting less than thirty seconds, they may go undetected by the individual and/or other nearby persons. They usually have no lasting effect on intelligence or other brain functions, although they may affect learning if untreated. They are associated with the following symptoms:

- twitching of eyelids
- brief staring spells
- jerking or twitching muscles

**Myoclonic Seizure**  When onset occurs before age two, this type of seizure may cause developmental delays for which the prognosis is generally poor. Associated symptoms may take one or more of the following forms:

- minor motor seizures such as twitches of upper body, arms or legs
- jerks of upper body, arms or legs

**Partial Seizure**

Partial seizures occur when the electrical disturbance occurs in just one part of the brain, affecting only whatever physical or mental activity controlled by that particular area. Such partial seizures are the most common form of seizure in adults, affecting six out of every ten people with epilepsy. Among children diagnosed with epilepsy, four out of ten experience partial seizures.
Epilepsy (continued)

Partial seizures are frequently described by reference to the area of the brain in which they originate. For example, someone might be diagnosed with “partial frontal lobe seizures.” Sometimes the seizure activity starts in one area of the brain and then spreads, eventually affecting the whole brain. When that happens, it is described as a “partial seizure secondarily generalized.”

Some people with partial seizures, especially complex partial seizures, may experience unusual sensations that warn of an impending seizure known as “auras.” These “auras” are actually just simple partial seizures in which the person maintains consciousness.

Partial seizures may be called “simple partial seizures” or “complex partial seizures.” The main difference between the two types is dependent on whether the person affected remains fully aware or experiences a change in consciousness during the episode.

Simple Partial Seizure  Consciousness remains, but there may be unusual feelings or sensations that can take many forms. The feelings are characterized by sudden and unexplainable feelings of joy, anger, sadness, fear, and/or nausea; or else the person may smell, taste, see, hear or feel things that are not real (“aura” reactions).

Complex Partial Seizure  Of quick duration, and generally affecting just one part of the brain (often in the temporal lobe), such seizures generally occur in late childhood and early adult life. They may be associated with the following symptoms:

- sensing a foul odor or taste (an “aura” reaction)
- loss of consciousness or altered states of consciousness involving dreamlike experiences
- arrest of activities (stopping, staring, remaining frozen, remembering poorly)
- hyperventilation
- strange, repetitive behaviors (blinks, twitches, mouth movements, walking in a circle)
Epilepsy (continued)

- gesture making, flinging objects, striking out at walls/furniture as if angry or afraid, etc.
- inappropriate and often misdiagnosed movements/behaviors (psychotic episodes, rudeness, absent-mindedness, etc.) sometimes resulting in arrest, being fired, or other negative consequence

Note: The symptoms of partial seizures can easily be confused with other disorders such as migraine headaches (which also can cause a dreamlike state), symptoms of narcolepsy, fainting, or even mental illness. It may take many tests and careful monitoring to tell the difference between epilepsy and other disorders.

Types of Epilepsy

Just as there are many different kinds of seizures, there are many different kinds of epilepsy. Doctors have identified hundreds of different epilepsy syndromes disorders characterized by a specific set of symptoms that include epilepsy. Epilepsy syndromes are frequently described by their symptoms or by where in the brain they originate and include these categories:

**Absence Epilepsy**  Repeated absence seizures that cause momentary lapses of consciousness usually begin in childhood or adolescence and may be genetic in nature. Some people with absence seizures have purposeless movements during their seizures, such as a jerking arm or rapidly blinking eyes. Others have no noticeable symptoms except for brief times when they are “out of it.” Immediately after a seizure, the person can resume whatever he or she was doing. However, these seizures may occur so frequently that the person cannot concentrate in school or other situations. Childhood absence epilepsy usually stops when the child reaches puberty.

**Psychomotor Epilepsy**  This type is characterized by recurrent partial seizures, especially seizures of the temporal lobe. (The term “psychomotor” refers to the strange sensations, emotions, and behavior frequently associated with these seizures.)

**Temporal Lobe Epilepsy**  The most common epilepsy syndrome with partial seizures, this type often begins in childhood. Repeated temporal lobe seizures can cause the hippocampus, the part of the brain associated with short memory, to shrink over time, thereby affecting memory and learning.
Epilepsy (continued)

Diagnosis of Epilepsy

Accurate diagnosis of the type of epilepsy is crucial for finding an effective treatment. The diagnosis process includes the following:

1. Obtaining a complete medical history, including the following information:
   - neurological development prior to seizure onset
   - seizure type
   - age of onset
   - family history of seizures

2. Administering an electroencephalograph (EEG) test in order to determine whether brain waves show any special patterns during or between seizures.

3. Utilizing imaging methods such as computerized axial tomography (CAT) or magnetic resonance imaging (MRI) to search for any growths, scars, or other physical conditions in the brain.

4. Monitoring brain activity through a magneto encephalogram (MEG) test and observing brain activity at different points in the brain over time in order to reveal different brain functions.

Ambiguous test results may make accurate diagnosis difficult. Therefore, careful medical monitoring of the child is fundamental, including descriptions of subsequent seizures. The use of home videos can augment those descriptions.

Significant Facts about Epilepsy

- Epilepsy affects people of all ages, nations, and races.
- All people inherit varying degrees of susceptibility to seizures.
- Brain injuries caused by child abuse (shaken baby syndrome, severe blows to the head, etc.) or neglect (withholding of or irregular intake of prescribed medication) may cause epileptic seizures or aggravate an existing condition.
- Epilepsy is not contagious and is not caused by mental illness or mental retardation.
Epilepsy (continued)

- About 1 in 100 people in the USA have experienced an unprovoked seizure or have epilepsy (more than 2 million).
- For 7 out of 10 people with epilepsy, no cause can be found.

Treatment Options

There are many different ways to treat epilepsy, including administration of medications, surgery, and/or following a special diet known as the Ketogenic Diet. Medication therapy is by the most common alternative, and it is usually the first recourse. However, constant medication therapy may adversely affect learning and behavior, so careful medical monitoring is crucial to prevent possible brain damage from certain medications. Once epilepsy is diagnosed, it is important to begin treatment as soon as possible. Research suggests that medication and other treatments may be less successful in treating epilepsy once seizures and their consequences become established.

Some seizures disorders of infancy and early childhood are still highly resistant to current therapies, and an estimated 20% of those children who have epilepsy do not achieve complete seizure control. On the other hand, approximately 70% of all children with epilepsy will eventually enter remission and remain seizure free either with or without medication therapy. Important factors affecting the likelihood of a child’s achieving remission include the existence other neurological conditions. Mental retardation associated with an IQ of less than 50, cerebral palsy, and/or autism all diminish the possibilities of achieving remission. However, other milder neurological disabilities (such as attention deficit disorder or learning disabilities such as dyslexia) do not alter the prognosis for remission. Additional factors include the specific epileptic syndrome involved and the age of seizure onset, with those beginning before adolescence having the least favorable prognosis.

Challenges and Obstacles

For many people, having epilepsy is less of a problem than overcoming widespread negative attitudes about their condition and the intellectual and physical challenges associated with it. Lack of understanding about the many different types of seizures is one of the biggest problems encountered by people with epilepsy. Onlookers who witness a non-convulsive seizure find it difficult to understand certain behaviors, which otherwise may look deliberate. In some cases, this has led to the affected person being fired or losing their employment, being arrested, being sued, or even being placed in a mental institution. (Some 20 to 30% of people with epilepsy who are physically able to work are unemployed.)
**Epilepsy (continued)**

**Resource List**

Epilepsy Foundation of America  
[www.efa.org/answerplace/faq/htm](http://www.efa.org/answerplace/faq/htm)

National Institute of Neurological Disorders and Stroke  

O’Dell, Christine, (March 2,000) Contemporary Issues in Epilepsy: First Aid for Seizures *Exceptional Parent Magazine* pp. 86-89

Original Case Planning and Management for Children with Developmental Disabilities Curriculum. No source quoted.


Shinnar, Shlomo, MD, PhD (December 2,000) Contemporary Issues in Epilepsy: Prognosis for Epilepsy, *Exceptional Parent Magazine* pp. 88-95

For additional resources on Epilepsy, please consult the Services for Children with Developmental Disabilities: Resource Guide.
The Ketogenic Diet for the Treatment of Epilepsy

John Hopkins University Hospital has been using the Ketogenic diet to treat epilepsy for decades. Dr. John Freeman reports that about 70 percent of children, including those with very difficult to control seizure disorders, sometimes accompanied by mental retardation and other neurological injury, show considerable improvements.

Ketosis occurs when the body begins burning fat for energy instead of glucose.

The Ketogenic diet maintains a state of ketosis after an initial fasting period. It is not well understood why ketosis helps to control seizures. The diet is a high fat, low protein and carbohydrate diet. Foods and liquids are calculated based on the child’s weight, age and activity level. Computer programs that make meal planning easier have recently been developed and provide for more variety in a child’s diet.

Many parents report an immediate response to the diet with improved or full seizure control, increased cognition, better behavior and other skill improvements. There are also parents who reported less significant results, or that their child could not tolerate the diet or maintain ketosis.

The Ketogenic diet is not something that a parent should initiate at home. Initial hospitalization followed by close medical supervision is necessary. For more information about the Ketogenic diet for the treatment of epilepsy please talk with your child’s neurologist. If you need information about the Ketogenic diet or parent-to-parent support contact: PHP—The Family Resource Center, 3041 Olcott Street, Santa Clara, CA 95054, Phone (408) 727-5775, www.php.com

Prepared by T.M. Grable on behalf of PHP-The Family Resource Center, Santa Clara, CA. PHP does not endorse any treatment method. This is for your information only. © 1996, Permission to copy and distribute granted. (408) 727-5775 FAX: (408) 727-0182.
Neurological Impairments

Neurological impairments include a group of disorders of the central nervous system characterized by dysfunction in one or more skills affecting communication, perception, cognition, memory, attention, motor control, and appropriate social behaviors.

Types of Neurological Impairments

1. Attention Deficit Disorder with/without Hyperactivity
2. Speech and Language Disorders
3. Learning Disability
4. Other neurological impairments (Tourette’s Syndrome, Prader-Willi Syndrome, Neurofibromatosis, Spina Bifida)

Common Characteristics of Individuals with Neurological Impairments

1. Potential for average intelligence on IQ tests
2. Difficulty with transitions
3. Difficulty organizing and focusing
4. Motor clumsiness and awkwardness
5. Distractibility/short attention span
6. Impulsivity
7. Hyperactivity
8. Difficulty with learning language skills, especially in preschool children
9. Difficulty in learning to read, write, spell, and do math, in school-age children
Neurological Impairments (continued)

Some Causal Conditions Associated with Neurological Impairments

1. Familial predisposition (heredity)
2. Maternal use of drugs, chemicals, alcohol during pregnancy
3. Lead exposure/poisoning
4. Child abuse

Child Abuse and Neurological Impairments

Children who are neurologically impaired (learning disabled, speech impaired), are at highest risk for physical abuse by parents. High incidence of physical abuse occurs among children who are neurologically impaired because parents mistakenly interpret the unintentional behavior of their child (who often has an undiagnosed handicap) as being intentionally “bad” and “out to get them.”

Implications for Parents with Neurological Impairment

Neurological impairments take many forms. Learning disabilities compromise the largest group of neurologically impaired/developmentally disabled. Parents with learning disabilities may have their parenting affected by the following:

1. Unintentional psychological or physical abuse may occur because of cognitive inflexibility or difficulty seeing “gray” areas in the management of their children—they tend to have an all or nothing approach.
2. They are often seen as noncompliant, resistant, unwilling to follow through, rude by other in the community.
3. Parents with learning disabilities, who are exaggeratedly active, impulsive, are poor social cue readers, and have a short attention span, often have a difficult time setting up family routines, listening to and understanding their children’s cues and representing their children’s needs to other professionals (i.e., physicians, school professionals, etc.).
Aphasia

Loss or impairment of ability to use words or understand language symbols in speaking, reading and writing. Developmental aphasia usually results from brain injury or delayed development of the central nervous system.
Myths and Misinformation about Attention Deficit Disorder

1. Children with attention deficit disorder (ADD) can always be recognized by their hyperactive behavior | T | F

2. ADD affects little boys, not little girls. | T | F

3. Family problems or parents’ poor childrearing ability causes ADD. | T | F

4. Children will eventually outgrow ADD. | T | F

5. ADD is recognized as an educationally handicapping condition which automatically entitles a child to special education services. | T | F

6. Frequently, children with ADD have friends who are either several years older or younger than themselves, but not peers. | T | F

7. A diagnosis of ADD is a fairly easy for a pediatrician to make. | T | F

8. Since there is no “cure” for attention deficit disorder, there is no treatment. | T | F
About Attention Deficit Disorder

Symptoms:

1. Poor concentration/inattention
2. Impulsivity
3. Difficulty delaying gratification
4. Hyperactivity
5. Emotional overarousal
6. Noncompliance
7. Social problems with other children
8. Disorganization
About Attention Deficit Disorder (continued)

Depression is common in mothers who have a child with attention deficit disorder. Caseworkers need to help caregivers focus on understanding and managing the disability, not blaming themselves or the children.

The behavioral problems which characterize ADD/ADHD can vary considerably across different settings, tasks, and caregivers (Barkley, 1987).

Children with ADD children may not “look as if they have ADD” in situations that are new, interesting, scary, or one-on-one. This is why a visit to a pediatrician’s office (which can include several of these characteristics) can leave the mother looking “crazy” or “over-controlling.”

At home, children with ADD/ADHD can leave a trail of broken furniture, chaos, and exhausted, stressed-out caregivers. Their behaviors, which are symptoms of the disorder, create problems with doing chores, getting ready on time, sleep, clumsiness, ripped-apart rooms, injuries from accidents, and verbal static when every request is challenged.

The same behaviors that occur at home will create problems in the school situation. The school-age child will have trouble staying seated, paying attention, working independently, following directions, completing assignments, and following rules.

When a child is disruptive, interruptive, disorganized, and appears unmotivated, a negative interactive cycle is likely to be established between the child and school environment.

These symptoms can create social isolation or rejection for the child who “can’t get along” with other children or has difficulty with the motor skills prerequisite to experiencing success in games like baseball or basketball.

These children are very vulnerable to “secondary” problems like low self-esteem and depression resulting from the consistently negative feedback they receive. This negative cycle must be broken.

It is critical that parents realistically view the issues posed by attention deficit disorder. Their child will need more supervision and will need supervision at an older age than most children. At home, parents need to look for the child if the child is not seen or heard for an extended period of time.
About Attention Deficit Disorder (continued)

Parents must provide the structure that helps children master specific behavioral goals (e.g., Johnny will not hit his brothers when he gets mad). Parents must help children learn that “even though it is hard, they can stop and think.” They can learn to “boss” themselves (Ziegler, 1988).

Parents must learn behavior-shaping skills and to discuss the problem with a child in a neutral way, before emotions take over.

Preventing trouble by close supervision is easier and more effective than punishment after the event.

For the school-age child, as with any child, the caseworker should stress that consistency is critical. Caseworkers should strongly urge parents to talk with the child’s teacher so they can share approaches to help the child manage behaviors.

Knowledge about ADD is critical for the parent to develop an accurate but positive acceptance of the child. Parents need to understand that accepting the disorder does not mean overlooking or excusing the behavior.
Intervention Methods

**Home/Behavior Management:** Since children with attention deficit disorder get parents excited, emotional, and “crazy,” parents must have a plan which is a kind, firm, and systematic method of discipline. Rules need to be clear, concrete, and brief. Parents must repeat rules often, and have the child repeat them back for understanding.

**Counseling:** The counseling is for the parent and child to understand attention deficit disorder. They need to know that it is no one’s fault. The goal of counseling is to reduce anger and teach parents and child to think “ADD/ADHD” and make a plan. Therapy can help the demoralized child and parent with secondary symptoms like low self-esteem and depression which result from the negative reactions of others to them. Parents need help in “discriminating between the different effects of the disability, the developmental period, and the unique needs and style of the family” (Ziegler, 1988).

**Medication:** Medication works for 75% to 80% of children. Medication can help improve attention and reduce impulsivity and hyperactivity. Since specific doses must be determined for each child, it is critical that regular monitoring take place. Parents, the school nurse, or other school personnel responsible for giving the medication should have regular contact with the prescribing physician. This is very important. Children should not be allowed to medicate themselves.

**Education Support:** Parent support groups are invaluable to parents of child with ADD/ADHD they allow for blowing off steam and sharing war stories with people who “really know.” Support groups can also provide parents with different techniques and successful strategies to use. Support groups have been shown to act as powerful buffers for the stress parents and caregivers of children with ADD/ADHD experience.
Home Tips: Support, Structure, Supervision

Support

- Teach new behaviors in periods of calm. Children do not learn new behaviors at the time of discipline or when they are upset.

- Teach the child positive self-talk:
  - “I can talk about my mistakes.”
  - “I can ask for help and learn new ways to do things.”

- Recognize achievement, however small:
  - “Wow, you set the table!”

- Remind yourself, “Each day is a new day for both me and my child.”

Structure

- Set up a daily routine and stick to it; for example:
  - Come home from school.
  - Let __________________________ know you are home.
  - Eat something
  - Do homework.
  - Play

- Provide clear, concrete rules, for example:
  - No hitting.
  - No TV before school.
  - Ask before borrowing.

- Provide immediate consequences for unacceptable behavior. Use few words, and a commanding and controlled voice. (See handout, TAKE FIVE.)

- Place as little attention as possible on behavior which is not pleasing you, if it is not destructive to people and property.
Home Tips: Support, Structure, Supervision
(continued)

- Help children become effective listeners by getting the child to focus:
  - “Listen, because I want to tell you something very important”
- Have a child make eye contact with you before giving directions.
- Make directions clear and simple.
- Give one direction at a time:
  - Wash your face. (wait until the task is completed.)
  - Brush your teeth.
- Ask the child to repeat back to you what you have said.
- Help a child organize, using pictures, stickers, and colors.
- Manage the environment more so you have to manage the child less.
- Help children prepare for changes and transitions:
  - “In ten minutes, we will be going to grandma’s.”
  - “In five minutes, it will be time to turn off the TV.”
- Make a behavior chart and check off with the child. Limit chart to three behaviors. (See handout, Things to Do Today, for a sample).
- Use natural consequences when setting up task demands. Make a demand just prior to a child’s favorite snack or TV program:
  - “When you finish the dishes, you can watch TV.”

Supervision

- Use a kitchen timer with a bell to help child stay on task.
- Help the child recognize personal sign that he or she is starting to get too excited (e.g., face feels hot; voice gets louder).
Home Tips: Support, Structure, Supervision
(continued)

- Look for things such as tiredness, time of day, hunger level, allergies, and social situations as cues to patterns in your child’s behavior.
- Intervene early in negative behaviors.
- When a rule is broken, ask the child what the rule is. If necessary, repeat the rule and the consequence.
- Determine patterns which come before your child’s misbehavior. They can be warning signs that intervention is necessary.
- Give a consequence, good or bad, immediately after any behavior.
- Increase attention to activity your child does that pleases you, e.g., give much eye contact; develop as much touch as possible.
- Give out medication, when prescribed, exactly as the doctor ordered.
- Keep harmful substances (bleach, cleaning fluid, medicine) out of the reach of children.
Things to Do Today. . . ★ ★ ★ ★ ★ =

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Take Five: Stopping Behaviors Like Arguing, Whining, and Temper Tantrums

Discuss with the child the behavior that you want stopped before it happens, by doing the following:

1. Sit the child down. In a serious and kind voice, explain what will happen when the child begins the behavior, by saying the following:
   - “When you start to __________________, I will begin counting to three.”
   - “After one and two, you will have a chance to stop.”
   - “At three, you must take a five-minute time-out.”

2. Ask the child to repeat what you have said to make sure it was understood.

3. When the behavior starts, do the following:
   - When the child begins to __________________ say, “That’s one.” Say nothing else. Wait five seconds.
   - If the child continues, say “That’s two!” Say nothing else. Wait five seconds.
   - If the child still does not stop, say, “That’s three. Take five.” Do not argue with the child. Do not get emotional. The child is to go to his or her room or designated spot. When five minutes is over, child returns. Don’t say anything at all.

Note: If the child stops the behavior at the count of one or two, good! If he or she starts again within a fifteen-minute period, continue counting “two” or “three” and make the child take the five-minute time-out. If more than fifteen minutes have passed when the child starts the behavior again, begin counting again starting with “one.” This will work, but you must be patient! Children will test you the first few times to see if you mean it.

Source: Adapted from the video, 1, 2, 3 Magic, by Thomas Phelan, Ph.D. Permission pending.
Learning Disabilities

IDEA (Individuals with Disabilities Educational Act) defines learning disabilities as a “disorder in one or more of the basic psychological processes involved in understanding or in using spoken or written language, which may manifest itself in an imperfect ability to:

- listen,
- think,
- speak,
- read,
- write,
- spell, or
- to do mathematical calculations.”

The Federal definition includes such conditions as:

- perceptual disabilities
- brain injury
- minimal brain dysfunction
- dyslexia
- developmental aphasia

According to the law, learning disabilities do not include learning problems that are primarily the result of:

- visual
- hearing or
- motor disabilities
- mental retardation or
- environmental, cultural or economic disadvantage
- The label “learning disability” assists in the classification of children, NOT in teaching them.
- These problems may mildly, moderately, or severely impair the learning process.
Learning Disabilities (continued)

Incidence

- 5% of school age children receive special education due to a learning disability (in 1996 according to U.S. Dept. Of Ed.).
- 50% of special education children are learning disabled.
- 80% of people with a learning disability have dyslexia.

Helpful strategies for learning disabled students: (applicable to parents as well)

- Capitalize on the child’s strengths.
- Provide high structure and clear expectations.
- Use short sentences and a simple vocabulary.
- Provide opportunities for success in a supportive atmosphere to help build self esteem.
- Flexible classroom procedures (use of tape-recorders for note-taking and test taking; note-takers, etc) when the child has difficulty with written language.
- Immediate feedback without embarrassment.
- Use computers for drill and practice.
- Provide positive reinforcement of appropriate social skills at school home (and the community).
- Access to the Individualized Educational Plan (IEP) by the parent(s)/caregiver is of great benefit to reinforce at home the work being done in school.

Source: National Information Center for Children and Youth with Disabilities: Special Education Disabilities and Disorders. Parent Pals. com-downloaded 10/21/97
Dyslexia

Dyslexia is a learning disability in the area of reading, not due to emotional problems, lack of motivation, poor teaching, mental retardations, or vision or hearing deficits.

80% of learning disability students have dyslexia. Many go undiagnosed or poorly diagnosed, and most have average to above average intelligence.

They experience problems:
- learning to translate printed words into spoken words with ease (decoding);
- with word identification and/or reading comprehension;
- reversing letters (e.g., “b” to “d”);
- mis-sequencing letters with words when reading or writing (e.g., b/d, brid/bird, on/no).

They may also have difficulties with one or more of the following:
- perceiving and/or pronouncing words
- understanding spoken language
- recalling known words
- handwriting
- spelling
- written language
- math computation

Some may have automatic word recognition skills, but cannot comprehend what they read. They may have trouble understanding spoken language.

Strengths

Many are highly creative, with special talents with visual/spatial/motor integration (music, drama, graphics, engineering, electronics).
Dyslexia (continued)

Causes

Unknown. However, some research shows that in many cases it is inherited.

Intervention

Comprehensive psycho-educational evaluation including hearing, vision, and intelligence testing. This evaluation should include all areas of learning and learning processes, not just reading.

Spina Bifida

- Spina Bifida is one of the most prevalent birth defects. It develops during the first month after conception - usually before a woman even knows she is pregnant.

- The cause in unknown, but it is believed that there can be a combination of genetics and environmental reasons. More females than males are born with it; in blacks, Asians, and Ashkenazi Jews (of Eastern European origin) rates are lower.

- There is exciting research on efforts to repair the damages caused by spina bifida through in-utero surgery.

- It literally means a split of the spine. The spinal cord forms abnormally and the arches of the vertebrae, the bones that surround the cord, fail to develop. The tissue covering the spinal cord, or the cord itself, may be displaced outside the spinal canal. Nerves supplying the legs, bladder, and bowel are incompletely developed or damaged.

- Types and severity of symptoms are determined by the particular spinal nerve involved.

- Symptoms can include:
  - varying degrees of muscle paralysis;
  - bladder and bowel problems (incontinence);
  - loss of skin sensation;
  - strabismus (cross-eye);
  - spine and limb deformities.

- Most babies with Spina Bifida develop hydrocephalus.

- Problems with fine motor control or poor visual or perceptual skills can cause learning difficulties later on.

- About 70% have a normal IQ.

- Two types exist:
  - Spina Bifida occulta (the defect is covered by a layer of skin)
  - Spina Bifida manifesta
# Abbreviations & Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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</thead>
<tbody>
<tr>
<td>ACD</td>
<td>Alternate Care Determination</td>
</tr>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>ADD</td>
<td>Attention Deficit Disorder</td>
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<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AFDC</td>
<td>Aid to Families with Dependent Children</td>
</tr>
<tr>
<td>AMA</td>
<td>American Medical Association</td>
</tr>
<tr>
<td>ARC</td>
<td>Association for Retarded Citizens</td>
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<tr>
<td>ATR</td>
<td>Art Therapist Registered</td>
</tr>
<tr>
<td>BD</td>
<td>Behavior Disorders</td>
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<tr>
<td>BOCES</td>
<td>Board of Cooperative Educational Services</td>
</tr>
<tr>
<td>BOE</td>
<td>Board of Education</td>
</tr>
<tr>
<td>BSW</td>
<td>Bachelor of Social Work</td>
</tr>
<tr>
<td>CA</td>
<td>Chronological Age</td>
</tr>
<tr>
<td>CAC</td>
<td>Certified Alcohol Counselor</td>
</tr>
<tr>
<td>CDR</td>
<td>Continued Disability Review Services</td>
</tr>
<tr>
<td>CMCM</td>
<td>Comprehensive Medicaid Case Management</td>
</tr>
<tr>
<td>CNS</td>
<td>Central Nervous System</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
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<tr>
<td>COTA</td>
<td>Certified Occupational Therapy Assistant</td>
</tr>
<tr>
<td>CPSE</td>
<td>Committee on Preschool Special Education</td>
</tr>
<tr>
<td>CQC</td>
<td>Commission on Quality of Care</td>
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<tr>
<td>CLP</td>
<td>Certified Leisure Professional</td>
</tr>
<tr>
<td>CR</td>
<td>Community Residence</td>
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<tr>
<td>CRC</td>
<td>Credentialed or Certified Rehabilitative Counselor</td>
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<tr>
<td>CSE</td>
<td>Committee on Special Education</td>
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<tr>
<td>CSW</td>
<td>Certified Social Worker</td>
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<tr>
<td>CTRS</td>
<td>Certified Therapeutic Recreation Specialist</td>
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<tr>
<td>DC</td>
<td>Developmental Center</td>
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<tr>
<td>DD</td>
<td>Developmental Disability Children</td>
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<tr>
<td>DDPC</td>
<td>Developmental Disabilities Planning Council</td>
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<tr>
<td>DDO</td>
<td>Developmental Disabilities Services Office/Organization</td>
</tr>
<tr>
<td>DOB</td>
<td>Date of Birth</td>
</tr>
<tr>
<td>DOE</td>
<td>Date of Evaluation, Department of Education</td>
</tr>
<tr>
<td>DFY</td>
<td>Division for Youth</td>
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<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
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<tr>
<td>DOH</td>
<td>Department of Health</td>
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<tr>
<td>DSAS</td>
<td>Division of Substance Abuse Services</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic &amp; Statistical Manual (for Mental Disorders)</td>
</tr>
<tr>
<td>DSS</td>
<td>Department of Social Services</td>
</tr>
<tr>
<td>ED</td>
<td>Emotionally Disturbed</td>
</tr>
<tr>
<td>ECDC</td>
<td>Early Childhood Direction Center</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram</td>
</tr>
</tbody>
</table>
### Abbreviations & Acronyms (continued)

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>EEOC</td>
<td>Equal Employment Opportunity Center</td>
</tr>
<tr>
<td>EIP</td>
<td>Early Intervention Program</td>
</tr>
<tr>
<td>EKG</td>
<td>Electrocardiogram</td>
</tr>
<tr>
<td>ERDS</td>
<td>Eleanor Roosevelt Developmental Services</td>
</tr>
<tr>
<td>ET Tube</td>
<td>Endotracheal Tube</td>
</tr>
<tr>
<td>FAE</td>
<td>Fetal Alcohol Effects</td>
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<tr>
<td>FAPE</td>
<td>Free Appropriate Public Education</td>
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<tr>
<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
</tr>
<tr>
<td>FSS</td>
<td>Family Support Services</td>
</tr>
<tr>
<td>GED</td>
<td>General Education Diploma</td>
</tr>
<tr>
<td>HCBS</td>
<td>Home &amp; Community-Based Services (Medical Waiver)</td>
</tr>
<tr>
<td>HCFA</td>
<td>Health Care Financing</td>
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<tr>
<td>HHS</td>
<td>(Department of) Health &amp; Human Services</td>
</tr>
<tr>
<td>HMO</td>
<td>Health Maintenance Organization</td>
</tr>
<tr>
<td>HSP</td>
<td>Habilitation Services Practitioner</td>
</tr>
<tr>
<td>HUD</td>
<td>Housing &amp; Urban Development</td>
</tr>
<tr>
<td>ICF</td>
<td>Intermediate Care Facility</td>
</tr>
<tr>
<td>ICM</td>
<td>Intensive Case Management</td>
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<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IEP</td>
<td>Individual Education Plan</td>
</tr>
<tr>
<td>IFSP</td>
<td>Individualized Family Service Plan</td>
</tr>
<tr>
<td>ILS</td>
<td>Independent Living Skills</td>
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<tr>
<td>IPP</td>
<td>Individual Program Plan</td>
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<tr>
<td>I.Q.</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>IRA</td>
<td>Individualized Residential Alternative</td>
</tr>
<tr>
<td>ISC</td>
<td>Individual Services Coordinator</td>
</tr>
<tr>
<td>ISE</td>
<td>Individualized Service Environment</td>
</tr>
<tr>
<td>ISP</td>
<td>Individualized Service Plan</td>
</tr>
<tr>
<td>ITP</td>
<td>Individualized Transition Plan</td>
</tr>
<tr>
<td>JCAHO</td>
<td>Joint Commission on Accreditation of Hospital Organizations</td>
</tr>
<tr>
<td>JD</td>
<td>Juvenile Delinquent</td>
</tr>
<tr>
<td>JTPA</td>
<td>Job Training &amp; Placement Act</td>
</tr>
<tr>
<td>LBW</td>
<td>Low Birth Weight</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Disability</td>
</tr>
<tr>
<td>LRE</td>
<td>Least Restrictive Environment</td>
</tr>
<tr>
<td>MA</td>
<td>Mental Age; Medicaid</td>
</tr>
<tr>
<td>M.A.</td>
<td>Master of Arts Degree</td>
</tr>
<tr>
<td>MR</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>MSW</td>
<td>Master of Social Work</td>
</tr>
<tr>
<td>NG Tube</td>
<td>Nasal-gastric Tube</td>
</tr>
<tr>
<td>NI</td>
<td>Neurological Impairment</td>
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## Abbreviations & Acronyms (continued)

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>NICHCY</td>
<td>National Information Center for Children &amp; Youth with Disabilities (formerly National Information Center for Handicapped Children &amp; Youth)</td>
</tr>
<tr>
<td>NYALD</td>
<td>New York Association of Learning Disabilities</td>
</tr>
<tr>
<td>NYSACRS</td>
<td>New York State Association of Community Residential Services</td>
</tr>
<tr>
<td>NYSARC</td>
<td>New York State Association for Retarded Citizens</td>
</tr>
<tr>
<td>OAD</td>
<td>Office of Advocate for the Disabled</td>
</tr>
<tr>
<td>OASAS (NYS)</td>
<td>Office of Alcohol &amp; Substance Abuse Services</td>
</tr>
<tr>
<td>OMRDD</td>
<td>Office of Mental Retardation/Developmental Disabilities</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>PA</td>
<td>Physician’s Assistant</td>
</tr>
<tr>
<td>PAC</td>
<td>Parent Advisory Council</td>
</tr>
<tr>
<td>PDD</td>
<td>Pervasive Developmental Disorder</td>
</tr>
<tr>
<td>PINS</td>
<td>Person in Need of Supervision</td>
</tr>
<tr>
<td>PISP</td>
<td>Preliminary Individualized Service Plan</td>
</tr>
<tr>
<td>PT</td>
<td>Physical Therapy</td>
</tr>
<tr>
<td>QMRP</td>
<td>Qualified Mental Retardation Professional</td>
</tr>
<tr>
<td>SAFE</td>
<td>Schools Are for Everyone</td>
</tr>
<tr>
<td>SED</td>
<td>State Education Department</td>
</tr>
<tr>
<td>SCIP</td>
<td>Strategies for Crisis Intervention</td>
</tr>
<tr>
<td>SIB</td>
<td>Self-Injurious Behavior</td>
</tr>
<tr>
<td>SIDS</td>
<td>Sudden Infant Death Syndrome</td>
</tr>
<tr>
<td>SNF</td>
<td>Skilled Nursing Facility</td>
</tr>
<tr>
<td>SOFA</td>
<td>State Office for the Aging</td>
</tr>
<tr>
<td>SSA</td>
<td>Social Security Administration</td>
</tr>
<tr>
<td>SSDI</td>
<td>Social Security Disability Income</td>
</tr>
<tr>
<td>SSI</td>
<td>Supplemental Security Income</td>
</tr>
<tr>
<td>SYEP</td>
<td>Summer Youth Employment Program</td>
</tr>
<tr>
<td>TASH</td>
<td>The Association for Persons with Severe Handicaps (formally The Association for the Severe Handicapped)</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>TDD</td>
<td>Telephone Device for the Deaf</td>
</tr>
<tr>
<td>TRAID</td>
<td>Technology-Related Assistance for Individuals with Disabilities</td>
</tr>
<tr>
<td>Tx</td>
<td>Treatment</td>
</tr>
<tr>
<td>UCPA</td>
<td>United Cerebral Palsy Association</td>
</tr>
<tr>
<td>VESID</td>
<td>Vocational &amp; Educational Services for Individuals with Disabilities (formerly OVR (Office for Vocational Rehabilitation))</td>
</tr>
<tr>
<td>WIC</td>
<td>Women, Infants, and Children</td>
</tr>
</tbody>
</table>
Glossary

Abduction: Movement of a limb, outward, away from the body.

Academic Aide: A person assigned to assist the special-needs student with academic tasks in the classroom.

Access Rights: The right of parents to inspect and review any educational records relating to their children that are collected, maintained, or used by each participating agency and to do so by request without unnecessary delay and before any meeting regarding an individualized educational program or hearing relating to the identification, evaluation, or placement of the child. (Time lines vary from state to state.)

Accommodation: See Reasonable Accommodation.

Achievement Test: A test that measures a student’s level of development in academic areas such as math, reading, and spelling.

Activity Center: A day program where staff members assist adults with disabilities, emphasizing community skill training (e.g., learning to use public transportation) and vocational skill development.

Acute: An episode, serious event, or illness that starts suddenly and lasts a short time.

Acquired Immune Deficiency Syndrome (AIDS): A serious and potentially fatal disease in which the immune system is no longer able to protect the body and the individual becomes easily ill over a period of years with infections, cancer, or other serious diseases.

Adaptive Behavior: The extent to which an individual is able to adjust to and to apply skills to new environments, tasks, objects, and people.

Adaptive Equipment: Therapeutic aids such as a special seat, spoon, or stander to facilitate correct positioning and movement.

Adaptive Physical Education: A physical education program that has been modified to meet the specific needs of a student with disabilities, e.g., inclusion of activities to develop upper body strength in a student with limited arm movement.

Adduction: Movement toward midline.
Glossary (continued)

Administrative Review: A review process whereby disagreements between parents and school systems may be resolved by a committee of school system individuals not directly involved with the case. Also called a conciliatory conference.

Adult Day Programs: Programs in which adults with disabilities receive training in daily living skills, social skills, recreational skills, and “pre-vocational” skills.

Advocacy: Speaking or acting on behalf of another individual or group to bring about change.

Advocate: A person who speaks or acts knowledgeably on behalf of another individual or group to bring about change.

Age Appropriate: Activities and materials are age appropriate when children who are the same age as your child (but who do not have a disability) would typically engage in the activity or use the materials.

Age Equivalent: A test score expressed in terms of the chronological age at which most children achieve this task or pass this item.

Aged Out (Aging Out): Refers to students with special needs who have reached the maximum age limit mandated in their state for special education and related services.

Aggression: Physical or verbal action that causes discomfort or damage to some person or object.

Americans with Disabilities Act (ADA): An anti-discrimination law giving individuals with disabilities civil rights protection similar to those rights given to all people on the basis of race, sex, national origin, or religion.

Amniocentesis: A medical test which occurs before the baby is born and which involves withdrawing and analyzing a sample of the mother’s amniotic fluid, which surrounds the fetus, to determine the presence of certain birth defects.

Annual Goal: Statement written into a student’s yearly Individualized Education Program describing the anticipated growth of a student’s skill and knowledge.

Annual Review: A meeting held at least once a year to look at, talk about, and study a student’s Individualized Education Program (IEP) in order to decide changes in the IEP, review the placement, and develop a new IEP for the year ahead.

Anoxia: A lack of oxygen to the baby, which may lead to brain damage.
Glossary (continued)

Anterior: Front or face side of body.

Apgar Score: Score given at birth to describe an infant’s neurological status.

Apnea: Temporary cessation of breathing.

Appeals Process: The procedures by which parents may request that their case be heard again at a higher court if they or the school disagree with decisions reached at a due process hearing.

Appropriate: Refers to an educational plan that meets the individual needs of a student with disabilities, in free, appropriate public education provided by the Individuals with Disabilities Education Act (IDEA).

Aptitude Test: A test that measures an individual’s potential in a specific skill area, such as clerical speed, numerical ability, or abstract thinking.

Associated Reactions: Increase of stiffness in spastic arms and legs resulting from effort.

Asthma: A chronic condition in which the tissues of the lungs are inflamed and breathing is difficult, especially following allergic reactions.

Asymmetry: Inequality or dissimilarity of one side to the other.

At-Risk: Term used to describe children who are considered likely to have difficulties because of home life circumstances, medical difficulties at birth, or other factors, and who may need early intervention services to prevent future difficulties.

Ataxic: No balance, jerky.

Athetoid: Child with uncontrolled and continuously unwanted movements.

Attention Deficit Disorder (ADD): A condition in which a child’s ability to organize and attend to the environment is impaired sufficiently to hinder learning and acquisition of social skills. Characteristics include short attention span, trouble concentrating, distractibility, difficulty following more than one command at a time, and not appearing to listen.

Audiologist: A professional nonmedical specialist who measures hearing levels and evaluates hearing loss.

Auditory Perception: The ability to obtain meaning from what is heard.
Glossary (continued)

**Auditory Discrimination:** The ability to identify and distinguish among different speech sounds, e.g., the difference between the sound of “a” in say and in sad.

**Auditory Stimulation Discrimination:** The ability to recognize and separate different sounds.

**Augmentative Communication:** Aids to communication such as a picture book, computer board, and sign language that enable a person who is unable to speak to communicate.

**Autism:** A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three. Often characterized by abnormal ways of relating to people, objects, and events; absent or delayed speech and language; difficulty with variation in the environment or routines; unconventional use of toys and objects; repetitive movements such as rocking, head banging, and spinning; and frequently exhibiting developmental delays and sometimes unusual developmental patterns.

**Basal Score:** The point on a test at which all previous items have been passed and which may be given in age-equivalent terms.

**Baseline:** A preintervention record of the child’s behavior which may be used by educators to compare information about the child’s behavior after intervention to determine its effectiveness.

**Behavior Disorders (BD):** Disorders characterized by disruptive behavior in school, home, and other settings and which can include attention deficit hyperactivity disorder (ADHD), conduct disorder, difficulty learning, and inability to establish satisfactory relationships with others. A chronic pattern of behavior that is considered inappropriate, excessive, chronic, and abnormal, and which violates social or cultural norms and expectations and may affect educational and personal performance, including difficulties in the following areas: relationships with peers or adults, self-care, or exhibiting inappropriate behaviors to express feelings.

**Behavior Management or Behavior Modification:** A strategy designed to help a child change specific behaviors by managing environmental stimuli and environmental consequences.

**Behavioral Observation:** A systematic way of observing, recording, and interpreting the behavior of a student at work on a job, in order to gain a broad picture of the student’s interests and abilities as part of a vocational assessment.

**Bilateral:** Involving both sides of the body.

**Bradycardia:** A slowing of the heartbeat often found in premature infants.
Glossary (continued)

**Brainstem Auditory Evoked Response (BAER):** A test used to evaluate hearing in infants in which electrodes monitor the child’s brain waves in response to different levels and frequency of sounds emitted by the testing apparatus.

**Bronchopulmonary Dysplasia:** A chronic lung disease sometimes seen in premature infants that sometimes follows respiratory distress syndrome.

**Buckley Amendment:** More commonly known name for the Family Educational Rights and Privacy Act of 1974, which gives parents and students (over age 18) the right to see, correct, and control access to school records.

**Cardiology:** A branch of medicine which is concerned with the heart and circulatory system.

**Career Education:** A progression of activities intended to help students acquire the knowledge, skills, and attitudes that make work a meaningful part of life. Career education has four stages: awareness/orientation, 2) exploration, 3) preparation, including vocational education, and 4) job placement/follow-up.

**Carl D. Perkins Vocational and Applied Technology Education Act 1990:** A federal law stipulating that students with disabilities be guaranteed the opportunity to participate in federally funded vocational programs that are equal to those afforded to the general student population.

**Case Manager:** See Service Coordinator.

**Categories:** Students with special needs grouped together because of shared characteristics. The names and definitions assigned to the categories vary from state to state.

**Ceiling Age:** The level on a test where the child can no longer pass more difficult items.

**Central Nervous System (CNS):** The brain and spinal cord.

**Cerebral Palsy:** A disability resulting from damage to the central nervous system which results in disturbances of muscle tone, posture, and movement.

**Child Find:** A state and local program mandated by the Individuals with Disabilities Education Act (IDEA) to identify individuals with disabilities between the ages of birth and twenty-one and to direct them to appropriate early intervention or educational programs.
Glossary  (continued)

**Child Life Worker:** In a hospital, specialists in child development who intervene to provide therapeutic play and learning activities.

**Child Protective Services:** Social workers or other professional specialists who investigate allegations and incidents of child abuse or neglect, and who may also routinely interview parents after serious accidents or unexplained illnesses.

**Children with Disabilities:** Those children identified in accordance with Regulations 300.530-300.534 as being mentally retarded, hard of hearing, deaf, speech-impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health-impaired, deaf-blind, multi-handicapped, or having specific learning disabilities, who because of those impairments need special education and related services.

**Chronic:** Disease or disability that tends to last a long time or has frequent recurrences.

**Cleft Palate:** An opening in the upper palate of the mouth, which is usually treated with surgery. It may occur alone or in combination with other disabilities.

**Clinical Social Workers:** A professional with a master’s degree in social work, with some states requiring a license and others requiring registration. Must have a minimum of two years of supervised experience.

**Clonus:** Shaky movements of spastic muscles.

**Cognition:** A term that describes the process people use for remembering, reasoning, understanding, and exercising judgment.

**Cognitive Development:** The development of the ability to think logically, remember, reason, and to process information about the environment.

**Colostomy:** An opening into the large intestine through the abdominal wall which allows waste products to be excreted into a bag.

**Communication Book/Communication Board:** A book or board with pictures or signs to aid a person who is unable to speak to communicate with others.

**Communication Disorder:** A general term for any language and/or speech impairment.

**Community Participation:** Activities by a person with disabilities within the community which contribute to the well-being and improvement of that community, such as volunteering at the hospital, planting trees, serving on the board of a nonprofit agency.
Glossary (continued)

Competitive Employment: Everyday part-time or full-time jobs with wages at the going rate in the open labor market.

Compliance File: School records containing all reports of meetings, correspondence, and other contacts between parents and school officials.

Conciliatory Conference: See Administrative Review.

Confidential File: A file having restricted access and containing records of a child’s evaluation and other materials related to special education (medical reports, independent evaluations, reports of eligibility meetings, etc.).

Confidentiality: The limiting of access to child’s or a family’s records to personnel having direct involvement with the child. Keeping information private. If someone assures confidentiality, they mean that they will not release the information without your permission.

Congenital: A term referring to a condition present or existing at birth.

Congenital Disabilities: A disorder or disability that is present at birth.

Congenital Rubella Syndrome: A condition in which the unborn fetus is exposed to the rubella (German measles) virus in the first trimester of pregnancy. It may result in various disabilities including cerebral palsy, cataracts, sensorineural hearing loss, microcephaly, mental retardation, liver disease, or heart defects.

Consent: Agreement or permission by a child’s legal guardian or surrogate parent for a certain medical procedure, educational program, placement, or intervention on behalf of a child; parental permission, usually given by signing a letter or form, agreeing to let the schools take an action affecting a child’s education. Consent is required before a child can be evaluated or receive special services under IDEA.

Continuum of Alternative Placements: A selection of alternative special education placements for a child, ranging from most restrictive to least restrictive.

Contract Services: Services provided to students with disabilities by private service providers (e.g., private schools, institutions, therapists) when the school system is unable to provide the needed service.

Contractures: Shortening of muscle fibers, which limits movement.

Coordination: Combination of muscles in movements.
**Glossary** (continued)

**Cumulative File:** A file containing report cards, standardized achievement test scores, teacher reports, and other records of a student’s school progress.

**Correlation:** A statistical method of measuring the relationship between two variables.

**CT Scan (CAT Scan):** A medical term that refers to an image of a cross section of a person’s body, which produces a 3-dimensional picture of the tissue density, used to obtain specific information to diagnose or monitor certain medical conditions especially of the brain.

**Cystic Fibrosis:** An inherited disease resulting in respiratory problem such as chronic coughing, wheezing, and recurring pneumonia.

**Cytomegalovirus (CMV):** A virus that can infect the fetus and cause birth defects and/or severe illnesses.

**Deaf (Deafness):** A hearing impairment so severe that an individual cannot process sounds even with amplification such as hearing aids.

**Deaf-Blind:** The combination of visual and hearing impairments causing such severe communication and other developmental and educational problems that a child cannot adequately be served in a special education program solely for deaf or blind children.

**Deformities:** Body or limbs fixed in abnormal positions.

**Developmental:** Having to do with the steps or stages in growth and development before the age of 18.

**Developmental Age:** A measure of development stated as an age equivalent.

**Developmental Delay:** Term used to describe slower than normal development of an infant or child in one or more areas.

**Diagnosis:** The process of identifying the nature of a condition or problem.

**Diplegia:** Paralysis of the identical part on both sides of the body, mostly affecting legs; cerebral palsy.

**Disability:** A short-term or permanent problem or condition which makes it hard for a person to learn or do things in the same ways as most other people.

**Distal:** Furthest from the trunk.
**Glossary** (continued)

**Distractable:** Not able to concentrate.

**Dorsal:** Pertaining to the back or back of a body part.

**Due Process:** A system of procedures ensuring that an individual will be notified of, and have opportunity to contest, decisions made about her/him. As it pertains to early intervention (Part H) and special education (Part B) of IDEA, due process refers to the legal right to appeal any decision regarding any portion of the process (evaluation, eligibility, IEP or IFSP, placement, etc.).

**Due Process Hearing:** A formal session conducted by an impartial hearing officer to resolve special education disagreements between parents and school systems.

**Dyslexia:** The impairment of reading ability.

**Early Intervention:** Providing services and programs to infants and toddlers (under age three) with disabilities in order to minimize or eliminate the disability as they mature.

**Echolalia:** Repetition or imitation of words without regard to their meaning.

**Education of the Handicapped Act (EHA):** See Individuals with Disabilities Education Act (IDEA).

**Educational Advocate:** An individual who speaks or acts knowledgeably for the educational needs of another.

**Educational Diagnostician:** A professional who is certified to conduct educational assessments and to design instructional programs for students.

**Educational Objectives:** In the evaluation of a child, the goals stated in the IEP towards which the child will be working and the skills to be accomplished.

**Electrocardiogram (EKG):** A graphic recording of the electrical activity of the heart.

**Electroencephalogram (EEG):** A graphic recording of the brain’s electrical activity used to diagnose seizures or locate lesions or tumors on the brain.

**Eligibility:** The determination of a child’s qualifications to receive early intervention or special education services based on meeting established criteria.
Glossary (continued)

**Emotional Disorders (ED):** Disorders characterized by their effect on an individual’s emotional state. They may cause separation anxiety, phobias, and post traumatic stress disorder. Other emotional disorders are affective or mood disorders, such as childhood depression, or bipolar disorder.

**Employability Skills:** Personal habits and traits such as cleanliness, dependability, and punctuality that are necessary for successful employment; sometimes called “work adjustment skills.”

**Encephalitis:** An infection or inflammation of the brain.

**Endotracheal Tube (ET Tube):** Tube inserted into the windpipe to allow artificial ventilation.

**Epilepsy:** A disorder of the central nervous system characterized by different types of recurring seizures.

**Equilibrium:** Balance.

**Esophagitis:** An irritation or inflammation of the esophagus, which leads from the mouth and nasal cavity to the stomach.

**Evaluation:** The process of collecting information about a student’s learning needs through a series of individual tests, observations, and talks with the student, the family, and others. Also, the process of obtaining detailed information about an infant or toddler’s developmental levels and needs for services. May also be called Assessment.

**Evaluation Team:** A group of professionals, including teachers, psychologists, and other pertinent specialists, who are qualified to administer assessments providing information on the disability of the child. This team is also involved in making recommendations regarding placement and services needed for the appropriate education of a child with special needs.

**Evaluation Team Meeting:** A meeting to discuss the findings of the assessment once an evaluation has been completed. The evaluation team is responsible for determining whether a child is eligible for special education.

**Eversion:** Turning out.

**Expressive Language:** The ability to communicate through speech, writing, augmentative communication, or gestures.

**Extended School Year:** Special education provided during summer months to students found to require year-round services to receive an appropriate education.
Glossary (continued)

Extension: To straighten the body or part of the body.

Eye-Hand Coordination: Use of the eyes and hands together in movement and manipulation of objects.

Facilitation: Making it possible for the child to move.

Failure to Thrive: A child whose weight is less than the 3rd percentile for that age or whose decreased growth has crossed 2 major percentiles in a short period of time. Failure to thrive is a symptom, not a diagnosis that signals the need for assessment to determine its cause. Causes can be organic, non-organic, or a combination of both.

Family Care: Care provided by individuals who are licensed by the state to provide family-like settings for adults with disabilities.

FAPE (Free Appropriate Public Education): Special education and related services provided at public expense, under public supervision and direction, and without charge. They must meet the state education standards. FAPE runs from preschool through secondary education. It strives to place the child with special needs in the least restrictive environment. The acronym and its definition are used in the federal law, the Individuals with Disabilities Education Act (IDEA), to describe a student’s right to a special education program that will meet his or her individual special learning needs, at no cost to the family.

Fetal Alcohol Syndrome (FAS): A baby born with physical and mental deficits as a result of maternal drinking during pregnancy. The effects include growth retardation, facial anomalies, and mental retardation.

Flexion: Bent body or part of body; bending of elbows, hip, knees, etc.

Floppy: Loose or weak posture and movements.

Fine Motor Skills: Body movements which use small muscles, for example, picking up a small object, writing, or eating.

Fragile X Syndrome: A condition found in individuals in which there is a defect on the X chromosome. The associated developmental problems can include mental retardation and behavior problems.

Functional Vocational Evaluation: See Vocational Assessment.
**Glossary** (continued)

**Gastro-Esophageal Reflux:** A condition that occurs when the valve between the stomach and the esophagus closes only partially and undigested food returns into the esophagus or is vomited.

**Gastrostomy:** An opening in the abdominal wall allowing an individual to be fed by tube when unable to eat normally.

**General Education Diploma (GED):** A method for obtaining a diploma for adults who did not complete high school. GED tests, which measures achievement in writing skills, social studies, science, literature, and mathematics, enable individuals to demonstrate that they have acquired a level of learning comparable to that of traditional high school graduates.

**Generalization:** Taking the skills learned with one person, environment, or set of materials and using them with different people, environments, or materials.

**Gestational Age:** The baby’s age based on the number of weeks since conception.

**Goal:** See Annual Goal.

**Gross Motor Skills:** Body movements which use large muscles, for example, sitting, walking, or climbing.

**Guidance Counselor:** The professional that provides students with advice on educational or vocational issues as well as social difficulties.

**Habilitation:** The process of helping an individual develop specific skills and abilities (e.g., dressing, eating, maneuvering a wheelchair) in order to become as independent and productive as possible.

**Handicapped Children’s Protection Act:** The law providing for the reimbursement of reasonable attorneys’ fees to parents who win their cases in administrative proceedings under IDEA.

**Hard-of-Hearing:** Having impaired hearing which can be corrected sufficiently with a hearing aid to enable an individual to hear and process sounds. Also used to describe hearing loss occurring after an individual has developed some spoken language.

**Head Control:** Ability to control the position of the head.

**Hearing Impaired:** Includes both individuals who are deaf and who are hard-of-hearing. The difference between deafness and hard-of-hearing is defined by amount of hearing loss.
**Glossary** (continued)

**Hearing Impairment:** A loss of hearing usually measured in decibels. It may be caused by permanent structural problems in the ear or may result from infection or serious illness.

**Hemiplegia:** Paralysis or weakness involving one side of the body.

**Hereditary:** Genetic characteristics passed on to children from one or both parents.

**High Risk:** At a higher-than-average risk of developmental disability or need for special interventions. Many factors can place children at risk, including low birth weight, prematurity, poor living conditions, and so forth. Not all children who are at risk have later developmental problems.

**HIV Positive:** A condition in which antibodies to the human immune deficiency virus are present in the body. The condition may potentially develop into AIDS.

**Homebased Services:** Early intervention services provided to a child and family in their own home.

**Homebound Instruction:** Educational instruction given in a student’s home when she/he is unable to attend school for medical or other reasons.

**Hydrocephalus:** Accumulation of excess cerebrospinal fluid in the brain that may result in rapid enlargement of the head.

**Hyperactivity:** An extremely high activity level that may be associated with a limited ability to stay with one task, short attention span, and distractibility and may interfere with school performance and family activities.

**Hypertonia:** Abnormally high muscle tone. The child may seem very stiff or rigid and may arch back, or have trouble bending or unbending his or her arms or legs.

**Hypotonia:** Abnormally low muscle tone. The child may have trouble maintaining an erect posture and may seem to sink into floor or chair.

**IEP:** See Individualized Education Program.

**IEP Meeting:** A meeting to develop the individualized education plan for a child with special needs, taking into consideration the recommendations of the evaluation team and input from the child’s teachers and parents. Placement decisions for the child are made at this time.
**Glossary** (continued)

**IFSP:** See Individualized Family Service Plan.

**Imitation:** Repeating the same movements, sounds, and activities observed of others.

**Impartial Hearing Officer:** Individual presiding over a due process hearing, appointed by the state education agency, and not connected in any way with either party in a dispute.

**Inclusion:** Ensuring that necessary supports and services are provided so that children with disabilities can participate in school, community, and recreation activities with children who do not have disabilities.

**Independent Educational Evaluation:** An evaluation/assessment of a student conducted by one or more professionals not employed by the school system. The person(s) doing the evaluation must be fully trained and qualified to do the kind of testing required.

**Independent Living Skills:** Basic skills needed by people with disabilities to function on their own, with as little help as possible. Skills include self-help (e.g., bathing, dressing), housekeeping, community living (e.g., shopping, using public transportation), etc.

**Individualized Determination Plan:** A written plan for each student who receives services, modifications, and accommodations under Section 504 of the Rehabilitation Act of 1973. In some schools, it is referred to as a “504 Plan.”

**Individualized Education Program (IEP):** A written plan for each student in special education describing the student’s present levels of performance, annual goals including short-term objectives, specific special education and related services, dates for beginning and duration of services, and how the IEP will be evaluated.

**Individualized Family Service Plan (IFSP):** A written statement for each infant or toddler receiving early intervention services that includes goals and outcomes for the child and family as well as a plan for making the transition to services for children over age two.

**Individualized Transition Plan (ITP):** Part of the IEP that states the services needed by a student with special needs in order to transition from school to post-school activities, such as post-secondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, or community participation.
Glossary (continued)

**Individuals with Disabilities Education Act (IDEA):** The authorizing federal legislation which mandates a free, appropriate public education for all children with disabilities. Formerly known as the Education for All Handicapped Children Act. Part B of the act refers to special education services for children age three through twenty-one. Part H refers to the early intervention program for infants and toddlers with disabilities from birth through age two and their families.

**Infant Stimulation:** A program designed to provide specific activities that encourage growth in such developmental areas as movement, speech, and language in infants with developmental delays.

**Inhibition:** Positions and movements which stop muscle tightness.

**Intelligence Quotient (IQ):** A measurement of thinking (cognitive) ability that compares an individual with others in the same age group.

**Integration:** Placing children with disabilities in programs which also serve children without disabilities.

**IQ:** See Intelligence Quotient.

**Interagency Coordinating Council (ICC):** Federal, state, or local group consisting of parents, advocates, and professionals who serve in an advisory capacity to plan and implement early intervention services for infants and toddlers with disabilities and their families.

**Intermediate Care Facility:** Licensed facilities operating under strict regulations and providing intensive support for people with disabilities in the areas of personal care, communication, behavior management, etc.

**Inversion:** Turned in.

**Involuntary Movements:** Unintended movements.

**Itinerant Teacher:** A specially trained teacher who usually travels between different schools or intervention settings where the child with unique educational needs receives his or her educational program.

**Job Coach:** A service agency professional who works with an individual with disabilities at the job site, providing support by helping the employee to improve job skills, interpersonal relations, or any other job-related needs.
Glossary (continued)

**Ketogenic Diet:** A rigid, mathematically calculated, doctor-supervised diet that is high in fat and low in carbohydrates and protein, used in the control of seizures. Calories and liquid intake are strictly limits as the diet simulates the metabolism of a fasting body. It must be prepared meticulously using a gram scale and completely adhered to under the supervision of a specially trained dietician and physician. It requires a level of high motivation and determination form the family as well as the child who is on it.

**Language Sample:** A way of assessing children’s communication skills by analyzing what children say.

**Lateral:** Related to the side.

**Lead Agency:** State agency, which has been designated by the governor to administer and implement a statewide comprehensive, coordinated, multidisciplinary, interagency service delivery system for infants and toddlers with disabilities and their families.

**Learning Disability:** A disorder in one or more of the processes involved in understanding or using language, spoken or written, resulting in difficulty with listening, thinking, speaking, writing, spelling, or doing mathematical calculations. This term does not include children with learning problems related to other disabilities such as mental retardation.

**Learning Style:** The unique way that an individual learns best, for example, by playing games, imitating, reading a book, listening to a lecture, or handling materials. Most children learn through a combination of processes.

**Least Restrictive Environment (LRE):** Placement of a student with disabilities in a setting that allows maximum contact with students who do not have disabilities, while appropriately meeting the student’s special education needs.

**Legally Blind:** An individual whose vision, even with corrective lenses, is 20/200 or less, which means being able to see at 20 feet what a person with normal vision sees at 200 feet.

**Low Birth Weight (LBW):** An infant weighing less than 2,500 grams at birth.

**Magnetic Resonance Imaging (MRI):** A diagnostic technique which provides information about the tissues and can distinguish between diseased and healthy tissue.
Glossary (continued)

**Mainstreaming:** The concept that students with disabilities should be educated with nondisabled students to the maximum extent possible.

**Major Life Activity:** Such activities as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, learning, and working.

**Means-end:** A term used to describe a child’s ability to solve a problem by considering a particular course of action (means) that will bring about a desired outcome (end).

**Mediation:** A formal intervention between parents and personnel of early intervention or school systems to achieve reconciliation, settlement, or compromise.

**Medically Fragile:** An expression describing infants or young children experiencing acute or chronic medical conditions which require frequent or intense medical care.

**Medicaid:** A federal/state program that provides medical services primarily to individuals with low income.

**Mental Age (MA):** Similar to developmental age. It is a measure of intellectual ability stated as an age equivalent.

**Mental Retardation:** A broad term describing delayed intellectual development resulting in delays in other areas such as academic learning, communication, social skills, rate of maturation, and physical coordination.

**Microcephaly:** Small head size which usually indicates a slowdown in the growth of the brain.

**Midline:** The vertical centerline of the body. Examples of midline skills involve bringing hands and toys together at the center of the body.

**Milestone:** A developmental indication that provides the typical age at which most children without disabilities exhibit a particular skill of behavior.

**Minimum Competency:** A requirement by many states that students pass a minimum competency test, demonstrating their academic skills to be at a state-defined level of achievement, in order to receive a regular high school diploma.

**Mobility Aide:** An individual assigned to assist a student in the school setting to move safely from one place to another.

**Modeling:** Demonstrating a behavior that you want imitated.
Glossary (continued)

Monitor: A machine that may be used to record breathing and heart rates and to sound an alarm if the rhythm becomes abnormal or ceases.

Motor Development: The development of activities or skills that are involved in body movements.

Multidisciplinary Evaluation: The testing of a child by a group of professionals, including psychologists, teachers, social workers, speech therapists, nurses, and related others.

Multiple Disabilities: An educational label given to students having a combination of impairments such as mental retardation and blindness or orthopedic impairments and deafness which cause such educational problems that they cannot be accommodated in programs for any one impairment. This term does not include deaf-blind children.

Muscle Tone: The degree of tension in the muscle at rest or during movement, which is regulated by the central nervous system.

Nasal-gastric Tube (NG Tube): A tube inserted through the nostril, down the esophagus and into the stomach to allow feeding of a person unable to eat or take fluids normally by mouth.

Natural Homes: Places that are generally thought of as dwellings for people, such as apartments, houses, townhouses, trailers, etc.

Negative (In response to a medical test): Indicating the absence of a disease, antibody, or condition.

Neurological Impairments: Include a group of disorders of the central nervous system characterized by dysfunction in one or more skills affecting communication, perception, cognition, memory, attention, motor control, and appropriate social behaviors. Neurological impairment is the most common developmental disability encountered in children.

Neonatologist: A physician who focuses on the development and treatment of diseases of newborns.

Neurologist: A physician who specializes in the nervous system and the treatment and diagnosis of its diseases and disorders.
Glossary (continued)

**Nonacademic Services:** Services that include counseling, athletics, transportation, health services, and recreational activities.

**Noncategorical:** Term relating to programs based on instructional needs rather than on categories of disabilities. Many states have only noncategorical programs, e.g., Maryland, Massachusetts, Minnesota.

**Nondiscriminatory Evaluation:** An evaluation in which the materials and procedures used are not racially or culturally biased. In addition, an individual’s disability must be accommodated such as by allowing more time, using a computer, etc.

**Nonverbal Behavior:** Behavior that occurs in the absence of spoken language. Communication occurs through gestures, facial expressions, physical closeness, and posture.

**Objective:** An objective is a short-term step taken to reach an annual goal. IEP objectives are the steps between a student’s present level of performance and an annual goal.

**Object Permanence:** A term used by psychologists and educators to describe a child’s ability to understand that objects continue to exist even when they are not visible.

**Occupational Therapist:** Specialist who focuses on such activities as fine motor skills, feeding skills, adaptation of equipment, and daily living skills.

**Occupational Therapy (OT):** Activities focusing on fine motor skills and perceptual abilities that assist in improving physical, social, psychological, and/or intellectual development, e.g., rolling a ball, finger painting, sorting objects.

**On-the-Job-Training (OJT):** Short-term training that enables a person to work on a job site while learning the job duties.

**Ophthalmologist:** A physician who specializes in the diagnosis and treatment of eye disorders.

**Orthopedic:** Refers to concerns involving skeletal structure of the body, including bones, muscles, and joints.

**Orthopedic Impairment:** A physical disability severe enough to affect a child’s educational performance. Orthopedic impairments can be congenital or caused by disease or injury.
Glossary (continued)

**Other Health Impairment (OHI):** Term used in IDEA to describe conditions that adversely affect a child’s educational performance and are not covered by other disability definitions (e.g., Learning Disabilities, Mental Retardation). This term is frequently used for various medical conditions such as a heart condition, diabetes, cystic fibrosis, leukemia, etc.

**Paraplegia:** Legs only affected.

**PAC (Parent Advisory Council):** Groups that meet on a regular (usually monthly) basis to discuss parents’ concerns with the special education programs, to invite speakers in the field, and to provide parents with an opportunity to meet other parents in the school district, keeping them abreast of changes, issues, and other relevant information.

**Parent:** A parent, guardian, or surrogate parent who has been appointed in accordance with Regulation 330.5 14. The state is not included in this term if the child is a ward of the state.

**Parent Participation:** When parents are permitted active and equal participation in discussing and developing an individualized education plan and in providing input regarding their child’s educational programming process.

**Part B or Part H:** See Individuals with Disabilities Education Act.

**Pathological:** Abnormal.


**Perseveration:** Unnecessary repetition of movement and/or speech.

**Petit Mal Seizure:** A type of seizure characterized by brief episodes of inattention. The individual may appear to be daydreaming or staring into space. It involves little physical reaction.

**Phenylketonuria (PKU):** A genetic disorder resulting from a build-up of phenylalanine due to an enzyme deficiency. Can result in mental retardation, hyperactivity, and seizures if left untreated. Treatment consists of a carefully controlled diet.

**Physical Therapist (PT):** A specialist concerned with physical movement and positioning, and development of gross motor skills.

**Physical Therapy (PT):** Activities or routines designed to increase gross motor skills.

**Physiotherapy:** Treatment of disorders of movement.
**Glossary** (continued)

**Pincer Grasp:** Using the thumb and index or middle finger to pick up a small object.

**Placement:** The setting in which a child with disabilities is educated. Placement includes the school, the classroom, related services, community-based services, and the amount of time a student will spend with peers and others who do not have disabilities.

**Positive (In response to a medical test):** Indicating the presence of a disease, antibody, or condition.

**Posterior:** Back of the body.

**Postsecondary Education:** Education programs for students who have completed high school, such as a community and junior colleges, four-year colleges, and universities.

**Prereferral Intervention:** Prior to making a referral to special education, the process by which teachers try to identify different means of assisting and resolving a student’s difficulties within the regular classroom setting and of accessing other available resources in the system outside of special education.

**Premature Infant:** An infant born prior to the 37th week of gestation.

**Prenatal:** Before birth.

**Primitive Reflexes:** A group of reflexes that are present at birth. Over time, these reflexes are integrated into more mature patterns of movement in children without disabilities. Examples include the sucking reflex and the rooting reflex.

**Procedural Safeguards:** The safety nets built into the law to make sure that parents are involved in decisions being made on behalf of the child with special needs.

**Pronation:** Turning of the hand with palm down.

**Prone:** Body is positioned lying face down.

**Proximal:** Nearest to the trunk.

**Psychiatrist:** A medical doctor with advanced training who specializes in the diagnosis and treatment of emotional, behavioral, and mental disorders.
Glossary (continued)

Psychological Evaluation: The portion of a child’s overall evaluation/assessment for special education that tests his or her general aptitudes and abilities, eye-hand coordination, social skills, emotional development, and thinking skills.

Psychologist: A professional, not a medical doctor, with advanced training in the study of mental processes and human behavior. A school psychologist conducts various evaluations, especially aptitude and ability tests, and may work with students, classroom teachers, parents, and school administrators on behavior assessments and behavior management programs.

Public Agency: Includes the state educational agency, local educational agencies, intermediate educational units, and any other political subdivisions of the state responsible for providing education to handicapped children.

Public Expense (Evaluation at the Public Expense): When the public agency either pays for the full cost of the evaluation or ensures that the evaluation is otherwise provided at no cost to the parent.

Quadriplegia: Whole body affected.

Qualified: A person has met state educational agency-approved or recognized certification, licensing, registration, or other comparable requirements that apply to the area in which he or she is providing special education or related services.

Reasonable Accommodation: The modification of programs in ways that permit students with disabilities to participate in educational programs that receive federal funding. The concept also applies to the modification of job requirements and equipment for workers with disabilities.

Receptive Language: The process of receiving and understanding written, gestured, or spoken language.

Reevaluation of the IEP: An every three year need to update a child’s existing educational plan to ensure that the services and goals are appropriate and reflect the current educational needs and support required by the child.

Referral: A formal notification to the early intervention system or local school that a child is experiencing difficulties which may require a full evaluation for early intervention or special education. A referral may be made by a family, teacher, or other professional.
Glossary (continued)

**Regulations:** Following the passage of a law, the procedures that need to be followed for compliance with the law.

**Rehabilitation Act of 1973 (Section 504):** A nondiscrimination statute, Section 504 of which stipulates that individuals with disabilities may not be excluded from participating in programs and services receiving federal funds and which also prohibits job discrimination against persons with disabilities in any program receiving federal financial assistance.

**Rehabilitation Act Amendments of 1992:** Federal legislation that requires state vocational rehabilitation agencies to work cooperatively with local agencies, including schools, to create a unified system to serve persons with disabilities.

**Reinforcement:** A consequence that is given as a result of the child’s behavior.

**Related Services:** Those services a student must receive to benefit from special education, for example, transportation, counseling, speech therapy, crisis intervention.

**Reliability:** In assessment, the extent to which a test measures the same thing consistently.

**Residential Services:** The placement of a student in a setting that provides educational instruction and 24-hour care.

**Resource Room:** A setting in a school where a student receives instruction from a special education teacher for a part of the school day.

**Respite:** A period of rest or relief.

**Respite Care:** Care given by an individual or an organization to provide temporary relief of the care-taking responsibilities for the parents of the special needs child.

**Review of IEP:** The annual review of a child’s IEP to determine the child’s progress, where he or she continues to need support, and the type of support needed.

**RhoGam:** The RH antibody that is injected into the mother either during her pregnancy, at 28 weeks gestation, and/or immediately following delivery. It is used only if the mother is Rh Negative and has previously been exposed to Rh Positive blood in her system.

**Righting:** Ability to put head and body right when positions are abnormal or uncomfortable.

**Rigidity:** Very stiff movements and posture.
Glossary (continued)

**Ritalin:** A stimulant medication to control hyperactivity in children.

**Rotation:** To revolve or turn on an axis.

**School-Based Screening Committee:** See Screening Committee.

**Screening:** A brief examination of a child designed to pick up potential difficulties and to identify children who need further evaluation and diagnosis.

**Screening Committee:** A local school-based committee whose members determine whether a student should be fully evaluated for special education eligibility.

**Section 504:** See Rehabilitation Act of 1973.

**Segregation:** The practice of placing children with disabilities in a group setting that includes only other children with disabilities.

**Seizure:** An excessive periodic discharge of electrical activity in the brain. It may be caused by a very high fever.

**Self-Advocacy:** The abilities required to take primary responsibility for one’s life and to make choices regarding one’s actions free from undue interference. Also called self-determination.

**Self-Determination:** See Self-Advocacy.

**Self-Help Skills:** The ability to take care of self-care needs such as feeding, dressing, and toileting.

**Self-Injurious Behavior (SIB):** Repetitive, self-stimulating behaviors which are destructive and which the child directs toward him- or herself.

**Self-Stimulatory Behavior:** Repetitive motor or posturing behaviors. Examples include body rocking, hand flapping, and object spinning.

**Sensory Integration:** Coordination of information from all the senses to allow for an appropriate response to the environment.

**Sensory-motor Experience:** The feeling of one’s own movements.

**Separate Classes:** The classroom that houses only special needs children with a teacher certified in special education who has primary responsibility for the educational plan.
Glossary (continued)

**Service Coordinator:** Someone who acts as a coordinator of a child’s and family’s services and works in partnership with the family and other service providers.

**Severe Disabilities:** A condition requiring a person to need extensive support throughout his/her life span in such areas as mobility, communication, learning, and self-care.

**Sheltered Workshop:** A work setting in which employees with disabilities perform contract work, usually on a piece-rate basis, such as preparing bulk mailings or refinishing furniture.

**Shunt:** A small tube, which is surgically inserted to allow excess fluid in the brain cavity to drain harmlessly into the abdomen where it can be easily absorbed. It is commonly used to treat hydrocephalus.

**Sickle-Cell Anemia (SCA):** An inherited chronic blood disease found chiefly among persons of African-American descent, which is characterized by an abnormal red blood cell containing a defective form of hemoglobin.

**Segregation:** The practice of placing children with disabilities in a group setting that includes only other children with disabilities.

**Seizure:** An excessive periodic discharge of electrical activity in the brain. It may be caused by a very high fever.

**Self-Advocacy:** The abilities required to take primary responsibility for one’s life and to make choices regarding one’s actions free from undue interference. Also called self-determination.

**Self-Determination:** See Self-Advocacy.

**Self-Help Skills:** The ability to take care of self-care needs such as feeding, dressing, and toileting.

**Self-Contained Classroom:** A classroom in which a group of students with disabilities receive their entire instructional program with little or no interaction with nondisabled students.

**Social Worker:** A professional who may provide services to the family, including arranging or attending parent-student conferences; providing family counseling, family education, information, and referral; writing a social-developmental history, and/or conducting a behavioral assessment. Social workers sometimes conduct parent education in the school and community.
Glossary (continued)

**Sociocultural Report:** The portion of a child’s overall evaluation/assessment for special education that describes a child’s background and behavior at home and at school. It is usually completed by a social worker.

**Spasm:** Sudden tightening of muscles.

**Spasticity (Spastic):** Stiffness (See hypertonia).

**Spatial Relations:** The ability of a person to understand the position of an object in space in relation to one’s self and to other objects.

**Special Education:** Specially designed instruction to meet the unique needs of a child with a disability, as defined in the Individuals with Disabilities Education Act.

**Special Needs:** A term to describe a child who has disabilities or chronic illness, or who is at risk for developing disabilities and who needs educational services or other special treatment in order to progress.

**Specialized Nursing Homes:** Licensed facilities operating under strict regulations and providing intensive support for persons with disabilities in the areas of personal care, communication, behavior management, etc.

**Specific Learning Disability (SLD):** See Learning Disability.

**Speech Impaired:** Having a communication disorder involving poor or abnormal production of the sounds of language.

**Speech-Language Pathologist:** A professional who evaluates and develops programs for individuals with speech or language problems.

**Speech Therapy:** Activities or routines designed to improve and increase communication skills.

**Spina Bifida:** A malformation of the spinal column caused by the failure of the spinal column to close completely in the unborn fetus. It results in paralysis below the lesion and is often associated with hydrocephalus. The individual’s intelligence may be normal.

**Spinal Meningitis:** A severe viral attack on the brain and spinal column tissue that can result in hearing loss, retardation, or death.

**Standardized Tests:** In a vocational assessment, tests used to predict how a student is likely to perform in jobs calling for certain interests and skills.
Glossary (continued)

Startle Response: A reflexive movement which can be elicited by a surprising event, a loud noise, or sudden movement. The child may jerk, blink his or her eyes, or throw out arms and extend fingers.

Stranger Anxiety: A fear of strangers, places, and separation from parents normally expressed by infants in the second half of their first year.

Substantially Limits (a major life activity): Refers to a disability that restricts the conditions, manner, or duration under which activities can be performed in comparison to most people, as defined by the Americans with Disabilities Act.

Supination: Turning of hand with palm up.

Supine: Body positioned lying on the back.

Supervised Living Arrangements: Homes or apartments for persons with disabilities that are managed by public or private agencies. Paid staff supervise the residents and assist them with budgeting, food preparation, transportation, etc.

Supplemental Security Income (551): A federal program administered through the Social Security Administration that provides payments to individuals who are elderly and/or who have disabilities. Children may be eligible for 551 if they have disabilities and are from families with low income. In addition, children who are hospitalized for 30 days or more and have a disability expected to last 12 months or more may receive SSI.

Supported Employment: Paid employment for workers with disabilities in settings with people who are nondisabled. A job coach provides support by helping the employee to improve job skills, interpersonal relations, or any other job-related needs.

Surrogate Parent: An individual assigned by a public agency to act as in place of the parents when no parents can be identified, when the whereabouts of a parent can’t be discovered, or when a child is a ward of the state. The surrogate may represent the child in all matters relating to: 1) identification, evaluation, and educational placement of the child and 2) the provision of a free and appropriate public education to the child.

Symmetrical: Both sides of body being the same or equal.

Tactile Defensiveness: Oversensitivity to touch.
Glossary (continued)

Tay Sachs: An inherited disorder found most frequently in those of Ashkenazic Jewish ancestry and marked by an enzyme deficiency. The deficiency causes lipids to build up in nerve and brain cells and results in blindness, mental retardation, neurological deterioration, and early death.

Tone: Firmness of muscles.

Tonic Neck Reflex: When the turning of the head causes one arm to straighten and stiffen and the other to bend.

Tracheotomy: A surgically created opening directly into the trachea to allow ventilation through a tube when an individual is unable to breathe normally.

Trade and Technical Schools: Schools which prepare students for employment in recognized occupations such as secretary, air conditioning technician, beautician, electrician, welder, carpenter, etc.

Transition: The process of moving from one situation to another. Frequently used to mean moving from preschool programs into elementary school or from school to work and the community.

Transition Coordinator: School personnel chosen to manage transition services for students with disabilities.

Transition Planning: Careful preparation by the student, parents, educators, and other service providers for the time when the student leaves high school. The plan is written in the Individualized Transition Plan.

Transition Planning Team: The persons who are involved in transition-planning for a student, including the student, parents, school personnel (teachers, guidance counselor, vocational coordinator, school administrator), and adult service agency representatives (vocational rehabilitation counselor, independent living center staff).

Transition Services: A coordinated set of activities for a student that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, or community participation.

Transitional Employment: A relatively short-term program designed to help an individual obtain a job or to develop the work habits and learn the skills needed for a particular job.
Glossary (continued)

**Traumatic Brain Injury (TBI):** An acquired injury to the brain caused by an external physical force causing a disability which affects a person’s performance, e.g., cognition, memory, language, motor abilities.

**Triennial Review:** The completely new evaluation/assessment given every three years to students in special education to determine the student’s progress and to make a new determination of eligibility for continued special education services.

**Work Activity Centers:** Programs for adults with disabilities providing training in vocation skills, as well as daily living skills, social skills, and recreational skills.

**Work Adjustment Skills:** See Employability Skills.

**Work Sampling Test:** The portion of a vocational assessment which tests a student’s hands-on performance in certain simulated and actual work environments.

**Work-Study Programs:** Education programs in which the student receives employment training and earns credit toward graduation through employment.

**Sources:**

